

# Emotion dysregulation in autism with Carla Mazefsky

The director of the University of Pittsburgh's Autism Center of Excellence talks about her new work investigating suicidality in autistic adults.

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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**

All right. Welcome to "Synaptic," *Spectrum*'s podcast that looks at the research, the people and the challenges of the autism research space, and sometimes the neuroscience field more broadly. My name is Brady Huggettt. I host this show and thank you for joining.

[transition music]

#### **Brady Huggett**

OK, let's go way back, all the way to 1773, which is even before the United States declared its independence from Britain. Let's go that far back. On October 12<sup>th</sup> in 1773, in Williamsburg, Virginia, the first mental hospital in the colonies was founded. It was originally called the Public Hospital for Persons of Insane and Disordered Minds, and it was set on less than four acres of land and placed a good distance back from the nearest road.

The kind of warning that this was not a place for casual visitors. Family members, or friends, or sometimes the sheriff would bring in new patients to occupy the 24 rooms, which were called cells. Chains and shackles were involved. There was no doctor on site, no nurse, no recreation room. The people of Williamsburg referred to it as a madhouse or bedlam. And then later it was also called the Eastern Lunatic Asylum.

So by today's standards, or really maybe any standards, this was a grim place, but it began to improve. Since its founding, it had been overseen by members of the Gault family, and in 1841 that became John Gault. John, however, was an actual physician, and he resided on site, and he was the first physician to do so, actually, instead of just visiting. He understood that the mentally ill were human beings with emotions capable of complex thought, and he treated them as such.

He installed carpentry and shoemaking shops, which gave the residents tasks and kind of pride of employment. And he brought in recreational games like cards and dominoes, and he installed the library, and that was a key shift. The hospital grew in size over the years, and treatment continued to improve as society and-and the medical community gained a better understanding of mental illness.

Today it's referred to as Eastern State Hospital, but most importantly for this podcast, more than 200 years after its founding, right around the year 2000, Carla Mazefsky frequented the Eastern State Hospital as a college student. She was at William and Mary then, doing her honors thesis on schizophrenia. She spent time interviewing patients at Eastern, and the things she saw, felt and experienced there changed her trajectory. And by the time she graduated, she knew that she wanted to study psychology. That's today's guest, Carla Mazefsky.

In this podcast, we talked about her experience at Eastern State Hospital, and we talked about her work around emotion dysregulation in autistic people, and we talked about her journey to the University of Pittsburgh, where she's a professor in the Department of Psychiatry and the Nancy J. Minshew chair in autism research. And we talked about her current research into suicidality and autistic adults. All of that coming in the next hour. So I interviewed Carla in Pittsburgh in late May. It was sunny, in the mid-70s, almost perfect weather.

The Pitt campus is located in the Oakland neighborhood of Pittsburgh, and we met in Carla's office. I put the mics across her desk, and we settled in. So let's start here, where she and I are talking about her childhood in Connecticut. This is your episode of "Synaptic" with Carla Mazefsky starting right now.

## [transition music]

## **Brady Huggett**

Yeah. But you — I had this feeling that you didn't actually grow up in Pittsburgh.

## Carla Mazefsky

No.

## **Brady Huggett**

Are you from — where are you from?

#### Carla Mazefsky

Connecticut.

## **Brady Huggett**

Oh, Connecticut.

## Carla Mazefsky

Yeah.

## **Brady Huggett**

Huh. OK. Well, good. I'm learning something already. Um, I mean, I saw that — I saw where you had done your undergrad. So where-where in Connecticut?

## Carla Mazefsky

I grew up in Easton. It's like a small town in Fairfield County.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

But I haven't been back there since I was 18.

#### **Brady Huggett**

Oh, yeah.

## Carla Mazefsky

So it's been a while.

#### **Brady Huggett**

Were you — Um, did you have any idea what you wanted to do when you were young like that?

## Carla Mazefsky

When I was in high school?

## **Brady Huggett**

Or even earlier?

## Carla Mazefsky

I mean, well, when I was younger I thought I wanted to be Paula Abdul, of course.

## **Brady Huggett**

Not a bad idea. Yeah-yeah.

## Carla Mazefsky

And then — um, no, in high school I thought maybe I was going to go into like pre-med —

Uh-huh.

### Carla Mazefsky

— um, or medicine. And then I also wondered about like, um, marine biology.

## **Brady Huggett**

Huh.

## Carla Mazefsky

And then in college is when I started to focus on psychology.

#### **Brady Huggett**

Were you — the marine biology, were you — Did you grow up on the coast at all in Connecticut? No.

#### Carla Mazefsky

No. I mean relatively close but no, not really. Not like we were there that much. I just thought it was interesting.

## **Brady Huggett**

And the-the same thing for the pre-med because, you know, doctor is a good job to have or-or did you actually have an interest in helping people or medicine?

## Carla Mazefsky

I mean, I had an interest in helping people, still, like, stayed in that line, I would say. Um, and I don't know, it just seemed like it would — could be a good fit for my skills. But —

## **Brady Huggett**

Mm-hmm. And were you good in the sciences in high school?

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

Science and math.

#### **Brady Huggett**

Why, uh, why Connecticut? Like, why was your family there? Was it a long history of people living in Connecticut, or?

## Carla Mazefsky

My mom did grow up in Connecticut, in Stanford. Um, and then my dad grew up in Rhode Island —

## **Brady Huggett**

Mm.

## Carla Mazefsky

— in Providence area.

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

He's a hundred percent Italian.

Oh, yeah.

### Carla Mazefsky

Um, and then, I don't know, they lived there. They lived there until-until I graduated. And then my dad moved to Virginia where — and like lived apart from my mom for two years doing long distance while my sister finished high school. And then-then they moved to Virginia also.

#### **Brady Huggett**

Uh-huh. OK.

#### Carla Mazefsky

So we both had like in-state tuition for William and Mary.

#### **Brady Huggett**

Got it. OK.

## Carla Mazefsky

Yeah.

#### **Brady Huggett**

Do you know how your parents met?

## Carla Mazefsky

I'm trying to think. I feel like they met at a party. And they were both skiing in, like, their ski club. That's what I think but —

## **Brady Huggett**

In Connecticut or something? No.

#### Carla Mazefsky

Yeah, in-in Connecticut.

## **Brady Huggett**

Yeah. OK. So you grew up, you're a New Englander sort of, right?

#### Carla Mazefsky

Sort of, yeah.

#### **Brady Huggett**

Yeah. And then you're thinking about — I don't know, you're good in the sciences in high school, you're thinking about maybe medicine because what else? You know, if you're good in sciences, what else would your career be, right?

#### Carla Mazefsky

Mm-hmm.

#### **Brady Huggett**

You're thinking you might want to help people. And then, um, where did you look at schools?

#### Carla Mazefsky

Well, that actually is an interesting story 'cause I-I was a good student, um, and like well-rounded, doing a lot of different things. So I looked — I was like aiming sort of high. I wanted to go into the mid-Atlantic region. Um, mostly I just liked the idea of it for some reason. So I was looking mostly at Duke —

## **Brady Huggett**

Mm.

— UVA and William and Mary. And then I also applied to University of Michigan.

## **Brady Huggett**

Mm.

#### Carla Mazefsky

Um, and I got into University of Michigan early, before I had heard about the others. So then I did not apply to any safety schools after that. And then I got —

#### **Brady Huggett**

You — So you were thinking no matter — I mean, I can —

## Carla Mazefsky

N-.

## **Brady Huggett**

— I can go to a good school no matter what. Michigan — [crosstalk]

#### Carla Mazefsky

Yeah. Michigan is, like, an awesome school.

#### **Brady Huggett**

Yeah, yeah. Great.

## Carla Mazefsky

Like, it would be great to go there, but then I didn't wind up getting into any of the other three. And then Michigan was really expensive out of state —

#### **Brady Huggett**

Huh.

#### Carla Mazefsky

And then, you know, there's like a little window when you can't get financial aid if your family makes too much. But —

#### **Brady Huggett**

Yeah.

## Carla Mazefsky

Anyway, long story short. So I wound up taking a year abroad and I went to, um, Belgium, the Flemish-speaking part of Belgium for a year as an exchange student.

#### **Brady Huggett**

Before?

#### Carla Mazefsky

Before college.

#### **Brady Huggett**

So you never enrolled in Michigan?

#### Carla Mazefsky

No. I didn't enroll.

## **Brady Huggett**

Uh-huh, OK.

In the end. Um, it was too expensive.

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

So — but I didn't want to — I didn't want to just go somewhere else. I decided to do the exchange student thing. We had hosted an exchange student in high school.

## **Brady Huggett**

Huh.

#### Carla Mazefsky

So it was always something I had thought about doing, and so it sort of prompted me to do that. So I did that in between high school and college.

#### **Brady Huggett**

Where-where, uh, where was the exchange student from?

#### Carla Mazefsky

Um, the one we hosted was from the Netherlands.

## **Brady Huggett**

Hmm. I'm just curious, like any reason why your parents did that? Because it's a great thing to do, or?

## Carla Mazefsky

I mean, we had been involved in — it was the — AFS is the program. We had been involved in the program, um, doing other things like throughout high school, and growing up, and I think it's just a good thing to do.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

It's like —

## **Brady Huggett**

Yeah. It's sort of like then your children, meaning you —

#### Carla Mazefsky

Mm-hmm.

#### **Brady Huggett**

— have this exposure to someone from a foreign country, which is also useful in the house and everything else.

#### Carla Mazefsky

Right.

## **Brady Huggett**

Yeah-yeah. OK. So you had — you already knew kind of what that was like.

## Carla Mazefsky

Right.

## **Brady Huggett**

And then why did you choose Belgium?

Well, um, since I decided kind of late, like, and I was already going to be 18 when I traveled, um, not all of the-the countries allowed AFS students who were 18 already. So that narrowed it down.

## **Brady Huggett**

Mm.

#### Carla Mazefsky

And then there were some that were ruled out because of too much political unrest, and my parents weren't comfortable with me going. And then, um, Belgium was left and it's like kind of in the middle of Europe.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

Pretty cool for traveling and, um —

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

— near the Netherlands where we obviously had the exchange student from. So it seemed like a good fit. This was when we didn't have — I didn't have email yet —

#### **Brady Huggett**

Yeah.

## Carla Mazefsky

— no cell phones. So it was very different like going abroad for a year, basically corresponding by snail mail.

## **Brady Huggett**

Right.

## Carla Mazefsky

Yeah.

#### **Brady Huggett**

OK. So-so you've got this year, you're thinking, well, I'm-I'm not going to go to college. I don't want to just sit around. That's —

#### Carla Mazefsky

Yeah. And the other thing that I really liked different from, like, the medicine or biology idea was, um, art. And I was really into

#### **Brady Huggett**

Yeah.

## Carla Mazefsky

— art and drawing and painting. So I did — when I was in Belgium, I was in an art school, but it didn't count. It was like redoing a senior year in a specialized art school.

## **Brady Huggett**

So you lived with the host family?

## Carla Mazefsky

Yeah.

You attended school every day at this art school?

### Carla Mazefsky

Yeah.

#### **Brady Huggett**

Well, that's kind of amazing.

## Carla Mazefsky

Yeah, it was cool. I mean, it was — everything was in Flemish too, so.

#### **Brady Huggett**

So did you pick — how much language did you pick up?

#### Carla Mazefsky

I was fluent by the end of the year. I mean, well earlier than that. My —

## **Brady Huggett**

Mm.

#### Carla Mazefsky

— my host family stopped speaking English after, I forget how long. They had, like, a-a period of time when they were gonna do it and then stop, which forced me, I think.

## **Brady Huggett**

I mean, given that you were sort of planning on college, you must not have had that much time to crash course Flemish. How did you pick that up?

#### Carla Mazefsky

No, and I don't think any of the other exchange students who were there that year really came in knowing any Flemish either. You-you start with one week of, like, language camps that AFS runs, and that's really cool. 'Cause it was exchange students from all over the world.

#### **Brady Huggett**

Mm.

#### Carla Mazefsky

So everyone who's in Flemish — I mean, in the Flemish part of Belgium basically was there together. And so that's sort of kickstarts it. And then it's just like the idea of immersion. Like you're just — like all the exchange students really, by the end were fluent in Flemish. I mean, now if you asked me to, it would be embarrassing.

#### **Brady Huggett**

You can't speak it anymore.

#### Carla Mazefsky

No.

## **Brady Huggett**

No.

## Carla Mazefsky

But I-I can understand some of it. Or when we, um, actually in- INSAR, the International Society for Autism Research meeting was in the Netherlands —

Mm.

#### Carla Mazefsky

— about four years ago. And-and I could remember it pretty quickly once I was back —

## **Brady Huggett**

Mm.

## Carla Mazefsky

— like understanding, but still not speaking as much.

## **Brady Huggett**

Mm. And you could order at a restaurant, that kind of thing.

## Carla Mazefsky

I could read the menu.

## **Brady Huggett**

Yeah-yeah.

[laughter]

## Carla Mazefsky

I wouldn't embarrass myself too much.

## **Brady Huggett**

OK. So you spent a year in Belgium?

## Carla Mazefsky

Yeah.

## **Brady Huggett**

And then that ends.

## Carla Mazefsky

And then —

## **Brady Huggett**

OK.

## Carla Mazefsky

Yeah, then-then I — at that point, like when I went to Belgium, my dad moved to Virginia 'cause still I really wanted to be, like, in that area.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

And then — and I had been wait-listed at William and Mary, um, and then didn't get in. So I had, um, reapplied to William and Mary, um, as a state resident at that point —

## **Brady Huggett**

Mm.

— um, and got in. Yeah.

#### **Brady Huggett**

And so that number-number one, your-your sort of application is probably bettered by now – "I've been in foreign exchange student for a year." That's —

## Carla Mazefsky

Yeah.

## **Brady Huggett**

— you know, something notable. And then also you-you would have in-state tuition.

## Carla Mazefsky

Right.

## **Brady Huggett**

Yeah. So did you only apply to William and Mary?

#### Carla Mazefsky

I think I only applied to William and Mary because I got in there.

## **Brady Huggett**

Huh.

#### Carla Mazefsky

That-that was — at that point then it was my top choice.

## **Brady Huggett**

It's like if you hadn't gotten in there, what would you have —

#### Carla Mazefsky

Well, I would have —

#### **Brady Huggett**

I mean, your career would've been really different.

#### Carla Mazefsky

I — yeah. My career would've been really different. Yeah. 'Cause I had several, like, key experiences while I was at William and Mary that led to me doing what I'm doing now.

## **Brady Huggett**

Yeah.

## Carla Mazefsky

Um, but I probably would've looked again at some of the same schools I applied to.

## **Brady Huggett**

Mm. So you get into William and Mary.

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

And do you still think you were, like, pre-med at this point?

I started out thinking I was gonna do a biology-psychology double major.

#### **Brady Huggett**

Mm.

#### Carla Mazefsky

And then I was taking all of those classes in the summer. I took classes 'cause my dad was there. So I stayed there year round. Um, and I took organic chemistry in the summer.

## **Brady Huggett**

Brutal.

#### Carla Mazefsky

Organic 1 and 2. And then I decided not to be a biology major.

## **Brady Huggett**

Yep.

#### Carla Mazefsky

And just focused on psychology. And I really loved psychology.

#### **Brady Huggett**

Mm.

#### Carla Mazefsky

My school and high school was smaller, so we didn't really have a lot of exposure, um, to psychology classes. And so, um, I think that after that freshman year, and especially in the summer, then it just became clearer that was what I wanted to do.

#### **Brady Huggett**

So-so your freshman year —

## Carla Mazefsky

In psychology, yeah.

#### **Brady Huggett**

— as you were going in though, you were somehow already thinking about psychology?

#### Carla Mazefsky

I think still along the, like, idea of, like, helping, you know, helping profession. Um, and I always thought it was interesting.

## **Brady Huggett**

You did. Yeah.

## Carla Mazefsky

Yeah.

## **Brady Huggett**

This idea of what's going on in the mind and analyzing it and —

## Carla Mazefsky

Mm.

## **Brady Huggett**

— yeah. OK. So you're like, I guess I'm not gonna be a doctor. They weeded you out, as they say, with your organic chemistry. Right?

I think Orgo weeded me out. Yeah.

## **Brady Huggett**

Yeah. Um.

#### Carla Mazefsky

Not my cup of tea.

## **Brady Huggett**

So-so then you're like, OK, well maybe I can apply this sort of, you know, I want to help in the psychology field.

#### Carla Mazefsky

Yeah.

#### **Brady Huggett**

And so how did you begin to do that?

## Carla Mazefsky

Um, well I did an honors thesis, um, to get research experience. And that was working with a man named, um, a professor named Glenn Shean, and he focused on schizophrenia.

#### **Brady Huggett**

Mm.

#### Carla Mazefsky

So, um, my honors thesis was on schizophrenia, and I went to, um, there's a hospital called Eastern State Hospital in Williamsburg. It's the oldest psychiatric hospital in the country, actually.

#### **Brady Huggett**

Wow.

#### Carla Mazefsky

Um, and I interviewed, um, patients who were there for primary diagnosis of, like, schizophrenia spectrum, um, for my honors thesis. And that was a really — I loved the whole research process experience. Um, so that was one thing that really I think got me more and more interested in it. Um —

#### **Brady Huggett**

So — but you-you applied for that. You-you must have seen — you had an interest when you applied, you thought, well, that looks like an interesting thing to do.

## Carla Mazefsky

Well, yeah, I guess I connected-connected with him, thinking it would be interesting to work with him and, um, learn more about kind of severe mental illness and get —

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

— some, like, actual experience. Um, and then I really love that. I also was kind of interested in, like, the idea of forensic psypsychology —

## **Brady Huggett**

Mm-hmm.

— and so I also volunteered at that same hospital. You know, I don't even know what the technical term is now, but at the time it was called "not guilty by reason of insanity" for people who were, um, there, who had been convicted of major crimes. Um —

### **Brady Huggett**

Oh. So they-they had been convicted. They-they'd been charged with a crime.

## Carla Mazefsky

Oh, they were charged with a crime and they found not guilty by reason of insanity.

## **Brady Huggett**

And then sent there.

#### Carla Mazefsky

And then sent there. Yeah. So I worked —

#### **Brady Huggett**

Huh.

#### Carla Mazefsky

— closely with a psychia — the psychiatrist who over — led that specialized, like, inpatient unit for I don't know how long, a long time.

#### **Brady Huggett**

The-the interviewing of people with, um, I guess just schizophrenia, right?

#### Carla Mazefsky

Mm-hmm.

#### **Brady Huggett**

What does that look like? Was that, just, this is for your honor's thesis?

## Carla Mazefsky

Yeah.

## **Brady Huggett**

So are you meant to interview a bunch of people and then come up with some sort of, uh, theory on the brain or schizophrenia or something like that.

#### Carla Mazefsky

Yeah. It was like, kind of like a smaller version of what you might do for like a master's thesis or a dissertation where you had like a research question and a whole plan. So the focus was on, um, language and language processing. So, um, I was interviewing them and then analyzed their speech patterns with —

## **Brady Huggett**

Mm.

## Carla Mazefsky

— with some programs. And it was focused on, you know, different patterns of speech and things like that.

## **Brady Huggett**

The interviews are based on their history, or did you have a set, you know, set of questions you're supposed to ask them and then —

I had a set of questions.

#### **Brady Huggett**

Oh.

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

Oh, that must have been fascinating.

#### Carla Mazefsky

It was fascinating. Yeah.

## **Brady Huggett**

What did — what did you learn from that?

## Carla Mazefsky

I mean, I don't even — there's — I feel like I can't even remember like a key finding that was so interesting. I just remember the experience of being on the unit, um, being so pivotal. And I mean, I remember specific things like, I don't know why it stuck with me, like one time getting, like, punched in the back. But I think that's something that has followed me through with my, like, some of my interest in autism actually. Um, just like some of the behaviors.

#### **Brady Huggett**

You mean you got punched in the back?

## Carla Mazefsky

Yeah, I got punched in the back. [crosstalk] Like I remember some of these interviews it was just really were like emotionally charged or intense or, um, just like the environment of being on the unit was really —

## **Brady Huggett**

Yeah-yeah.

## Carla Mazefsky

— um, interesting for me.

#### **Brady Huggett**

Well, you were — you were punched in the back by the person you're interviewing, or someone came?

#### Carla Mazefsky

Another patient?

#### **Brady Huggett**

Uh-huh. OK.

## Carla Mazefsky

Yeah.

## **Brady Huggett**

Right. So-so I mean, you were 19 at this point.

## Carla Mazefsky

Yeah.

I mean —

## Carla Mazefsky

Roughly.

## **Brady Huggett**

— it's a little scary —

## Carla Mazefsky

19, 20, yeah.

## **Brady Huggett**

— to be doing that.

## Carla Mazefsky

It was a little scary, but I-I felt like I took it as like a challenge. Like, I was kind of fascinated and trying to learn more. So —

## **Brady Huggett**

OK, so this-this happens when you're like 19 —

#### Carla Mazefsky

Mm-hmm.

#### **Brady Huggett**

— and suddenly you think, all right, I want to — I want to do psychology.

## Carla Mazefsky

Yeah.

## **Brady Huggett**

Yeah. And then what-what about the forensics?

#### Carla Mazefsky

So that was like, kind of around the same time. Then I started also doing that other volunteering in the hospital. Um, and then I thought I wanted to get more experience with that side of like, if-if I was gonna go into forensics, like other aspects of like, I don't know, violence prevention's not the right terminology, but other sides of that. And so I volunteered with the Williamsburg Police Department.

## **Brady Huggett**

Uh-huh.

#### Carla Mazefsky

Which was another interesting experience. I, like, pretended to be a hostage when they did SWAT team training. Very different from what I'm doing now.

## **Brady Huggett**

So they would —

## Carla Mazefsky

But —

## **Brady Huggett**

You volunteered as a — like a — like a psychologist? No. You —

No, I was just, like, helping out.

#### **Brady Huggett**

I see.

#### Carla Mazefsky

Like just to help out and get like more exposure to like the police process basically.

## **Brady Huggett**

What that world looks like?

#### Carla Mazefsky

Yeah.

#### **Brady Huggett**

Yeah. And they said, OK, we're gonna do an enactment today of a hostage situation. You be the hostage.

## Carla Mazefsky

Yeah. Yeah.

## **Brady Huggett**

So the —

#### Carla Mazefsky

It's random experiences, but, um —

## **Brady Huggett**

And you're thinking, all right, well maybe what I can do is apply psychology to, um, a way to prevent crime almost. If you can get —

#### Carla Mazefsky

Yeah.

#### **Brady Huggett**

— people into treatment, maybe that'll be a reduction in crime.

#### Carla Mazefsky

Right.

#### **Brady Huggett**

Wow.

#### Carla Mazefsky

I think that was what I was thinking at that time. But then I felt like I needed more, like, clinical experience to be able to apply to graduate school. Um, and that's where, like, my autism interest came, or that's where my first, like, exposure to autism —

## **Brady Huggett**

What happened there?

#### Carla Mazefsky

— came about. I was just — I was taking some classes in the School of Education. There was, like, a flyer posted that said, "Do you wanna help make a miracle?" And I was like, that sounds like me. And it was just like this picture of a cute, really, really cute little boy with, like, the biggest blue eyes. I mean, I can actually picture the poster in my head still. And so I-I called to find out what it was about and it turned out to be a 9-year-old boy on the spectrum who's completely nonspeaking. And they were work — looking for someone to like, work with him —

Brady Huggett Uh-huh.
Carla Mazefsky — one on one. So —
<b>Brady Huggett</b> The-the poster, "Do you wanna make a miracle," that didn't say anything about psychology or it — or it did?
Carla Mazefsky No. Well, it said, like, do you wanna help work-work with this boy?
Brady Huggett So you knew it —
Carla Mazefsky It didn't say anything about psychology in particular —
Brady Huggett OK.
Carla Mazefsky — but it was,, like working one on one with a-a kid at the time. They said, you know, special needs.
Brady Huggett Uh-huh. They didn't even know that it was autism.
Carla Mazefsky No. He was diagnosed actually, and I-I should have looked up, I forget what the rates were back then, but it was still when when things were, like, thought to be very rare —

Mm-hmm.

## Carla Mazefsky

Um, and he was, you know, more typical of those who were diagnosed with autism back then, um —

## **Brady Huggett**

Right, so he's nonspeaking at 9 —

## Carla Mazefsky

Yeah.

## **Brady Huggett**

— which means there's-there's probably no intervention early on at all.

## Carla Mazefsky

Not much —

## **Brady Huggett**

Yeah.

## Carla Mazefsky

— and then he was getting a lot of intervention at 9 —

Right.

### Carla Mazefsky

— um, yeah. I mean, we worked with him on just, like, trying to have a reliable — like, yes, no response. He would dart into the street, so we worked on, like, safety, walking —

## **Brady Huggett**

Mm-hmm.

## Carla Mazefsky

— outside or, like, knowing like what room is the kitchen, um, and things like that. But I really enjoyed my time working with him.

#### **Brady Huggett**

How did you know how to do that? Had you already had training?

#### Carla Mazefsky

I was, like, trained under somebody, so she sort of, like, told me what to do.

#### **Brady Huggett**

All right. We're gonna try to — today, we're gonna try to focus on this. No — stop darting, number one. Number two, this is where the kitchen is.

#### Carla Mazefsky

Yeah, like, we had a very specific, like, treatment plan and goals and — so I knew every day what I was supposed to be working on.

## **Brady Huggett**

Hmm. How long did that go on?

## Carla Mazefsky

I worked with him an entire summer and then my entire senior year, and then I started working with some other, um, younger children —

## **Brady Huggett**

OK.

#### Carla Mazefsky

— on the spectrum.

## **Brady Huggett**

So well over a year with him.

#### Carla Mazefsky

Oh, yeah. Yeah.

## **Brady Huggett**

And-and this was your first introduction to autism, and I think it sounds like this, you grav — you began to gravitate to it.

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

Instead of forensic psychology instead of schizophrenia or crime —

Yeah.

### **Brady Huggett**

— it's more like —

#### Carla Mazefsky

It was like my — I-I, like, felt like it was my-my thing. I don't know —

## **Brady Huggett**

Mm.

#### Carla Mazefsky

— I really connected with him. He was, um — he had a lot of difficulties, and I think some of the specific experiences with him also sort of stuck with me. Um, like he had a lot of behaviors, um, spitting or aggression of all kinds, um, and at the time, you know, I was — again, I was young —

#### **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

— like, so I was really doing —

## **Brady Huggett**

20 or 21 or something.

## Carla Mazefsky

Yeah. And I was treating or doing what was the treatment plan. Like, so if he had a behavior, then the person who was above me who had a master's, I think she would, like, evaluate and say, "OK, this is what — how we're gonna handle it." Um, so like, for example, for the spitting, what he would do is he would spit, like, pull spit in his hand and, like, put it on my face —

## **Brady Huggett**

I mean —

## Carla Mazefsky

- and -

#### **Brady Huggett**

— gen — like you could see it coming, or he would just reach out and gently do it and you would know this was gonna happen.

#### Carla Mazefsky

No, I could see it coming.

#### **Brady Huggett**

Uh-huh.

## Carla Mazefsky

Um, but she determined she thought it was for attention. So, like, the plan was to ignore it.

### **Brady Huggett**

Got it.

## Carla Mazefsky

And that was like kind of the plan for most of his behaviors. And basically what would happen is it would work and his behavior would go away.

So if you were —

### Carla Mazefsky

The spitting would go away, but then something else would start, like, maybe less pleasant, like fecal smearing. And so, I mean, I think that experience really stuck with me because I always felt like we were missing something with him and, you know, my big area of research now is on emotion regulation —

## **Brady Huggett**

Right.

#### Carla Mazefsky

— and emotion dysregulation. And I mean, I think clearly — I think back, like, this clearly he was like distressed and what — you know, we could get rid of the behavior but we weren't really addressing the root of the issue. Um —

## **Brady Huggett**

So it's not — OK. So-so their thinking is it's attention seeking.

## Carla Mazefsky

Yeah.

## **Brady Huggett**

Ignore it and it's gonna go away, and it did work.

#### Carla Mazefsky

Mm-hmm.

## **Brady Huggett**

Right, but —

## Carla Mazefsky

Yeah, it worked.

#### **Brady Huggett**

— but also you're thinking that maybe it's not about getting attention because he already had — he already had your attention. He's sitting right in front of you.

#### Carla Mazefsky

Right.

#### **Brady Huggett**

And you're like, maybe it's something else that is causing this activity.

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

Hmm, OK. And did you talk about that with your-your mentor at the time?

## Carla Mazefsky

Yeah. I mean, I didn't have a men — I mean my — I didn't have a mentor, you know, in college who was focused on autism, really like — But-but the —

#### **Brady Huggett**

I'm sorry, the woman who was saying, you know, this is what we're gonna do today.

Yeah. Yeah, I did. And I think, you know, at the time, well, I didn't know — you know, I don't have much — I didn't have any credentials behind —

## **Brady Huggett**

Right. Right.

#### Carla Mazefsky

— behind me and like on face value, like the behaviors were stopping or, you know, the particular behavior in question would stop so —

#### **Brady Huggett**

So this was just something in your mind, you're thinking, I don't know if we got — I don't know if we're getting this right.

#### Carla Mazefsky

Yeah.

#### **Brady Huggett**

Hmm, OK. And you're still — this is your senior year?

#### Carla Mazefsky

Mm-hmm.

## **Brady Huggett**

All right, what happens after that?

#### Carla Mazefsky

Um, then I applied to graduate school and, um, you know, even though I was loving the autism experience, I still was thinking — I mean I still on my resume, I looked like a perfect match for like violence prevention.

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

Um, so I matched at Virginia Commonwealth University with, um, Al Farrell, a big violence prevention researcher. So it was exciting, I got into graduate school right out of college and went there. I did my master's thesis on violence prevention, um, but I wasn't, like, happy —

#### **Brady Huggett**

Are you —

#### Carla Mazefsky

— or not — or not fulfilled by it. And I just kept feeling like I was missing the autism piece.

#### **Brady Huggett**

Huh.

## Carla Mazefsky

And I was able to seek out Donald Oswald, he was at Virginia Treatment Center for Children at the time. Uh, he was a psychologist and doing a lot of autism work and clinical evaluations. And, um, he was willing to take me on to work with him, like for clinical, um, hours, and then I just decided it was really where I wanted to be. And my primary advisor, um, Dr. Farrell, was supportive, and I —

## **Brady Huggett**

Mm.

— started — so my dissertation was on autism.

#### **Brady Huggett**

Mm.

#### Carla Mazefsky

Um, and I pretty much focused whenever I could on autism after that point.

## **Brady Huggett**

This — did — when you're doing your master's in violence prevention, what does that look like?

## Carla Mazefsky

Yeah, I mean my master's thesis was looking a lot at, like, parenting and, like, community.

#### **Brady Huggett**

Oh, even further down the line, yeah.

#### Carla Mazefsky

Uh yeah. And it was with existing data and like, you know, looking at different relationships of how things, um, contribute to.

#### **Brady Huggett**

So it's like — it's useful but it wasn't your heart.

## Carla Mazefsky

Right.

## **Brady Huggett**

Yeah, OK. And you were like — you kept thinking about this, I don't know — this 9-year-old boy and how that had been. So that must have obviously been very rewarding for you, the 9-year-old.

#### Carla Mazefsky

Yeah. Yeah. I still wonder about him 'cause now he's an adult. But —

#### **Brady Huggett**

Have you tried to find him?

#### Carla Mazefsky

I have not been able to find him, but I would love to know what he's up to.

#### **Brady Huggett**

Yeah-yeah. What about his parents?

#### Carla Mazefsky

Yeah, I haven't been able to —

## **Brady Huggett**

Yeah, you looked — you've actually looked.

### Carla Mazefsky

Yeah.

#### **Brady Huggett**

Yeah, OK. All right, so then — so you roll that master's into a Ph.D. at VCU?

Yeah. The program was-was a doctoral program that I was accepted into —

#### **Brady Huggett**

Oh, I see. OK.

#### Carla Mazefsky

— a masters stage where you do the masters and then the dissertation.

## **Brady Huggett**

Yeah. OK. So then when you-your plan — All right, so let's talk about this, then your plan when you get the Ph.D. is to be your professor someplace, I guess.

## Carla Mazefsky

Yeah.

## **Brady Huggett**

And — but focus on autism.

## Carla Mazefsky

Yep.

## **Brady Huggett**

All right. So what — how did you — what happened then?

#### Carla Mazefsky

Well, um, so in clinical psychology you have to do an internship —

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

— a predoctoral internship, which is like-like medicine where you have to match somewhere. So you do interviews and then you match, um, and so I matched at Brown, which I was very excited about. They have great autism work there.

#### **Brady Huggett**

Providence?

## Carla Mazefsky

Yeah.

## **Brady Huggett**

Some family history.

## Carla Mazefsky

Yep. Yep. Um so, um, the only glitch was I had just gotten married to, uh, my husband Matt, who had just taken the bar exam in Virginia. Uh, he's a lawyer —

## **Brady Huggett**

Uh-huh.

#### Carla Mazefsky

- so, um, we had to spend that year apart. Um, not ideal for the first year of marriage -

## **Brady Huggett**

Yeah, Yeah,

— but, OK. Um, so like after that, my goal was to get back to where he was. So then I came after internship back to Virginia, um, and at the — at that time, um, there was an opportunity for a T32, like a research-focused postdoctoral fellowship at the Virginia Institute for Psychiatric and Behavioral Genetics —

## **Brady Huggett**

Uh-huh, OK.

#### Carla Mazefsky

— um, so that's what I did my postdoc year on, um, but because I was in clinical I needed additional clinical hours to get licensed. So I-I went back to also working with Donald Oswald at Virginia Treatment Center for Children and had the opportunity to meet Susan White then, who was, um, at the time an assistant professor with a career-development award. And I started working closely with her and she's, like, still to this day one of my long-time —

## **Brady Huggett**

Mm.

#### Carla Mazefsky

— longest collaborators. We just got a big multi-site clinical trial together. So that — I think even though I didn't really stick with any of the psychiatric and behavioral genetics piece, like that year was really — really had an important impact on my career.

## **Brady Huggett**

Yeah. Yeah.

#### Carla Mazefsky

Um. and then —

## **Brady Huggett**

But, so your husband's practicing at this point in Virginia and you — I don't know if you —

## Carla Mazefsky

Yeah, [crosstalk] he's at a law firm.

#### **Brady Huggett**

Did you — have you started a family yet?

#### Carla Mazefsky

No, he had a dog.

#### **Brady Huggett**

OK, you had a dog. Well, that's-that's how you start, right?

#### Carla Mazefsky

A very needy German shorthaired pointer, yeah —

#### **Brady Huggett**

Mm-hmm.

## Carla Mazefsky

—but sweet.

## **Brady Huggett**

Yeah.

Um, and no-no children yet. Um, and then a job posting opened up at the University of Pittsburgh for — they were looking for someone in pediatrics who would do like halftime, clinical halftime research. And I thought that sounded perfect —

## **Brady Huggett**

Perfect, right.

#### Carla Mazefsky

— um, and it was probably one of the only places that a year after taking the bar exam my husband would have retaken the bar exam. Um, 'cause he grew up in Pittsburgh until he was 12.

## **Brady Huggett**

Oh, he did, OK. All right.

#### Carla Mazefsky

So people in Pittsburgh are like usually die-hard Pittsburghers forever.

## **Brady Huggett**

That is 100 percent true, and I don't know why that is.

#### Carla Mazefsky

I-I think it's like it's not too big of a city and the people are really into this sports team. So there's a lot of like —

## **Brady Huggett**

Community.

## Carla Mazefsky

— community. Yeah.

#### **Brady Huggett**

Yeah. I-I mean, I agree. Everybody that I've ever met from Pittsburgh will tell me how great it is.

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

I mean, this is a-a side story, but like — I think outside of Pittsburgh, there's still sometimes the thought that it's maybe a city past its heyday almost, right? Because it, you know, it was the steel capital and everything else, and that no longer is the case. I don't think they've quite figured out what UPMC has done, what Carnegie Mellon has done, and how —

#### Carla Mazefsky

Right.

#### **Brady Huggett**

— much the-the city sort of built itself around health care.

#### Carla Mazefsky

Yeah. I think it's totally an underrated city.

## **Brady Huggett**

I-I mean it's ideal —

#### Carla Mazefsky

I mean, it's awesome to live in Pittsburgh, and yeah. Tons of health care, tons of, like, tech. Um, so —

So you're a convert?

### Carla Mazefsky

Yeah. Oh yeah. Now I am a die-hard Pittsburgher. [laughter] I don't know how — It's actually really funny that that happened because my husband did grow up here. His parents moved to Florida, but his uncle's still here. And we came — when we were dating, we came here for a wedding, and it was fun. We went to a Steelers game.

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

It was, like, snowing.

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

It was, like, this perfect experience. And on the drive back, he was like, "Do you think we could ever move to Pittsburgh?" And I was like, "95 percent no." [laughs]

## **Brady Huggett**

Wow.

#### Carla Mazefsky

And then here we are today, and I'll probably be here, I dunno, forever.

## **Brady Huggett**

Well, yeah, but so when the job comes up, you'd been 95 percent no, but suddenly there's a 5 percent chance.

## Carla Mazefsky

But it was, like, a good fit for him 'cause he wo-would've been excited to go there. Perfect job.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

And my main- my main reason for saying that was the weather, so —

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

Yeah.

#### **Brady Huggett**

Yeah. Well, OK, so you obviously you get the job.

#### Carla Mazefsky

So I got that job. Yeah. And so then, um, so then I was an assistant professor in pediatrics and, um, I was in that job for three years, and half of my time was spent doing diagnostic evaluations —

## **Brady Huggett**

Uh-huh.

— which I enjoyed. It's — but it's a lot of report writing and —

## **Brady Huggett**

Like for autism.

## Carla Mazefsky

Uh, all, yeah, all autism.

## **Brady Huggett**

So like —

## Carla Mazefsky

Or like questions of autism.

## **Brady Huggett**

You do the ADOS.

## Carla Mazefsky

Almost exclusively, um, yeah.

## **Brady Huggett**

Yeah. OK.

#### Carla Mazefsky

Mm-hmm. And then when I started that job, the child development unit where-where I was working was, like, children of all ages —

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

— but, like, everywhere. I had really long waiting lists. And so the approach to handle that was to, like, reduce the age range, um, maximum.

## **Brady Huggett**

Right.

#### Carla Mazefsky

So we started seeing like a maximum of age 7, I think. But what I really enjoyed and sort of specialized in the most, I would say was teenagers.

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

Um, so that was part of the reason I started to think about doing something different, um, than staying in pediatrics.

## **Brady Huggett**

Because-because your favorite part, which was about 7 and above, you're saying?

#### Carla Mazefsky

Yeah. They-they started —

## **Brady Huggett**

They had sort of been curved out.

— seeing only 7 and under.

### **Brady Huggett**

Yeah.

#### Carla Mazefsky

So no more, like, teenagers. So then I was at that time starting, like, applying for grants also, um, and had gotten a grant looking at, like, psychiatric diagnoses in teens —

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

— um, as compared to, like — based on structured interview as compared to, like, what they'd been diagnosed with kind of across their life to that point. And, um, so then there became a little more of a disconnect between my research interest and the clinical. And it's 50 percent clinical is really not 50 percent clinical anyway.

## **Brady Huggett**

Hmm. Like 70 —

## Carla Mazefsky

It's like full-time.

#### **Brady Huggett**

Oh really?

#### Carla Mazefsky

I mean it's just like clinical work, you know, for me, it became hard to really balance the two and I really wanted to spend more time on research. So I —

## **Brady Huggett**

But you also — you also had — you also taught, no?

#### Carla Mazefsky

No.

## **Brady Huggett**

Oh, no. OK.

#### Carla Mazefsky

No.

#### **Brady Huggett**

Just research-based.

## Carla Mazefsky

So in the medical school it was just — it was just, um, clinical work and research.

### **Brady Huggett**

Yeah. OK.

## Carla Mazefsky

And mean teaching in terms of like supervising, um —

Yeah, but not like — [crosstalk]

### Carla Mazefsky

— like trainees, but not formal coursework or anything. No.

#### **Brady Huggett**

OK. So what did you start to think about then?

## Carla Mazefsky

So then I also applied for a career-development award, which is like a kind of NIH award where they're really basically investing in your potential as an investigator. And then you have, like, training goals, but it's also tied to research plan. And it can really — The-the benefit of it doesn't come with a lot of money for the research project, but it comes with money to protect your salary —

#### **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

— for research, um, time up to 100 percent —

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

— or, you know, down to 75 percent. Um, so I applied for one of those grants. Um, and while it was under review, I just had an opportunity working with Nancy Minshew who was here at the psychiatry department. And at the time she had an Autism Center of Excellence award and needed more psychology support for her studies. So I basically took a pay cut to come over into psychiatry at that point, fully funded on her projects until, um, my grant came through. And I did get that career-development award, which allowed me to then focus on building kind of my own, you know, program of research.

## **Brady Huggett**

Did that feel like a risk?

#### Carla Mazefsky

It did feel like a risk, I guess. Um, but it just felt like, I don't know, I never really questioned it that much because it was the opportunity to do more of what I wanted to do.

#### **Brady Huggett**

Yeah.

## Carla Mazefsky

Um-

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

— and be in a department really focused on the kind of research I wanted to be doing. Um, so it just felt like an opportunity more than a risk —

## **Brady Huggett**

Yeah. Like the right move.

#### Carla Mazefsky

— given that of course, the little downside of salary.

Yeah. I mean, your husband has a salary too, so.

#### Carla Mazefsky

Yeah. Right. So I was fortunate.

#### **Brady Huggett**

OK.

## Carla Mazefsky

I was fortunate. Yeah.

#### **Brady Huggett**

I feel like — so it seems like this is — we're about to start talking about emotion dysregulation. Yeah.

#### Carla Mazefsky

Yeah, sure.

## **Brady Huggett**

OK. Well, start telling me about that research.

## Carla Mazefsky

OK. So then, um, my career-development award, though, was focused on neuroimaging. It was an FMRI study.

#### **Brady Huggett**

Uh-huh.

## Carla Mazefsky

Um, at the time it seemed like that made sense to do, get training in that area. It's not something I-I had exposure to before, but then in the end, I didn't really enjoy it that much. Um, just not really, um, for me, like directly applied or clinical enough. Um —

## **Brady Huggett**

Yeah, it's not hands-on enough.

#### Carla Mazefsky

Right. So after — so it was part of — like, during that process, I also applied, um, for a Slifka/Ritvo Autism Research Award for Innovation in Autism Research at, um, through INSAR. And that was to develop- to develop a measure of emotion dysregulation. 'Cause one of the things I noticed in my imaging study was like we weren't able to capture the variability and emotion dysregulation well enough to map it onto whatever we were finding in the brain-

## **Brady Huggett**

Mm.

#### Carla Mazefsky

-imaging. Um, and so that was really like a turning point for me because I- It gave me pilot data to then get a big NIH R01 to develop a measure called the motion dysregulation inventory and collect like huge amounts of data on motion dysregulation and really start to get all into that area and also really into measure development. Which is another thing I've like continued to do even when I was back, like on internship where, you know, I rotated in a day treatment program on an inpatient program and you see so much severe emotion dysregulation.

But then I would turn to literature like, what-what should I be doing for these patients? And people really weren't talking about emotion dysregulation and autism as much. The focus was more on the core, like, diagnostic symptoms.

## **Brady Huggett**

Yeah.

Or sometimes from the angle of like, you know, some focus on like psychiatric co-occurring conditions, but, which I've definitely done some of that work too. Um, but I prefer the emotion dysregulation angle because it's just — it's not an — it's the lines between what, you know, different psychiatric diagnoses are kind of blurry. And I just feel like we get a lot more out of looking at emotion dysregulation-

## **Brady Huggett**

Mm.

#### Carla Mazefsky

-as a process. Um, yeah. So at the time, like really there wasn't much happening in that area.

#### **Brady Huggett**

So how did you go about — It's called the EDI, right?

#### Carla Mazefsky

Mm-hmm.

## **Brady Huggett**

How did you go about setting this up? This sort of, um, I mean it's a survey.

## Carla Mazefsky

Mm-hmm.

#### **Brady Huggett**

Yeah. How did you figure out which questions to-to go after that get you the information that's most meaningful for this?

## Carla Mazefsky

Yeah. I followed — there's-there's some established measure development standards from like something called the PROMIS, which is an NIH initiative focused on patient-reported outcome measures. So luckily, one of the things I love about the psychiatry department at Pitt is there's, like, an expert in everything —

## **Brady Huggett**

Mm-hmm.

#### Carla Mazefsky

— in our department, I feel like. [chuckles] So there was a original PROMIS PI, Paul Pilkonis here, and I was able to connect with him, um, through that project. And we followed pretty closely their process. Um, so like doing a big review of what's out there in the literature and what existing measures, but then included a lot of, I think my clinical experience.

So some of the items we wrote for the EDI were like really almost word for word, like ways-

#### **Brady Huggett**

Mm.

#### Carla Mazefsky

-parents have described their children's emotions to me. And then we were trying to make it something that could be used across a spectrum. So avoiding things that, you know, would require a child to tell you what they're feeling.

#### **Brady Huggett**

Right.

## Carla Mazefsky

Um, and then yeah, then we like —

Well, I'm sorry.

### Carla Mazefsky

Yeah, sorry, go ahead.

## **Brady Huggett**

That means because if-if some children are nonverbal-

## Carla Mazefsky

Mm-hmm.

#### **Brady Huggett**

-they wouldn't be able to participate in this survey. Yeah, I guess.

#### Carla Mazefsky

Right. Yeah.

## **Brady Huggett**

OK.

#### Carla Mazefsky

And we wanted it to be something that could be used like really across the spectrum.

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

So, um, and then we interviewed parents, um, 'cause we — this started as a parent report measure, um, for children and then asked them to, like, think aloud as they're answering the items and say it back in their own wording. And I think all of that really helped make sure it was like really getting it what we thought it was getting it. And then by that time, I was also doing a lot of other research also with, um, Matt Siegel, um, the Autism Inpatient Collection.

Um, so I had access to, um, a large psychiatric inpatient sample too. So when we then evaluated the measure, we included people from that inpatient study plus like a big registry, um, called Interactive Autism Network, kind of a predecessor at assignment Simon SPARK Initiative.

#### **Brady Huggett**

Yep.

#### Carla Mazefsky

Um, so we had both like the representation from like a general community kind of professional diagnosis sample and an inpatient sample. So we had the real range of like, um, from like no motion dysregulation to the most severe forms, and I think that really helped make sure-

## **Brady Huggett**

Mm.

#### Carla Mazefsky

-we were, you know, then capturing the items that are most distinguishing.

## **Brady Huggett**

Right. So then you had this — uh, how big was the dataset? I mean, I'm sure it's growing but —

## Carla Mazefsky

Yeah. Um, we had like 1,300 something.

And then I think — now tell me where I'm wrong, but then I think, you know — O-OK, so you've done this survey and you started to gather this data, and then the next logical step is almost, well what-what can be done with this data? What might be done for treatment?

## Carla Mazefsky

Mm-hmm.

## **Brady Huggett**

And that's where your-your EASE program came in.

#### Carla Mazefsky

Yeah, so EASE is our emotion dysregulation intervention with, um, Kelly Beck, Caitlin Conner, and Susan White. And, um, it really was informed by the EDI because, um, we really tried to target those specific things that we learned are most characteristic of emotion dysregulation in autism. Um, and we were fortunate enough to get a DOD-like clinical trial award. Um, first I guess we had like other funding to develop basically a manual. Um, so that was actually — I glossed over that.

That was very long process, actually [laughs] of a lot of writing revisions. Um, and then a lot of input from parents from, um, there's an autistic psychiatrist who I still collaborate with closely who like read the whole manual, gave us a ton of feedback and we really iteratively developed it, basically.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

And then this was like our treatment manual of the EASE program. So, um, that, but we all developed that together and then we piloted it with teenagers, then we got the DOD Randomized Control Trial Award, and we just finished that. Um, and we're a-analyzing the data right now.

## **Brady Huggett**

You are.

## Carla Mazefsky

Like literally right now. [laughs]

## **Brady Huggett**

Yeah. When I leave this office, you're gonna-

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

-go back to analyzing it.

#### Carla Mazefsky

Yeah. Um —

#### **Brady Huggett**

I mean, can you talk about any of the findings at a low level?

## Carla Mazefsky

Yeah, I mean — S-so I can definitely talk about what we saw and I think what we — what I know or what I expect is that both groups are gonna improve. So we looked at, um, EASE, our treatment, which is like a mindfulness-based and motion regulation treatment versus, um, individualized supportive therapy.

Mm.

#### Carla Mazefsky

Um, and definitely we saw improvements in both groups, I think or hope that the improvements are gonna be even greater in the EASE group. Um, maybe in some surprising ways like I think we were really thinking about reactivity, um, as-as one of the primary targets but the groups might differ most in like dysphoria-

## **Brady Huggett**

Mm.

#### Carla Mazefsky

-which is the other area of the EDI. I don't know for sure-

#### **Brady Huggett**

Mm.

#### Carla Mazefsky

-'cause I'm still, like, analyzing, but, um —

#### **Brady Huggett**

But the-the-the mindfulness intervention part, it's sort of like, um, almost like it's OK to have these emotions, just let it sit for a while, um, breathe through it, etc., instead of, um, taking the next step, which might be lashing out or something like that. It's — is that —

#### Carla Mazefsky

Yeah. Yes. And that's like still something we really are focusing on in our research. So like all — like the idea like all emotions are OK.

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

Like experiencing emotion is like very nor-you know, normal. It's part of being a human. And, um, and I actually think we see more negative effects when people are trying to suppress those-those emotions kind of like you see with things like masking where you're trying to like-

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

-hold it in. And so-

#### **Brady Huggett**

Yeah.

## Carla Mazefsky

-that's a big part of EASE is like, it's much more of an acceptance-based, you know, model and like how you have those strong emotions but like still like stay in control enough to meet your goals. Um —

## **Brady Huggett**

Right. It's not-it's not like, "Hey, you shouldn't be feeling this way."

### Carla Mazefsky

Right.

It's OK to feel this way, but how do we handle it?

#### Carla Mazefsky

Right.

#### **Brady Huggett**

Yeah. Hmm. OK. And just do you have any idea when that paper might be coming out?

## Carla Mazefsky

Hopefully soon. I think we're gonna try and, um, publish it as soon as we have that data in.

#### **Brady Huggett**

Good, OK.

#### Carla Mazefsky

So, hopefully, this spring or summer.

## **Brady Huggett**

OK.

#### Carla Mazefsky

Um, and we've been fortunate enough to just get a Cory Award so we're moving on with our research to compare EASE to, um, something called the Unified Protocol, which is, um, kind of a standardized cognitive behavioral therapy, um, in-in 10 community clinics here and in Alabama with Susan White.

## **Brady Huggett**

Do you — so there's been a lot of — a lot more people looking at, uh, emotional dysregulation than before-

#### Carla Mazefsky

Yeah.

#### **Brady Huggett**

-or emotion dysregulation. Do you feel like you were at the forefront of something or-or just you happened to catch the wave at the same time as everyone else or-or what happened?

## Carla Mazefsky

I-I dunno. [laughter] Hopefully, I was at the forefront. I don't know. I-I think like- I think I was kind of like lucky that we started publishing on it. I don't know if we were lucky or we inspired some people or, um —

#### **Brady Huggett**

Probably both. A little bit of both.

#### Carla Mazefsky

Yeah, maybe a little of both. Um, but it's what — for whatever the reason may be, it's like gratifying to see, like, how the field has changed and how many more people are focusing on emotion regulation and dysregulation. Sometimes I do like a little like Google search of how many abstracts have that in the, um, or how many, yeah, how many papers have that in the abstract emotion regulation and autism and it's like skyrocketed-

## **Brady Huggett**

Really?

#### Carla Mazefsky

-since our first paper. So it-it's-it's something people are thinking about a lot more, which I think is, you know, in line with what a lot of you-you know, what you hear from a lot of, um, autistic adults and priorities 'cause it's really-

Right. Exactly.

### Carla Mazefsky

-linked w-with quality of life.

## **Brady Huggett**

Right. So that's there's a need that's clear. Right. Um, but when you, like, when you stop and think about it, it just makes sense.

## Carla Mazefsky

Yeah.

#### **Brady Huggett**

And just no one had really stopped to think about it, I think.

#### Carla Mazefsky

Yeah. Because I mean, if you're not regulated, like you can't really, I mean it interferes with everything-

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

-like with learning, with social interaction, with getting, you know, what you should out of other therapies or working, you know-

## **Brady Huggett**

Yeah.

## Carla Mazefsky

-school, everything. So — [laughs]

#### **Brady Huggett**

Yeah-yeah. Um, I know that you-you've also talked about something called the autism services cliff.

#### Carla Mazefsky

Mm-hmm. Yeah.

#### **Brady Huggett**

Yeah. Let's-let's talk about that. And this I think relates to, you know, your interest before of like dealing with teenagers and —

#### Carla Mazefsky

Yeah-yeah. I mean, I did start really focused on teenagers. I might be even more focused on adults, but adults and teenagers for sure. Um, and our treatment trial is like kind of that transition to adulthood especially. Um, but yeah, I mean, I also think — so there's a treatment cliff going into adulthood. We don't know as much about adulthood, yet we spend most of our time in adulthood, um, versus childhood, and the other thing is like, I think societal expectations for adult behavior are very different from children. Um, so, you know, some of the impact of emotion dysregulation is different or how to navigate that in the workplace is challenging. So we've, um-

## **Brady Huggett**

Mm.

## Carla Mazefsky

-we have really started to focus a lot on adulthood in our research program, um, including a new big like center grant focused exclusively on adults.

I mean, why-why don't we know as much about adults as we do children?

#### Carla Mazefsky

You know, I feel like people sort of thought of autism as a childhood thing back in the day. Um, and I mean, I think that there was so much emphasis on early intervention as like the answer, um, at the time, um, that-that it wasn't gaining attention like it does now. Um, and then I think also with expanding recognition of like the spectrum of autism-

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

-now we're, you know, fortunate that autistic adults are speaking up about their needs and interests and what they want, um, to be focused on and including like just adulthood in general but, you know, helping to guide those research priorities more and I think that's helped shift attention to adults.

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

Um-

#### **Brady Huggett**

Yeah. So this — the services cliff you're talking about is, well, it's partially attention, I guess is what you're saying —

## Carla Mazefsky

Yeah. I mean, well, at least when you're in school and if you do stay in school till you're 21, um, if you're in, like, if you have an IEP, and you can, um, then you at least have some structure and some way to have covered services-

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

-and then like even navigating after that, like what's covered well, really variable from state to state but then pairing that with that, we haven't really focused on autism, so there aren't even that many like great programs out there to know, like, how to support adults in what they need. Um, it does feel like a cliff for many people, um, like what to do. And —

#### **Brady Huggett**

Yeah, and the moment, let's say that you do, you're in school until you're 21, the moment you get out, it's like, "Well, I've lost most of my support."

#### Carla Mazefsky

Exactly.

## **Brady Huggett**

Yeah.

## Carla Mazefsky

Yeah.

## **Brady Huggett**

Um, OK, there's two things that I wanna ask you before we're done.

## Carla Mazefsky

OK.

And the-the first one goes back to your time at the Eastern State Hospital.

### Carla Mazefsky

Yeah.

#### **Brady Huggett**

So knowing, well first off, you said it was the oldest one in the country?

## Carla Mazefsky

Yeah.

#### **Brady Huggett**

So in my mind, I'm assuming that that was built in like the 1700s or something like that?

#### Carla Mazefsky

Yeah, something like that.

## **Brady Huggett**

Yeah. And I'm, which would make it maybe a grim place, like I'm imagining hard floors and grates on the windows, that kind of stuff.

#### Carla Mazefsky

Yeah. The original building, it's-it's no-no longer in the original building. But I think it's still there in Williamsburg. But yeah, it was not a — like, it was more like, well-well we wouldn't want today for any psychiatric-

## **Brady Huggett**

Ye-yeah.

#### Carla Mazefsky

-hospital, more like an asylum-

## **Brady Huggett**

Right.

#### Carla Mazefsky

-more like a negative-

#### **Brady Huggett**

Right.

## Carla Mazefsky

-thing. [laughs]

## **Brady Huggett**

And when you think about the people that you saw in there and if they had had any sort of access to — so they were charged with something, if they had been able to have help on emotional regulation, would they not have been in there? H-have you thought about that?

### Carla Mazefsky

Huh, I haven't thought back about that in particular. Much like the same —

## **Brady Huggett**

Like how many of those crimes were like-

Yeah.

### **Brady Huggett**

-letting loose of emotion, were, I don't know whether it's-

#### Carla Mazefsky

Right.

## **Brady Huggett**

-physical or I-I don't know. I don't know.

#### Carla Mazefsky

Yeah. I mean, it's hard to say for sure, but I'm sure it wouldn't reduce some of it.

#### **Brady Huggett**

Yeah.

## Carla Mazefsky

Um, I mean, I kind of feel like — I mean, I obviously focus almost exclusively, basically on autism, but I often feel like emotion dysregulation would be like — or emotion regulation, you know, intervention-intervention [chuckles] just basic, like no one can see my air quotes-

## **Brady Huggett**

Yeah. Yeah. Intervention, right.

## Carla Mazefsky

[chuckles] -on a podcast, in — Yeah. Like not intervention, but just like, kind of like you have like, you know, like sex ed in school.

## **Brady Huggett**

Right.

#### Carla Mazefsky

Like it-it should be like a — I feel like maybe we would all be different if we all had, you know, some of that.

## **Brady Huggett**

Yeah. Or it's I mean — or anger management. Right?

#### Carla Mazefsky

Right.

#### **Brady Huggett**

You having these emotions, what do you do with them? How do you not bottle-

#### Carla Mazefsky

Right.

#### **Brady Huggett**

-them up? How do you not let them explode? Yeah.

#### Carla Mazefsky

Yeah. And not feel ashamed of them.

## **Brady Huggett**

Yeah.

Like be able to talk about them and-

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

-um —

## **Brady Huggett**

You've been studying, you got a grant, I think to study suicidality in adults.

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

Tell me about that.

#### Carla Mazefsky

Yeah, we — very excited. We just got a big Autism Center of Excellence grant focused all on adults and mental health broadly, but with a big suicide focus. Um, so we're gonna do like, I think the first big deep dive into suicidality. People have been talking about how it's much more prevalent, some stats up to seven times more common in autism.

## **Brady Huggett**

Yeah.

## Carla Mazefsky

Um, so now we're gonna really try and understand what that's about. We're looking at kind of every angle and what's exciting about it is it's three linked projects. So we have tons of like clinical — Well, the same 300 people will go through the whole study. So we're gonna have neuroimaging, physio with, um, questionnaires during their daily life.

## **Brady Huggett**

Mm.

#### Carla Mazefsky

Like, so eight — they'll get eight surveys throughout the day. Half of them prompted by changes in their like heart rate, and-

#### **Brady Huggett**

Whoa.

#### Carla Mazefsky

-half are just random time points. Um, and then, um, we'll also be following people over a year. So we'll be able to pull-pull all this together. And I'm excited that, I think we'll probably uncover things that people didn't even think about, you know-

#### **Brady Huggett**

Mm.

## Carla Mazefsky

-related to suicidality or positive outcomes. 'Cause we'll be looking at things like flourishing and —

#### **Brady Huggett**

So they're wearing a-a, like, a biosensor of some kind-

#### Carla Mazefsky

Yeah.

-that's tied to their phone. That'll ping them that it's time to take the survey again.

### Carla Mazefsky

Yep.

#### **Brady Huggett**

And that's gonna go on for a year?

## Carla Mazefsky

No, that part is two weeks.

#### **Brady Huggett**

Oh, OK.

#### Carla Mazefsky

But then we follow them up six months later and a year later. And they also do neuroimaging and a whole bunch of questionnaires, a new suicide questionnaire that we're developing, um, that also covers like a wider range of possible contributors. So —

#### **Brady Huggett**

I mean, I don't think I've heard of anybody doing that.

## Carla Mazefsky

I don't — Well, anybody doing that in — on suicide and autism?

## **Brady Huggett**

Yes.

#### Carla Mazefsky

No. [laughs] No, I think, I mean, I think this will be — this is exciting 'cause I think most of the research out there, there's some good qualitative studies that are coming out or like some big online samples, but they're mostly, like, samples of, like, convenience. Um, so I think this will be a really exciting opportunity to take, you know, really see what we can figure out is related-

## **Brady Huggett**

Right. With some —

#### Carla Mazefsky

-and what's protective.

## **Brady Huggett**

With biometrics like that.

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

That's-that's kind of amazing.

#### Carla Mazefsky

Yeah. I'm excited to see what we find.

## **Brady Huggett**

So that's one year and then you'll start — when the year's done, you'll start analyzing the data.

No, it's a five-year project, so, um, it's-it's one of the NIH Autism Centers of Excellence.

### **Brady Huggett**

Right.

## Carla Mazefsky

So we're finishing like the year one ends this summer, and then we'll have four more years.

## **Brady Huggett**

Got it.

## Carla Mazefsky

But we're following people up for a year and then if we're lucky, we can get more funding to follow them longer. [chuckles]

#### **Brady Huggett**

Right.

## Carla Mazefsky

Um, and we'll also be able to look at things like brain age and, you know, really just that, um, opportunities are kind of endless with the data.

#### **Brady Huggett**

And when you say adults, what's the age range?

## Carla Mazefsky

Oh, 18 to 65.

## **Brady Huggett**

Oh, oh, OK.

## Carla Mazefsky

Yeah, that's —

#### **Brady Huggett**

All of adulthood basically.

## Carla Mazefsky

Yep.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

Yeah. And hopefully, we get a good range. So —

## **Brady Huggett**

Smart. OK. The other thing I wanna ask-

## Carla Mazefsky

Yeah.

#### **Brady Huggett**

-'cause-'cause you said that you came across this picture of this 9-year-old boy and it said, "Do you want to help make a miracle?"

Yeah.

### **Brady Huggett**

And you said, that sounds like me.

#### Carla Mazefsky

Yeah.

## **Brady Huggett**

Why does that sound like you?

#### Carla Mazefsky

Well, I think it just sounded like my goal of wanting to like do something that gives back or something, you know, for other people, was like one of my kind of career goals.

## **Brady Huggett**

Yeah. Have you thought about why that is? Because I don't know that everybody's like that. Every — Some people are like, I wanna make a lot of money. I want to-I want to, you know, be a lawyer. I want to — But you're like, I'd like to help people.

#### Carla Mazefsky

Hmm. [laughter] That's a good question.

## **Brady Huggett**

You've never-you've never thought about it.

## Carla Mazefsky

Well, I mean, I know that people all have, you know, different things that drive them.

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

I don't think too many people that go into, like, research are like going into it for the money.

#### **Brady Huggett**

Right.

## Carla Mazefsky

Or are they gonna be sorely disappointed. [laughs] Um, but yeah, I don't know. I don't know where that, you know, interest in me came from. I mean, my mom was a teacher, so maybe.

## **Brady Huggett**

Hmm. Maybe. Do you have siblings?

#### Carla Mazefsky

I have a sister.

#### **Brady Huggett**

You do?

## Carla Mazefsky

Just one sister.

#### **Brady Huggett**

Yeah. OK. And over your shoulder, I see that you have the picture of three children-

Yeah.

#### **Brady Huggett**

-in Pittsburgh Steelers gear. I'm assuming those are your kids.

#### Carla Mazefsky

Yes, those are mine.

## **Brady Huggett**

Yeah.

#### Carla Mazefsky

I have two teenagers and a 9-year-old.

## **Brady Huggett**

And they are die-hard Pittsburgh people, it looks like.

#### Carla Mazefsky

Yep. Die hard. They're born here, so.

#### **Brady Huggett**

Yeah.

#### Carla Mazefsky

They're gonna be bleeding black and gold forever. Yeah. [laughter]

## **Brady Huggett**

OK. Um, that's good. I'm gonna-I'm gonna stop this.

## Carla Mazefsky

OK.

[transition music]

#### **Brady Huggett**

What is it about Pittsburgh? I wonder. I mean, I have family ties there. I spend a lot of time in Pittsburgh myself, and I love it there, but even I'm not fully certain why the locals are so fanatical about it. Anyway, thank you, Carla, for having me into your office for this interview. OK. This podcast can also be found on <a href="mailto:spectrumnews.org">spectrumnews.org</a> where there's a transcript on this talk. You can find and subscribe to this podcast on whatever platform you use for podcasts. Apple, Spotify, Google, whatever. If you have comments on this or anything we do at *Spectrum*, you can find us on Twitter. Our handle is <a href="mailto:osepectrum">osepectrum</a>.

Some of the information for the intro on Eastern State Hospital was taken from a promotional video put together by Colonial Williamsburg and also from the thesis, "A history of the Eastern State Hospital of Virginia under the Galt Family, 1773 to 1862" by James Harding Siske, which he completed in 1949. Our theme song was written and performed by Chris Collingwood. And that's it. I'll let Chris' music play us out.

[ending theme music]

## Carla Mazefsky

Are you in Pittsburgh visiting people?

## **Brady Huggett**

To be honest, um, I'm quite familiar.

Well, yeah.

## **Brady Huggett**

Moderately familiar. My-my dad grew up here. My-

## Carla Mazefsky

Oh really?

**Brady Huggett** -my dad's side of the family is from Pittsburgh.

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