

## Diagnosing autism with Catherine Lord

In this inaugural episode, Lord discusses her entry into autism research, what the future of the field might look like and how drama club saved her in high school.

1 April 2023 | by BRADY HUGGETT

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*This transcript has been lightly edited for clarity; it may contain errors due to the transcription process.*

[opening theme music]

### **Brady Huggett**

This is “[Synaptic](#).” The first episode. You’re at the beginning, actually. It’s our very first one. This podcast is put out by *Spectrum*, and it is going to explore the people, the science and the challenges of autism research, and to an extent the greater neuroscience space.

I’m the host of this, and my name is Brady Huggett. All episodes will be dropped into this feed, and you can subscribe to it wherever you find podcasts: Google, Apple, Spotify, or in your favorite podcast player app. They will also be posted and archived on the *Spectrum* homepage, if you prefer to listen there.

OK, now, for this episode. In the second half of October I flew out to Los Angeles International Airport, also called LAX. Here’s some background. The airport was first established after World War I. Back then, a collection of small, private airfields tried to meet the needs of this growing demand, which was mostly hobbyists, enthusiasts. But in 1928, Los Angeles city leadership selected a “bean and barley field,” located to the south of the city for an official airport. It was 640 acres, and at first it was called Mines Field, after a real estate developer, until it was officially designated the Los Angeles Municipal Airport in 1930.

It has been growing ever since. After WW II, four passenger airlines – TWA, American, United, and Western – began commercial operations there. Jet service began in 1959, and by 1961, the airport had four runways. Terminal 1 opened in 1984, and the Tom Bradley terminal in 1989.

By last year, in 2022, LAX was hosting more than 63 million passengers annually. And in October, the month I flew there, more than 46,000 planes took off and landed.

So that is LAX. This airport is located in a neighborhood called Westchester. And that is the neighborhood where Cathy Lord grew up.

Which is why I’m telling you all this. Cathy Lord is our first guest. She grew up right next to the Los Angeles airport. We talk about that in this interview. We also talked about her family lineage, and the way stations of her long career, including Minnesota, and why she had a tough time there. And of course we talked about autism diagnosis, and the importance of it, whether that’s for families or autistic people themselves. And we talked about what the future of autism research might hold.

All that is coming up in this next hour. So anyway, it was a warm, sunny day in LA when I visited her. She lives on a nice side street, with trees, and the homes have trim little lawns, and because we were nearing Halloween, Cathy had a sort of day-of-the-dead wreath on her front door, in a nod to the season, I suppose. In all honesty, between all the coordinating emails between her and her assistant and me, I think she forgot I was coming, at that specific hour, to the house. I knocked on the door, and she said, Oh my gosh is that now? But she could not have been more gracious, she let me in, introduced me to her husband, and then she and I retreated to a side room where I could set up microphones.

Part of the risk of doing recordings in the field is that you cannot fully control the environment. And I had to stop and close some windows and shut off some lighting that was making a buzzing sound after we’d started, so you’ll hear me pause the tape to do that in the interview. But we had a great talk. Cathy was as friendly and open as everyone says she is. That’s partly why I wanted to interview her, but mainly it’s because Cathy is viewed as a kind of living matriarch of the autism research field. Her shadow is very long in this space. And she seemed like a great person to launch this show.

So let's pick the interview up here, where I'm chatting with Cathy about an extended family member of mine, whom she diagnosed with autism many years ago.

So this is it, Synaptic Episode 1, with Cathy Lord, starting right now.

[transition music]

**Cathy Lord**

Oh gosh. Oh, Booker. I love Booker.

**Brady Huggett**

Right, you were with him for a long time.

**Cathy Lord**

Yeah. Yeah. How's Booker?

**Brady Huggett**

He's great. He's in college.

**Cathy Lord**

He is? Oh, good. Where?

**Brady Huggett**

I can't remember the name of the school. It's in New York. He's about 6'1".

**Cathy Lord**

Oh my gosh.

**Brady Huggett**

Studying Spanish, maybe.

**Cathy Lord**

Yeah. His Spanish is incredible. His Spanish is unreal. Oh, that is so cool.

**Brady Huggett**

Yeah. And so his mom wanted me to tell you and say hello and that... she said you're one of her favorite people, so...

**Cathy Lord**

Oh, yes. Say hello. And oh I would love to hear about Booker. I love Booker.

**Brady Huggett**

Yeah, he's a great guy.

**Cathy Lord**

For a while he was sending me little video clips of the subways.

**Brady Huggett**

He still does that.

**Cathy Lord**

Does he still? Yeah, I was thinking about him the other day, because we had long discussions about what do you have to do if you really want to drive a subway, be a subway driver? So I learned, I mean, I was like, I better learn about this. Because for a kid who doesn't want to drive cars, and doesn't want to do engineering, I was just like, what do they have to do? They have to have a license to drive a truck first, and then you try out to be the like...

**Brady Huggett**

Subway driver. So that's like a class for someone with a truck license.

**Cathy Lord**

Yeah, it is. So we did discuss that; he did not believe me. But I was just like...

**Brady Huggett**

He was asking you what it took to... ?

**Cathy Lord**

Well, I was — he was talking constantly about, "this is what I want to do. I don't need to do this. I don't need to do that. Because that's what I'm gonna do. I'm gonna be a subway driver." And I was like, "well, let's just learn a little bit." I mean, I learned. I didn't know, what do you have to do to drive a subway?

**Brady Huggett**

I didn't know either.

**Cathy Lord**

I don't think he's probably going to be a subway driver. But it's great that he's in college. And he's such a smart, charming...

**Brady Huggett**

Yeah. So anyway, yes. So I did not know that you'd actually moved back to UCLA until I started looking it up. Why did you make the move?

**Cathy Lord**

I came out because my daughter's here with the two other kids. And so she had — we came to New York because both of our adult children were there. And it really looked like they were going to stay there. But my daughter was married to a musician who said he would never leave New York. And then he graduated from Yale with a sort of equivalent of a Ph.D. and got recruited to USC. And he decided it would be really nice to have a salary. He's a composer. So they came. And so they were here and then they got divorced. So she was here with two kids. So we decided we would follow her and my husband retired.

**Brady Huggett**

Your daughter, is she artistic?

**Cathy Lord**

No, she's a physician. You know, actually she's pretty musical. But she's a physician. So she's in public health.

**Brady Huggett**

Okay. And your son's in film?

**Cathy Lord**

Yeah.

**Brady Huggett**

Amazing, ok. But were you born here?

**Cathy Lord**

Yes. I was born here. In Los Angeles.

**Brady Huggett**

Oh wow.

**Cathy Lord**

Yeah, I grew up here. I went to Santa Cruz first year and then came back to UCLA. So I was at UCLA till I was 20. And then I, then I hadn't lived here since.

**Brady Huggett**

Right, since you left.

**Cathy Lord**

Yeah.

**Brady Huggett**

But why were you here? What was your family's history that you were born and raised in LA?

**Cathy Lord**

Yeah, both of my parents were born here. So their parents both moved here during the Depression, to work, to find some jobs.

**Brady Huggett**

So they left.

**Cathy Lord**

Yeah, my grandparents. My grandparents were from New Mexico. But my grandmother was born in Prince Edward Island and her family emigrated when there was a potato famine to New Mexico, which seems absolutely amazing. And then she and my grandfather got married right after World War One, and came out here because they were — actually, during the Depression. Because there was more work.

**Brady Huggett**

The potato famine was in Prince Edward Island?

**Cathy Lord**

Yeah, yeah.

**Brady Huggett**

What's the — so were they... was she French Canadian?

**Cathy Lord**

She's — no, they're actually Scottish.

**Brady Huggett**

Scottish, uhuh.

**Cathy Lord**

So they had come from Scotland to Prince Edward Island.

**Brady Huggett**

Okay.

**Cathy Lord**

And my other — the other side of the family is half Eastern European Jews who all converted to Catholicism at some point and, like, Irish. So they were, my grand... yeah, I guess my grandfather — I never knew him — was a train conductor. So they were from Chicago, but he got out here and thought this was wonderful. So they moved out here.

**Brady Huggett**

He came out for some trip, or whatever, and fell in love with it.

**Cathy Lord**

Yeah, on the train.

**Brady Huggett**

So your background is Scottish, Irish, Jewish? All mixed up.

**Cathy Lord**

Yeah.

**Brady Huggett**

And your grandparents — yeah, your grandparents?

**Cathy Lord**

Yeah.

**Brady Huggett**

Pushed west during the Depression, you were saying.

**Cathy Lord**

Yeah, both sets.

**Brady Huggett**

Okay. But that's not because they were... just, were pushing west to find work. They did.

**Cathy Lord**

Yeah. So they settled here. And then my parents were both born here.

**Brady Huggett**

Wow. So where did you grow up? What part of LA?

**Cathy Lord**

I grew up in Westchester. Do you know where that is?

**Brady Huggett**

No.

**Cathy Lord**

By the airport.

**Brady Huggett**

Okay.

**Cathy Lord**

Our town was like, eaten away by LAX, which used to be tiny and then got bigger and bigger and bigger and bigger. It was awful, actually. I mean, it's, I go back there and think — and when I went to our high school, we had over 1,000 students in my graduating class, all white; we had one Asian child, one Jewish boy. So it was —

**Brady Huggett**

But the school was 4,000 kids or something.

**Cathy Lord**

Yeah.

**Brady Huggett**

Wow. Wow.

**Cathy Lord**

It was grim. I mean, it was run by what was basically a sorority; it was run by the football team, which was very powerful. But it was silent, really. And then the girls — there was like, there were clubs. And so I knocked myself out to get into the beautiful girls club as opposed to the smart or nice girls club. I was determined. I was not going to be nice or smart. I mean, it was awful!

**Brady Huggett**

That didn't work out for you, though.

**Cathy Lord**

No.

**Brady Huggett**

You're both of those things.

**Cathy Lord**

No, but I tried really hard.

**Brady Huggett**

Did you get in?

**Cathy Lord**

I did get in because I was the star of the drama.

**Brady Huggett**

Aha. So you were into drama in high school.

**Cathy Lord**

I love drama.

**Brady Huggett**

When you say the high school was grim, or the neighborhood was grim.

**Cathy Lord**

Yeah.

**Brady Huggett**

Are you saying it was like impoverished or you just didn't enjoy your time?

**Cathy Lord**

No, it was not impoverished? It was — my parents were teachers. So we were the poorest people on the street. But it was not impoverished. People came back with the GI Bill. And my parents bought a — my dad, my dad was from a family with Huntington's disease. So they were... his dad died from suicide when he was 12. His mother got progressively ill; his grandmother lived in the attic, and was quite mentally ill from Huntington's disease. So he was from a very horrible family. So he was really from poverty. And my other grandparents were very straight arrow, but did not have a lot of money. I mean...

**Brady Huggett**

I mean, I'm struck by this concept of the grandmother having Huntington's and left in the attic.

**Cathy Lord**

Yeah.

**Brady Huggett**

That is a... I mean, healthcare has come — healthcare is not perfect by any stretch. But we've come a long way from that.

**Cathy Lord**

Yeah, we have. I mean, it was awful. I mean, she ended up in the state hospital.

**Brady Huggett**

Yeah.

**Cathy Lord**

Is where she died. Both of them did. But they, for a long time, tried to keep her there.

**Brady Huggett**

This is your grandfather we're talking about?

**Cathy Lord**

This is my great-grandmother.

**Brady Huggett**

Yeah. Great-grandmother. So your grandfather grew up with his grandmother in...

**Cathy Lord**

My father grew up with his grandmother in the attic.

**Brady Huggett**

Right, Father. So that must have...

**Cathy Lord**

Yeah, it was bad. Both of my parents actually, my mother's grandmother came to visit from New Mexico, broke her hip and never left. Also. [Laughs.] I know. So it's, I mean, I think what they experienced was poverty. And what happened and people tried to — I mean, their grandmother lived, she and her grandmother shared the same bedroom for years until eventually she ended up in this, also in the state hospital.

**Brady Huggett**

Your mother's mother?

**Cathy Lord**

My mother's mother.

**Brady Huggett**

So your father's mother and your mother's mother both ended up in the state hospital?

**Cathy Lord**

Yep. Yeah.

**Brady Huggett**

One for Huntington's and one for a broken hip.

**Cathy Lord**

Well, for a broken hip, and then I think dementia.

**Brady Huggett**

A decline of sorts. Okay. All right. Well, so you're, you're growing up in this house. In a nice neighborhood, it sounds like, but you're not enjoying high school. You're kind of struggling to fit in, which it sounds like you did. Maybe drama was your saving grace?

**Cathy Lord**

I tried really hard. Yeah. Yeah. I mean, I had nice friends. The beautiful girls were actually quite nice.

**Brady Huggett**

Yeah.

**Cathy Lord**

But it was just... now I look back on it and think [gasps] that is so horrible. So horrible. Oh man.

**Brady Huggett**

But it was... you were... you didn't... when you left high school, were you like, thank God that's over, or?

**Cathy Lord**

Yeah, I mean, it was also 1968.

**Brady Huggett**

Yeah.

**Cathy Lord**

So it was — I was very liberal. Oh, also, the neighborhood was completely Republican, completely conservative.

**Brady Huggett**

Was it Catholic?

**Cathy Lord**

A lot of Catholics but also Catholics, Mormons and Protestants.

**Brady Huggett**

Oh okay.

**Cathy Lord**

You know, so it wasn't, I mean, it wasn't sort of what you see today, but it was absolutely conservative. So my brother and I, my brother was a rock musician, eventually. But my brother and I were like the two liberals of the high school. We were like, the only, I mean, we could have had a Democratic club just of the two of us.

**Brady Huggett**

Just of the two of you, yeah.

**Cathy Lord**

And I mean, there were other kids beginning to be sort of hippies. I was still — I'm behaviorally quite conservative. And, like, I'm just, I was not into drugs, or, I mean, I love the music and my brother's music. But otherwise, I was — I'm just not wild at all. So I was really trying to figure out like, how do you be liberal but not wild?

**Brady Huggett**

Yeah.

**Cathy Lord**

And then I went to Santa Cruz, and I was actually mortified. Because when I got to Santa, I mean, my parents wouldn't let me go to Berkeley.

**Brady Huggett**

You wanted to?

**Cathy Lord**



I wanted to go to Berkeley. My parents said, "absolutely not." I mean, I should have just said, "too bad." But that would not have occurred to me.

**Brady Huggett**

Yeah. At that age.

**Cathy Lord**

Went to Santa Cruz, and then Santa Cruz had a lot of kids from the East Coast who were very liberal. And I was like, Oh my God, they're burning their draft card. You know, I mean, you know, and these kids had cars and money.

**Brady Huggett**

Yeah.

**Cathy Lord**

I'd never been around anybody like that. I mean, I'd been around Westchester, which had young, you know, people that were really going, like — almost everyone went to college — but on the whole, probably, one kid went to Yale, one kid went to Carnegie Mellon, one kid went to Wellesley. And then a very few people even went to UCLA; they went to Cal State Long Beach, where, you know... I mean, people literally, like my parents tried very hard to get me to go to a junior college, because they felt like the teachers would be better, which is maybe possible, but they just didn't have any sense of what it was like to be in a more, like, science-oriented community.

**Brady Huggett**

Right.

**Cathy Lord**

None.

**Brady Huggett**

Can I do one thing?

**Cathy Lord**

Sure.

**Brady Huggett**

Hold on. I'm gonna pause this — that's much, much quieter. Yeah. So I'm struck by this... So your parents were sort of conservative as well, it sounds like.

**Cathy Lord**

Well, no, they were politically liberal, actually. Absolutely. Completely Democrats, in favor of unions.

**Brady Huggett**

All that.

**Cathy Lord**

All that. I mean, I think they recognized both... my dad recognized what horrible circumstances he came from. And the only reason he went to college was the GI Bill.

**Brady Huggett**

Right. Oh, he was in the service?

**Cathy Lord**

He was, yeah.

**Brady Huggett**

Huh.

**Cathy Lord**

So he was in the Merchant Marine and then the Army. So he was — and he had been a conscientious objector to World War Two!

**Brady Huggett**

Woah, he was ahead of his time.

**Cathy Lord**

I know. And then, so he was very, he was the editor of his high school newspaper, very liberal, a conscientious objector — got granted it, I don't know on what basis — but then went in the Merchant Marine, because he wanted to do something. And then he realized that he was manning boats that were carrying ammunition and just thought, This is ridiculous. I'm wrong. So joined the Army. So he came back from the Army.

**Brady Huggett**

Meaning he thought, Well, I'm not — I'm already part of the war. If I'm Merchant Marine, I might as well go in the Army.

**Cathy Lord**

Yeah.

**Brady Huggett**

Okay. Interesting.

**Cathy Lord**

So he was also very sick of boats at that point, but then, of course, got in the Army and got put on a boat because that's how he knew what to do. So he, so they were... and my mother would have probably gone along with whatever my father said. And my grandparents were, like, union; my grandfather was a printer. So I think they were quite liberal. But behaviorally very conservative. I mean, we could have lived in rural Iowa for what we did in Los Angeles.

**Brady Huggett**

Yeah.

**Cathy Lord**

You know, they just didn't do, you know, didn't do much.

**Brady Huggett**

Yeah. So they weren't like, outspoken about it.

**Cathy Lord**

No.

**Brady Huggett**

They weren't politically active although their politics leaned left, you're saying.

**Cathy Lord**

Yeah.

**Brady Huggett**

So you're in this high school, which is sort of conservative and it's ruled by the football team and this cliquish group of women or young girls, but you're in drama and your brother's, there's just the two of you?

**Cathy Lord**

No, there's a sister too, so she converted. It's a long story but my sister was very nice. My sister was quiet. And my brother converted to Mormonism.

**Brady Huggett**

Your brother did?

**Cathy Lord**

Yes. Briefly, when he had a Mormon girlfriend. So he was very wild in high school and this, like, star rock musician of our school. He's two years younger. He got a Mormon girlfriend, converted to Mormonism, brought my sister, who's two years younger than him, into Mormonism.

**Brady Huggett**

But not you.

**Cathy Lord**

Not me, no. I was — by that time I was, I couldn't have been a Mormon. But he, he did that. And then he — eventually the girlfriend broke up with him. And he got sick of being, like, the token rock musician Mormon, and so he left the Mormon church, but my sister stayed in. So she was very, well, well behaved. But my brother and I were more the troublemakers.

**Brady Huggett**

Was she a Mormon for life, your sister?

**Cathy Lord**

Yeah, she did. She passed away a few years ago, but she has five kids and...

**Brady Huggett**

Lived in the church.

**Cathy Lord**

Yeah.

**Brady Huggett**

Wow. Did your brother become a musician in life?

**Cathy Lord**

Yes, he did. So he was, he did guitar lessons, played in a band that never made very much money, but played in a band and well, that's...

**Brady Huggett**

That's his career. Right?

**Cathy Lord**

Yeah.

**Brady Huggett**

Okay. So when you were going to college, did you, I mean, was it you were thinking about drama, or what were you thinking about doing?

**Cathy Lord**

I didn't know. No, I think I got from my parents that that is not a good — that is a hard life. So I wanted to do something stable, but I didn't want to be a teacher. I saw, I was in and out of classrooms my whole life with my parents being teachers. And I was like, This is just too restraining. So originally, I wanted to be a neurosurgeon, actually. But I mean, I grew up — I'm one of the last vestiges of like, girls don't do that. You know, it would be from everyone. I got, "what a waste of time to train you to be a neurosurgeon."

**Brady Huggett**

Because you're never going to be that.

**Cathy Lord**

Yeah. And actually, I'm pretty clumsy. So you not really want me to be a neurosurgeon. But at the time I didn't...

**Brady Huggett**

But do you know why that interested you?

**Cathy Lord**

I think I was interested in the brain. I was interested in how people function, and why we do what we do and what causes it. I mean, I really know very little about what causes it on a basic level. But that's sort of where I started.

**Brady Huggett**

Yeah.

**Cathy Lord**

So I sort of started, I didn't — by the time I started college, I really thought, actually, I went to Santa Cruz in Cal College, which is the humanities college. I thought, I think I want to be a psychologist, but it was sort of a new field. But I want to learn everything about literature and art before I become a psychologist. So I had a miserable year at Santa Cruz, because I just never, I love to read and I had no idea what people do when they're really serious academics about, like, reading and materials. And so — and I'd never been around highly verbal people, like people who really were very articulate and could really talk.

**Brady Huggett**

That was foreign to you.

**Cathy Lord**

Yeah. Absolutely.

**Brady Huggett**

And did you feel... you felt out of place?

**Cathy Lord**

Yes. I felt, I mean, I went through my first term without saying a word in my seminar, which was very out of character for me.

**Brady Huggett**

Because, because why? Because you felt... well, you felt they would judge you? For the way you spoke?

**Cathy Lord**

Yeah, I think I felt like I couldn't keep up with them. And also, I hadn't been around a lot of people that talk to impress other people. So there was that sort of going on. But it was more just they were so quick. And so verbal, and I was in, you know, Cal College, which is this combination of humanities and arts and writing, and that's who was in it. And I thought, Oh, I'll be one of those people for a while, even though I don't want to do it forever. And then I was like, Oh my gosh, I can't keep up with them.

**Brady Huggett**

Yeah.

**Cathy Lord**

I mean, it was really interesting to see.

**Brady Huggett**

So is that why you transferred?

**Cathy Lord**

So then I came back — well, that and a boyfriend.

**Brady Huggett**

Oh.

**Cathy Lord**

I came back, I was like, This is just not the place for me. And also because it was 1968. And so the politics, even though when I came back here, it was, I mean, we had Reagan coming into UCLA, but it was much more... It was less tied to sort of absolute actions, you know, like burning your draft card, or...

**Brady Huggett**

So you're saying that Santa Cruz was more politically active than UCLA was?

**Cathy Lord**

Well, it was just different because UCLA was the, I mean, there were lots of students and we marched. And we had long discussions, like, were we willing to be arrested? We were not arrested. I mean, no one was arrested. But we all had marches. But we weren't as flamboyant about it.

**Brady Huggett**

As you know, there's a lot going on at that time. Were the marches strictly anti-war, or was the whole, you know, this was gay rights, feminist rights, it's all kind of coming together in the '60s?

**Cathy Lord**

It was pretty much — at that point, it was the war, you know, it was... the feminism was beginning but didn't, hadn't actually really hadn't hit UCLA, I think, even by the time I left. You know, I mean, people were beginning to talk about it, but not much. I mean, it was just such a crazy time to go to college.

**Brady Huggett**

I'm sure.

**Cathy Lord**

Like, there were professors who would, you know, they would say, "well, I'm not going to teach" or, "I am going to teach" or, you know, because of the, like, we had National Guard troops. They brought in National Guard troops and buses that sat around the UCLA and people took over buildings. I mean, I didn't do that. But we did have, like, protests.

**Brady Huggett**

So the guard was there as a constant presence, just in case a protest got out of hand. Just in case.

**Cathy Lord**

Yeah, or there were people who took over the administration buildings. So they were trying to figure out what to do to get them out.

**Brady Huggett**

So that actually happened first, and then the guard came in.

**Cathy Lord**

Yeah.

**Brady Huggett**

Okay. And meanwhile, you're trying to go to class in the middle of all this.

**Cathy Lord**

Yep, trying to learn perception.

**Brady Huggett**

So this sort of feels like... this sort of seems consistent with what you already told me. But you were aligned with those people. But you were not going to be at the front of the group. Right?

**Cathy Lord**

Yes, that is absolutely true. I mean, I am not, I am not a — it's, you know, I'm not someone that wants to lead a big group. I want to lead a little group. [Laughs.] Little group. I love my lab. But not 100 people or 1,000 people or 32,000 people.

**Brady Huggett**

So when you're — and now at UCLA, you've sort of given up on trying to take in all the art and literature as a base. You're like, Now I'm just going to study psychology?

**Cathy Lord**

Yeah.

**Brady Huggett**

Okay. You had three years to do that, basically?

**Cathy Lord**

I did, yeah.

**Brady Huggett**

So what did you learn? What did you...

**Cathy Lord**

So I mean, I learned a lot. I mean, I was very dismissive of a lot of it because I was in huge classes, but I learned a lot of things, you know, so I learned perception and physiological psychology and social psychology. I mean, the nice thing about the quarter system, which is also the bad thing, is it's 10 weeks, and you do so many things. So I did a lot of psychology. I worked for Lovaas, you know, so I started, I, you know, was like a student volunteer. And I had two autistic kids that I saw. And I just, I took his class unintentionally, actually. I signed up for his class, which was theoretically on developmental psychology, but turned out to be on ABA. And he was very charismatic, and he was convinced this was going to change the world. And so, and he had very explicit standards of what you had to learn to do. So I was like, I'm gonna do this. So I learned to do that. And then I did it for a couple of years. And then I also worked with another professor who did complicated statistics, who was also interested in sort of psychopathology. And so that was really nice, because he was so thrilled to have someone who liked math, you know.

**Brady Huggett**

Which you did.

**Cathy Lord**

I did, although I didn't have a lot of math, I just liked it. And so I took extra statistics classes and worked with — he had a postdoc who barely spoke English. So I was like, a good in between person.

**Brady Huggett**

Do you like math because of the, you know — verses essays or art, even — math gives you a concrete answer. It's right or it's wrong. That idea?

**Cathy Lord**

I don't know. No, I think I just like numbers. I like the fact that you can go different places with numbers, I mean, that you can move around. And you can — I like statistics. I mean, now I'm terrible. But for a while, I was very interested in statistics. And just the fact that you can use it to figure things out. And so... And tell you things you wouldn't necessarily know. And so I think I always liked that. I mean, I liked algebra, and I liked geometric proofs, and...

**Brady Huggett**

Yeah, there's like an element of discovery to math.

**Cathy Lord**

Yeah.

**Brady Huggett**

So you finished I think '71 with a psychology degree?

**Cathy Lord**

Yeah.

**Brady Huggett**

And what were you thinking of doing then?

**Cathy Lord**

I wanted to be a psychologist. I applied to grad school: I applied in developmental and clinical. And then I went, and then I got into Harvard.

**Brady Huggett**

Right.

**Cathy Lord**

They had had a clinical program, but it just decided they were not going to get — they were going to give up their APA accreditation. And so they divided up the clinical courses. But I was so enthralled at getting into Harvard, I went anyway.

**Brady Huggett**

Well who wouldn't.

**Cathy Lord**

Yeah, and I really liked the person who contacted me; his name was Marshall Haith. He was actually a researcher who studied infants. And what I, what I'd sort of come out of after working with Lovaas was: these behavioral principles don't work. I mean, they really, I mean, in the end, sometimes they do work. But I had two very, very different kids. And one of them — they were kids brought out of an institution.

**Brady Huggett**

Yeah.

**Cathy Lord**

And one of them just was ahead of me the whole way. I was trying to teach him things that he already knew. And I didn't realize he already knew these things. He just wasn't doing them, because he had been institutionalized. And then I was trying to teach a little boy who didn't talk. And we were doing sound imitation, and he didn't understand it. And so it was really a waste of time. And I was trying to figure out with this little kid who I'm — he's stuck with me for an hour a day, what are we going to do? So we did other things, which research-wise is horrible.

**Brady Huggett**

Well, you mean for your results?

**Cathy Lord**

Yes, 'cause the results was terrible. But I taught him. He liked water. And I taught him to wash his hands. And I taught him to get a towel out of the, you know, towel thing in the bathroom. And so we could hang on, you know, and then go back and try to say, "baa." So I came out of that saying, "wow, we need to know something else." We need to know what's going on.

**Brady Huggett**

Because you have these two almost opposites. You had one who was so far ahead of you and the other that you were sort of almost like trying to teach them anything.

**Cathy Lord**

Right.

**Brady Huggett**

So you're like, these basic principles that we've been — that have been laid down, that we're going to use — do not apply on an individual basis.

**Cathy Lord**

Right. I mean and really, the principles — I mean, I ended up, years later, I ended up teaching a preschool class for kids. It was right when IDEA first came out, which is the right to education. So it was in Vermont and these kids in rural Vermont who had never gone to school, and I ended up teaching it just because the teacher — I was supposed to be the psychologist — the teacher didn't show up. So I had to make sense out of, "what are we going to do with these kids?" And then I was pretty behavioral. But I think what I was looking for I did find in graduate school which was development, and the idea of "where are you?" On an individual basis. And then let's go the next step up. And let's not just apply things.

**Brady Huggett**

Got it. So this, this is why you start leaning toward diagnosis.

**Cathy Lord**

Yeah.

**Brady Huggett**

Because you have to figure out each child individually before you can lay down some sort of plan.

**Cathy Lord**

Right.

**Brady Huggett**

And that was your own thinking in your Ph.D. program?

**Cathy Lord**

Yeah, I don't know that I'd even, I mean, I think that I... I don't think I called it a diagnosis at that point, but I think that my idea was: you have to see the kid. And you have to put that information into something so that you can make sense out of it, and then make decisions about what are you going to do next. And that was the case for the kids in my class. I certainly, thinking back of the kids that I worked with in doing ABA, it would have been a lot better to do that. And then going forward, I think that I — I went to TEACCH as an intern, and TEACCH, the thing that TEACCH taught me was we did that somewhat more systematically, the idea of, like, what are strengths and weaknesses, what are emerging — in TEACCH, they call them emerging skills. So what is a solid skill that a kid can absolutely do? What is emerging, so he can almost do it, and what do we do to help them? So that we can think about that. And then the other component was parents. So at TEACCH, the whole point, initially, was parents are co-therapists. And even though I don't love the idea of like, calling them co-therapists, parents are critical. And so you need to figure out: what is the parent need?

**Brady Huggett**

Yeah, well the parents are critical, because they spend the most time with the children.

**Cathy Lord**

They do. And what are they thinking? And if you just come in from, you know, another planet, it's, this is not going to help them.

**Brady Huggett**

TEACCH, also, tell me where I'm wrong. But you know, for the parents it helped them understand that, "if we're working with this child, you also need to help lay out expectations for the day."

**Cathy Lord**

Yeah.



**Brady Huggett**

So that the whole thing is more holistic in that way.

**Cathy Lord**

Yes, absolutely. It's like, how do you make the world make sense for the kid? And so that was something I had never thought about. And so it was like, wait a minute, you know, this kid doesn't know if we're gonna be doing this forever, or for two minutes. He doesn't know if I do this, then this is going to happen. And so — and that is sort of, that is behavioral. But it's from a sort of more cognitive point of view. And that was just earth shattering to me, was this idea of, like, I can help this child know what's going to happen. And then he can make choices, or she can make choices, if they have some idea what their choices are.

**Brady Huggett**

So you — I think — you graduate with your Ph.D. in '76. Is that right?

**Cathy Lord**

Yeah.

**Brady Huggett**

And then when — I think maybe you did an internship at Chapel Hill.

**Cathy Lord**

Yeah. That's when I went to TEACCH, so yeah.

**Brady Huggett**

Okay. And when that was finished you were still not fully — I'm trying to remember when your ADOS paper came out?

**Cathy Lord**

Yeah, that was not —

**Brady Huggett**

'89.

**Cathy Lord**

Yeah, I wasn't in the ADOS at that point. That was — so at that point, we — my husband was teaching at Dartmouth. They did not want me, they did not want to — they had one woman professor. And they were like, that's enough. So we left.

**Brady Huggett**

Honestly — they honestly said that? Like we can't have another woman on the...

**Cathy Lord**

Honestly. Honestly. Eventually they said, "there are nine wives who have Ph.D.s in psychology who are married to Dartmouth faculty, we would divide — maybe we could divide up a position among the wives." I was, I mean, at that point, I was like...

**Brady Huggett**

Among the nine wives?

**Cathy Lord**

Yeah, it was so... I mean, it was like, you know, the six wives.

**Brady Huggett**

And these, these wives would collectively equal one position.

**Cathy Lord**

One person, yeah.

**Brady Huggett**

I mean, you wouldn't believe this stuff if someone didn't tell you that.

**Cathy Lord**

I know, you wouldn't believe it now.

**Brady Huggett**

Oh my God.

**Cathy Lord**

But it happened. So we went to Minnesota. My husband gave up his position. We went to Minnesota. And I had a really good job. So we were there for four years. And then we went to Canada.

**Brady Huggett**

Well, I forgot I should have asked: how did you meet your husband?

**Cathy Lord**

I met him in graduate school. So he was a postdoc when I was just starting.

**Brady Huggett**

At Harvard. And what's his discipline?

**Cathy Lord**

He's a developmental psychologist.

**Brady Huggett**

Oh okay.

**Cathy Lord**

So he studies reading, primarily in literacy.

**Brady Huggett**

Got it, okay. All right. So you are often working — did you work collectively? Or do you?

**Cathy Lord**

We did a little bit. I mean, we spent a year in the middle there in Guatemala. So we worked together there, but mostly we haven't. He works with typical kids and is too — he gets too heartbroken around kids with problems.

**Brady Huggett**

He does?

**Cathy Lord**

Yeah.

**Brady Huggett**

You know, for somebody whose parents, you know, weren't sure they wanted you to go, you know, too far away, you've been all over.

**Cathy Lord**

I have, yeah. I really, I mean, part of it is my husband. We've, you know, he came from Toronto. So we were both trying to figure out where on earth we live. And we had talked briefly about, I mean, both going back to Toronto and coming here. But you obviously couldn't do both at the same time.

**Brady Huggett**

Yeah.

**Cathy Lord**

And then, you know, we really wanted to have a family, and living here and getting two jobs that were miles away, was just impossible. And so we tried to — we've lived a lot of different places. And for different... we have always thought, Okay, we're staying here, and then something else comes up.

**Brady Huggett**

You have. I wonder, so when did the children come? Where were you?

**Cathy Lord**

The children came, the daughter came when we were in Minnesota.

**Brady Huggett**

Minnesota, okay.

**Cathy Lord**

Yeah. So she was born then. And then she was one reason we left. I mean, my husband started saying "we need to live in a civilized country." We want to go back to Canada.

**Brady Huggett**

Oh, he meant Canada versus the U.S.?

**Cathy Lord**

Yeah. [Laughs.]

**Brady Huggett**

Oh, really.

**Cathy Lord**

So we went, we moved to Canada. And at that point, I was very fed up with academics. I mean, I had had, we'd had a baby that died.

**Brady Huggett**

You did?

**Cathy Lord**

My daughter before my daughter was born.

**Brady Huggett**

Oh, I didn't know that.

**Cathy Lord**

It was awful.

**Brady Huggett**

How did you... survive that?

**Cathy Lord**

Well, I was just, I mean, I was depressed. And then I was determined to get pregnant. Which career-wise was the absolutely stupidest thing to do. But I just thought, If I don't do this now, I will never do it again. It's too terrifying. So we — I had two pregnancies in the four years of Minnesota.

**Brady Huggett**

And you lost the first one.

**Cathy Lord**

Yeah.

**Brady Huggett**

Did she die after she was born?

**Cathy Lord**

Yeah.

**Brady Huggett**

Oh, I am sorry.

**Cathy Lord**

It was bad. I mean, she was sick all along, the poor baby. But so we then had my daughter. My daughter, I had a lot of trouble when I was pregnant. And so it was out of, you know, in and out of the hospital. But she was fine, thank God.

**Brady Huggett**

Yeah.

**Cathy Lord**

But that was, that put me off. You know, somebody said — I mean, literally, I had the chief of our department, at the end of my third year, which would have been the year my daughter was born, said, like, "I don't know what happened to you." I mean, literally, that's what he said to me: was like, what, "you know, you just haven't gotten a grant." You know, and I didn't even apply for grants.

**Brady Huggett**

Did he know what you'd been through personally?

**Cathy Lord**

Yeah, he knew. He knew. But it was just like, he forgot. It was bad. But I think that people, I mean, people are better now. You know, they said, reset the clock and... but I still think it's, you know, in academics, you're only what you do, you know, and he — they were very disappointed in me. I mean, they really thought that I was going to be a superstar. And I had arrived, you know, under circumstances that were... well, I had arrived and got going and then I'd really been thrown off by the two pregnancies, so...

**Brady Huggett**

Well, but he was right, though.

**Cathy Lord**

Yeah.

**Brady Huggett**

It just wasn't gonna happen under his watch.

**Cathy Lord**

Yeah. Right. I mean, it was a good lesson in that I just was like, Alright, forget it, we'll go. And then I took a clinical job in Edmonton when my husband got an endowed chair. And I was like, I'll just be a clinician. But I had a department chair. I was in a, like, teaching hospital. The department chair was, like, what are you doing? You should be doing research!

**Brady Huggett**

Really?

**Cathy Lord**

Yeah, really. And so it turned out I literally applied — it was a newspaper ad for Alberta mental health, saying, "anyone want to study children's health?" And I, so I applied for it and got money. And then Alberta Heritage Fund, which when they make a

lot of money on oil in Alberta, they put it into support for scientists. And so people were like, "you can apply for this." So I applied for that. And then I applied for the Canadian equivalent of NIH. So I was like, Oh, great. This is great.

**Brady Huggett**

This man who said you should be doing research — but you had already gotten sick of that. Why did you listen to him?

**Cathy Lord**

Well, I liked it. I mean, I had liked the research. I just didn't like the fact that I didn't want to be going home every night and waiting for my kids to fall asleep so I could work over things that I was tense. And so what I figured out was I could get up early in the morning, before my daughter woke up, and I could work for a couple hours. And I could get enough done. And then I wouldn't have to feel like that at night.

**Brady Huggett**

Don't be tense at night.

**Cathy Lord**

Yeah. And then the expectations in Canada were much lower.

**Brady Huggett**

Civilized. Civilized.

**Cathy Lord**

Yeah. [Laughs.]

**Brady Huggett**

Okay, so you started getting grants in Canada, and you're studying up there. What were you learning? What were you figuring out?

**Cathy Lord**

A lot. I mean, I think at that point, I had met Michael Rutter in Minnesota. And he had — I had actually arranged to go for a sabbatical, like a quarter sabbatical to England, to work with him when we moved, so I didn't go. So he actually, I think due to no understanding of geography, came to see me in Edmonton on his way to Detroit, I think.

**Brady Huggett**

Of course.

**Cathy Lord**

But I got to spend a fair amount of time with him. And then he convinced me we should go to — we got money from the British Council to go to England. So we went on sabbatical. But he and I, I started working with him, even then, and he was starting a project, which was the first family study of autism. He was doing it with Susan Folstein, who was in — at Hopkins, at Johns Hopkins. And so, and I realized that basically, there was no standard diagnosis at that time. I mean, he did too. So there was his diagnosis. There was the U.S., like, the Autism Society had a diagnosis.

**Brady Huggett**

Michael, he'd come up with his own.

**Cathy Lord**

Yeah, he had his own diagnostic criteria, the Autism Society — because Ritvo, who's at UCLA, had had a different set of criteria. And then I had been at TEACCH. And I knew they were using something completely different. So at that point, Mike was like, he was very invested in investigator-based interviews, which are interviews where the person who is asking the question gets the other person to talk. And then the investigator codes the answer. So rather than asking yes/no, or asking you, do you pick A, B or C, I get you to talk and then I interpret what you've said, and code it. And so that was the beginning of the ADI, which is the parent interview. So that was really Mike's. And then a psychiatrist named Ann Le Couteur.

**Brady Huggett**

Can I — I want to ask this question, because what you had seen early on at UCLA where you had one child who was really advanced and one who you were struggling to teach — did you think it was possible to get a standardized test?

**Cathy Lord**

Yeah, well, I didn't know. I didn't know, I thought that it was — yes, I thought that it was important to try. And the kids were very different. But they're similar too, I mean, that's what's amazing about autism is that — and that's a huge issue right now — is, you know, people that are verbally articulate, are in such a different position than somebody who can hardly talk.

**Brady Huggett**

Right, yeah.

**Cathy Lord**

Or who has very limited practical skills.

**Brady Huggett**

Yeah.

**Cathy Lord**

But then there are things that are shared. So I think I, I guess I thought we could do this for autism. But then we also had to know about intellectual disability and language. And so I'd really spent, like, the last couple years at Harvard working on language stuff. And I felt like, we need to know more about that. And Mike Rutter was actually one of the first psychiatrists who was willing and interested in that, in sort of cognition and language. So we worked on the ADI and that was really mostly the three of us, Mike and Ann Le Couteur, and me. But other people, too. But then, it was the advent — I don't know if I probably haven't told you this before. But we, when I was in Canada, we had this incredible media guy in our hospital. And he was like, "you can make videotapes!"

**Brady Huggett**

Oh, I want to ask about this. Okay, keep going, keep going.

**Cathy Lord**

And so he was like, he had this giant camera. And he was amazing. And I was like, wow, Mike, you know, we could video these kids. And then we could go back and look at them later and see if we miss things. It was like, well, what are we going to video them doing? And I had learned from TEACCH, that sort of TEACCH approaches: when a kid comes in the room, you try to make them comfortable, you try to make things predictable, you try to make things make sense. And then you test them.

**Brady Huggett**

Right.

**Cathy Lord**

Mike was much more of a psychiatrist of like, don't do that. I'm going to talk to the parents and let the kid wander around the room and see what he does.

**Brady Huggett**

And we will see what they're interested in.

**Cathy Lord**

Yeah. We'll see what they do. And so I was really interested in, can we do both? Can we set up contexts where the kid is comfortable enough so that they're not wandering out of the room? But where we aren't telling them what to do? And then can we make things make more sense gradually? And can we have tasks that we present to the child so that they know what we want from them? Or at least they know what the opportunities are? And then gradually we kind of narrow it down a little bit and can we video that so then we have this permanent record? I mean, now looking at what those old videos they're not so permanent, but a permanent record of what they're like. So that's where we started the ADOS.

**Brady Huggett**

Does that also — the video, I mean — does that also allow, you know, much... more people can look at the... you basically have widened your dataset at this point.

**Cathy Lord**

Absolutely.

**Brady Huggett**

Or your data points because other people can look and say, “well, I noticed this, did you notice that” and...

**Cathy Lord**

Yeah.

**Brady Huggett**

Okay. And then that goes in the file for the child as well.

**Cathy Lord**

Yeah.

**Brady Huggett**

Okay. So that was a first.

**Cathy Lord**

Yeah. So that's what we did. And I literally had a basket of toys in my office in Canada that I used when I was playing with kids. And some of it was very built on stuff we'd done at TEACCH, but not necessarily the same task. But it was like, you have to have something somewhat systematic. It can't be total chaos. On the other hand, the kids like different things. So you have to be flexible enough to say, "yeah, you really want to sit down and you're going to be moving or you like to put stuff in and you don't."

**Brady Huggett**

Yeah.

**Cathy Lord**

So that's sort of where we started with the ADOS. I mean, I think people — I just came back from Poland. And I, you know, mostly I get grief about the United States. But it was amazing to be there. And then people coming up and saying, you know, Slovakia is getting the ADOS, you know, Latvia is getting the ADOS. I mean, I think it's been useful, not necessarily in the ways that we planned. I mean, the way we planned was to be able to see if the diagnoses were uniform across, you know, Johns Hopkins, and Edmonton, Alberta, and the U.K., and across the various sites in the U.K. And then we were also interested in, like, sex differences.

**Brady Huggett**

Right.

**Cathy Lord**

And so we could see that. And I think that was important. And people do use it like that. I mean, it has provided, like, a base of sort of standards. But I think clinically, the usefulness is you spend 45 minutes doing stuff that you already know how to do. So I don't have to think about what toys should I get? Or what should I do next? Because I memorized it. But I get to see the kid do these different things. And especially with the younger kids, the parents get to be there too.

**Brady Huggett**

Yeah.

**Cathy Lord**

And so they can see what I'm trying to do, what the kid does, which often surprises them, what they don't do, and when do they do it? And we've got this shared base of knowledge.

**Brady Huggett**

It seems like you were, as you said, you're originally going to get — you wanted to see if like... the what happened in this part of the country, this part of the world, the diagnoses were similar.

**Cathy Lord**

Yeah.

**Brady Huggett**

But what actually happened is it became a way to diagnose a child.

**Cathy Lord**

Yeah.

**Brady Huggett**

Why do you get grief about it in the US still?

**Cathy Lord**

Well, I think people, people feel like if they don't know how to do it, they feel like they don't want to have to ask somebody else to do something. They feel like they can make a diagnosis faster. People worry that there are long waiting lists. Now, I mean, I don't think the ADOS is the problem on the waiting lists; I think it's not having skilled...

**Brady Huggett**

Technicians or practitioners, yeah.

**Cathy Lord**

I think it's developmental pediatricians, psychologists, child psychiatrists, all can do this, but there aren't enough of any of us because we all lose money.

**Brady Huggett**

Yeah.

**Cathy Lord**

You know, and so, but people will say, Well, they're waiting for the ADOS. You know, I think now because some insurance companies are asking for ADOSs, you know, that also makes people mad. I mean, there's an article in JAMA Pediatrics, I think it's this month, where a bunch of developmental pediatricians made diagnoses without an ADOS referred kids for ADOSs, got the ADOSs back and didn't change their diagnosis. So they're saying, we don't need the ADOS.

**Brady Huggett**

Well, what was the difference between the two? Did they say?

**Cathy Lord**

Well, I mean, they don't say, and also, they, I mean, they already made their diagnosis. So really, this is a study of do developmental pediatricians change their diagnoses? No. The other thing is, what were they doing in the time that they saw the kids? Because a lot of developmental pediatricians, some do the ADOS, but mostly, some of them, they take pieces of it, you know? And there is a question of like, could you do something faster?

**Brady Huggett**

Faster meaning with less of a wait to see...

**Cathy Lord**

Oh, no, could you do something faster, like, instead of 45 minutes, could you do it in 15 minutes? So I feel like we should lobby to say, look, you guys, these kids — I mean, they do not need an ADOS every three months, they need an ADOS, you know, at the start, and then it's really nice to have a follow up. But you don't even need it every year. You know, it's up to the family and



who — what kind of information are you getting? But you ought to be able to have an hour of someone attending to you and listening to you and watching you.

**Brady Huggett**

But I wanted to ask about that too. Because, you know, most of your career has been about diagnosis, it seems like. And I want to ask about the importance of a diagnosis. Because — we're talking about Booker — Jen, Jen said that, you know, she had been to see people and they were just like, hey, too bad. We don't know. But you were the first person who said, hey, there's something that we can — here's a diagnosis and there's something that we can do and she said she never forgot it, actually gave her hope. So what is — I want to ask about that, like, what does a diagnosis mean to both families and autistic people themselves?

**Cathy Lord**

I think it just gives, I mean, it gives us access to more information. And it gives you a sense that — I mean, first of all, you didn't do this. I mean, no one did this. This is a difference. You know, it is a difference that comes from our brain. And we don't exactly understand it, but we know quite a lot about it. So it gives us strategies, too, for what are we going to try to do when things are hard? What can we do to support a kid who's doing well? So I think, I think it's a starting point, you know? And it's, and again, it's shared information. And it's not, I mean, because autism is so various, it doesn't tell you everything about somebody, but it's a start, you know, and just to begin to think, like, why did that happen? You know?

**Brady Huggett**

Right. So for parents, it's sort of like, my child is not developing as quickly as we thought, they don't have the language we thought, and then they get a diagnosis and they go, okay, now I know what's happening. And same for adults. So it's part of understanding who you are.

**Cathy Lord**

Yeah. And that there's other people that have same or similar overlapping issues. Yeah. It's not just you.

**Brady Huggett**

Yeah, yeah. So do you think that's kind of like your — I mean, I don't want to say legacy, but kind of your legacy is this, you know, the weight? That's, I think that is your largest impact on the field.

**Cathy Lord**

Yeah, I think that's true. I mean, I also am very invested in the longitudinals in our longitudinal study, but I think that that has less broad effect.

**Brady Huggett**

Yeah. I also wanted to ask about the Lancet Commission.

**Cathy Lord**

Yeah.

**Brady Huggett**

Right. So can you just tell me why that was important to do? And a little bit of the history of why it came together?

**Cathy Lord**

Yeah. So I think Lancet decided that it was time. I mean, who knows what goes on in the minds of Lancet? But that it was time to do something about autism that was less piecemeal than what they had done. And, so they had asked me to put it together; they wanted it to be international. And that was really the only criteria they really gave me was they wanted an international group, and they wanted to check. They had sort of, I mean, they really didn't veto anybody, but they had ideas of how we should put this group together. So, interdisciplinary. And then I think the group decided, and partly, I think it was really my impetus, that rather than focus on long-term, we wanted to focus on short-term.

**Brady Huggett**

Five years, right?

**Cathy Lord**

Yeah. Because I think the idea was that our field has so many groups and a big investment. I mean, NIH certainly is very invested — NIH in long-term things. I mean, there are short-term issues, but on the whole, that's where they're... they feel like, we need to understand basic biology, biological mechanisms. And it's clear, I mean, I think 50 years ago, we thought, wow, we're gonna get some simple answers here.

**Brady Huggett**

Yeah.

**Cathy Lord**

But that is not... but it isn't going to make a quick difference for the people that are alive today. So we decided we were really going to focus on that, is like, what can we do now? We had a committee of about 30 people. And then some of my staff and some other people helped in the end, you know, making figures or tracking down information. But we, I mean, we, what I tried to do, and I think I did not do this perfectly, was just represent different disciplines, different countries, you know, different continents, different perspectives. So that was my goal, you know, and people from different ethnicities, and then some parents, some self-advocates, you know, so...

**Brady Huggett**

So when it was done, the Committee of 30-plus, right, you were happy with the product, as they say.

**Cathy Lord**

Yeah. I mean, I think Lancet, you know, Lancet wanted to support it, and they sort of pooped out in the end. So I think that we could have, it could have had more sort of power to it if they, like — they are making paper copies, but we haven't seen them.

**Brady Huggett**

Oh, I see.

**Cathy Lord**

And it's been, like, a year. And paper copies aren't the answer to all things. But I think that the process was definitely interesting. And I think we came up with some things that, if people would take seriously, would be helpful.

**Brady Huggett**

Oh, for sure. So I mean, I read it. It was a fascinating read and I thought there were a lot of really smart things in there. But the thing that — the thing that caught the zeitgeist, if you will, is profound autism.

**Cathy Lord**

Yeah.

**Brady Huggett**

Right. Was that a surprise?

**Cathy Lord**

No. I mean, I think we were hoping it wouldn't be the only thing people remembered. And I don't think we expected the adamant negativity from some of the self-advocate communities. I mean, we thought people might not be super happy about it. But because we had self-advocates on the committee, and the first thing one of them said was, what about me? I don't have it, you know, is this gonna hurt me?

**Brady Huggett**

Oh, I don't have profound autism.

**Cathy Lord**

Yeah, I don't have profound autism. So why are you talking about this. And — but I think that, I think in that case, we convinced them, you know, it was, like, you don't, you know, but we need to be careful that we don't forget about these people, because it's so much easier to talk to you. And so much easier — I mean, you have a blog, you know.

**Brady Huggett**

Yeah.

**Cathy Lord**

It's so much easier for you to communicate with these other people. And in the meanwhile there are laws being passed, that really hurt people that have more severe needs. And we need to be careful that they don't just get forgotten.

**Brady Huggett**

You mean like laws around housing?

**Cathy Lord**

Yes.

**Brady Huggett**

Yeah, exactly. But the thing — so when I read it, I thought, okay, well, here's somebody who is saying, autism is a spectrum, of course. There's lots of needs here, but we cannot forget this one group, they are the most needful. They cannot advocate for themselves. Let's call it profound autism. And let's see what happens.

**Cathy Lord**

Yep.

**Brady Huggett**

And I thought, Okay, well, this might be some sort of progress one way or another, but then, you know, not long afterward, Liz Pellicano put out her paper and it said, We disagree with this. And I thought, well, we're just going to have more fighting.

**Cathy Lord**

Yeah. I know.

**Brady Huggett**

Is that what it feels like?

**Cathy Lord**

I think, I mean, the fighting is hard. I feel terrible about that fighting, because I think it doesn't help anybody.

**Brady Huggett**

Yeah.

**Cathy Lord**

You know, it does not help to not be united on the fact that everybody needs help. And it's complicated. I mean, I think we're, I'm — I'm part of a small group, where we're trying to see like, where do we go next? And it's not simple. You know, I mean, I think that, you know, Allison Singer, who was very adamant behind profound autism, is like, why don't we just bring Asperger's back? But Asperger's didn't work.

**Brady Huggett**

Yeah.

**Cathy Lord**

And I think what we're trying to do is figure out, well, if we have other, you know, different categories, what would they be? Because my, I mean, my general feeling as a clinician is, you know, there are people in the middle, you know, there are people that are very skilled and articulate. And that includes many of the self-advocates, but also often from really quite financially supported backgrounds. And there are people that are equally articulate, but are not, have not had as many resources or don't

have as many resources, who are really struggling. And people who are very bright, but who have other problems that really limit their ability to be independent. And I don't want to — I mean, we spend, I spent part of my life fighting for SSI, for bright autistic people that cannot support themselves. And if we had a better society, maybe they would, but at this point, you know, they can't bring in enough money to pay for bills, and they could not manage living on their own. And so what do we do with them? You know? I mean, we don't want to say things about them that imply that they are, that they don't need help, because they do.

**Brady Huggett**

Yeah.

**Cathy Lord**

You know, I mean, I hope we didn't, by picking out one group, we didn't screw everything up for everybody else.

**Brady Huggett**

Well, it doesn't feel — I mean, it doesn't feel resolved, right?

**Cathy Lord**

No, it is not resolved.

**Brady Huggett**

I think there's a long way to go, still. It feels like — okay, so 50 years ago, when you first started this, maybe the biggest hurdle to the field was — I don't know. Maybe it might even have been diagnosis back then, right?

**Cathy Lord**

Yeah, it was. I mean, I remember, oh my God, Denny Cantwell, who was a professor here, saying in a study section, you can't, you know, there's no rule. It's not a reliable diagnosis. So how could we possibly fund this?

**Brady Huggett**

Right. And that's been sort of taken care of.

**Cathy Lord**

Yeah.

**Brady Huggett**

And do you think this is the hurdle now? The biggest hurdle is sort of how do we move forward with this, with this spectrum?

**Cathy Lord**

I hope not. I hope not.

**Brady Huggett**

What might be the biggest hurdle then? Like, what's the biggest hurdle in front of the field?

**Cathy Lord**

Well, I mean, I do think you're right. I think the biggest hurdle is how do we have support services for everybody that are going to be quite different? And how do we mobilize what has been defined as a primarily medical problem? Where many of the solutions are not medical: they really are social.

**Brady Huggett**

Yeah.

**Cathy Lord**

And how do we do that? And I think that our, you know, in our culture in the United States, we don't do that well. So I think that there are other similar problems where we have not figured out what to do. And that's, I think that's the challenge. I think it does... I think that the self advocates are right that to emphasize that this is a medical condition does not get us where we need to go. But I also think that we need to acknowledge that there are huge individual differences, and also that there are people that cannot speak for themselves and that often the most appropriate person to speak for them are parents. Not a self-advocate who really doesn't know them.

**Brady Huggett**

Yeah, I want to ask one more thing. I'm already going over an hour. But mentoring — because I know that's important to you. Like, I think you've had some good mentors in your career?

**Cathy Lord**

I have. I have had wonderful — oh, both mentors for me.

**Brady Huggett**

Yes.

**Cathy Lord**

I've had incredible mentors, myself. And I have had wonderful graduate students. So between the two of them, I sit.

**Brady Huggett**

But you feel like because you've had good mentors that it's important to bring along the next generation and everything else?

**Cathy Lord**

Absolutely. And there's, I mean, there's just nothing except probably having your own family that is as good as having a really good graduate student or postdoc. I mean, they are wonderful. And they make everything better. I mean, they, I mean, all of the things like the ADOS and the ADI and all the things we've done, have been group efforts where people are like, oh my gosh, that doesn't work. And let's try that. And I think having this incredible group, or I have been so lucky to have this incredible group around me. And then I also did have people like my brother and Eric Schopler. You know, and Roger Brown even, you know, above me, you know, doing somewhat the same thing.

**Brady Huggett**

Yeah. Who helped bring you along.

**Cathy Lord**

To me, yeah.

**Brady Huggett**

That's all I had.

**Cathy Lord**

Okay.

**Brady Huggett**

Thank you so much, so much for doing this.

[transition music]

**Brady Huggett**

Wasn't that nice? Wasn't she nice? I walked out of her house and thought about that talk for the rest of the day, at least. A big thank you to Cathy for having me into your home for this interview.

This podcast will be archived at [spectrumnews.org](http://spectrumnews.org). The next episode will be out June 1<sup>st</sup>. A reminder that you can find us on Twitter, where our handle is [@spectrum](https://twitter.com/spectrum). You can tell us what you thought of this podcast, or actually anything else that we do here at *Spectrum*. Our theme song was written and performed by Chris Collingwood. And that's it. I will talk to you on the next one, and I'll let the music play us out.

[end theme music]

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