

## SickKidsVS- S3E3-Parent Stress Pt2-i-interact-V3.mp3

### INTRO

[00:00:02] **Hannah** Parenting is hard on a good day. Self-doubt, guilt and frustration are par for the course, but for some families, these challenges are more acute. Here's Stephanie talking about her daughter Faith. Faith had heart surgery as a newborn, and when she was a toddler, Stephanie and her husband began noticing that their daughter was uniquely challenging.

[00:00:26] **Stephanie** If she would get in trouble, it didn't bother her. If she was told, no, don't do something, she would still do it. A lot of times you chalk it up to a toddler, the terrible twos and those things, and then we realized, my husband and I, we were spending a lot of time frustrated. And then we would go to bed feeling guilty for being so frustrated with a child who had experienced so much.

[00:00:56] **Hannah** Here's another mom, Engy, talking about parenting her son, Jacob, who has epilepsy.

[00:01:02] **Engy** I didn't know anyone that was going through this. And I don't know if I'm doing right, if I'm doing wrong. You know, and I would lose it sometimes, and I would yell. Right before bed. I'm like, Oh, what did I do wrong today? Oh, I could have done this with them. Oh, I'm such a bad mom, you know.

[00:01:18] **Hannah** Lots of parents feel this way, once in a while or even regularly. But Stephanie and Engy felt like this most days. Both of their children had medical issues early in life, and both parents wondered if that had something to do with their kid's behavior. Why, for example, they were resistant to punishment or the usual parenting strategies. As part of their care at SickKids, Stephanie and Engy were offered a spot in a pilot research program addressing the very issues they were having at home. The program aims to treat behavioral challenges of kids with early medical conditions. It does this by zeroing in on a key, often overlooked aspect of child development, the parents. The program is part of a growing realization in pediatric medicine that parents need care too. Stephanie and Engy said yes immediately.

You're listening to SickKids VS, where we take you to the frontlines in the fight for child health. I'm Hannah Bank and this is SickKids VS Parent Stress Part 2.

### ACT 1

**Hannah** It's well known that some medical issues can disturb a child's developing brain. Strokes, prematurity and certain congenital heart diseases can deprive the brain of oxygen. And this brain injury can affect thinking and behavior.

[00:02:50] **Tricia** So any time there's changes in the brain, whether or not it be by an injury or a condition, it can alter the way a child thinks and the way a child may behave. For example, children may become more frustrated easily. They may have shorter attention spans. They may have less control over their emotions or their behaviors. And for parents, this can be very confusing, and sometimes traditional parenting strategies may not work as well or may not work.

[00:03:22] **Hannah** That's Dr. Tricia Williams, a neuropsychologist and researcher at SickKids. She sees patients like Faith and Jacob in her clinic. She assesses their motor skills, learning and communication, then recommends certain therapies. Through this work, Tricia encounters a lot of stressed-out parents. Parents like Stephanie and Engy, who are constantly frustrated, who felt like they were failing their kids.

[00:03:49] **Tricia** Parents of children with early medical conditions have stresses that are unique in that they may never have seen their child sort of developing typically. So they have that question and how much of this is my child? How much of this maybe is the injury or the illness? And most importantly, what can I do as the parent to optimize my child's outcome, make it the best it can be?

[00:04:10] **Hannah** When children have serious medical issues early in life, parents may experience their own trauma, which can also affect their child.

[00:04:18] **Tricia** And that's why supportive programs for the parents are so key because whether or not it's related to the condition directly or this is maybe who the child would have been. Another possibility is these parents have gone through considerable trauma in the early days and years of their child's life and their response and how they've coped and their circle of support. And all of these things are really impactful on the child's later development.

[00:04:46] **Hannah** Tricia saw an opportunity to help these parents, first by listening. With input from SickKids families, Tricia and her team developed a detailed survey that they hoped would shed light on the parent experience. What were their main stresses, struggles and roadblocks?

[00:05:04] **Tricia** And this was our first patient-oriented research study, and you know that's a fancy word for really parents sitting with us at the table. If they contributed to what questions they wanted us to prioritize and even how they thought they would be the most sensitively asked. And the results of the study in the survey really identified parents wanted more mental health support, not just for their children, but for themselves. You know, one of the things one parent said was no one asked me, the parent, how I was doing. There's such a focus on the child.

[00:05:36] **Hannah** It was a collective cry for help. Many parents of kids with early medical conditions or brain injury were struggling, struggling to support their kids and feeling guilty about it. Faith, who you heard about earlier, was born with several congenital heart defects. Surgery was successful. Today, she's a healthy six-year-old. And though Faith's heart disease didn't necessarily cause brain injury, behavioral challenges emerged for reasons that aren't yet totally understood by the medical community. Here's Stephanie again.

[00:06:12] **Stephanie** When it's a physical ailment or an issue, it's linear. There are things to do. There's a heart defect, well, there's a surgery that will fix it. There are gross and fine motor skill delays, there is physiotherapy and there's occupational therapy that will address those issues. The behavior took us a bit longer, so she was probably around three years old. She was a very late walker. She didn't walk until almost two. And by that point, we had a third child. So a lot of the excuses almost were made for the behavior that she's the second born. They are typically very stubborn. We would say, go brush your teeth and get pajamas on. My oldest would do exactly that. She'd go upstairs, brush her teeth, get her pajamas on. And Faith would go upstairs, find a marker and write on the wall. And it

happened once. It happened twice, and then we realized, OK, this is not this is not working the way we thought. And it wasn't like she was unsupervised for long periods of time. She was fast. I would collect markers and try to keep them in one spot or pens, and she would find that lone pen that was like under a piece of furniture, and she would write on walls, furniture, doors, anything.

[00:07:41] **Hannah** But you didn't chalk that up to like, oh, she's just mischievous or she's just a toddler like I, you know, that must have been so difficult to be able to distinguish.

[00:07:52] **Stephanie** At first, yes, you feel exactly that. OK, toddlers do things like that. They get into trouble. We shouldn't leave markers or pens or anything like that out. It evolved. She did things like cut her own hair with small scissors that I used for, like sewing. She would find those, so I had to hide them. It was the repetition. She cut her own hair three times. She wrote on walls multiple times. It's that she wasn't like learning and realizing, Oh, I did this, I got in trouble even as time went by.

[00:08:28] **Hannah** Inattention and impulse control are common challenges Tricia sees in her clinic. She says across the board there's a frequency and intensity to the behaviors, which can be overwhelming for parents to manage. Stephanie lovingly attributes this to Faith's warrior spirit.

[00:08:46] **Stephanie** So I'm Catholic, and I prayed a lot when I was pregnant. My faith helped me get through those really dark times, and I would pray to God, Please God, this is going to be a journey. Please give her strength. Give her courage. Give her, let her be stubborn. Let her be a fighter. And he answered my prayers. I believe that. I didn't think about what it meant to raise a fighter stubborn. All of the things that I asked for, but I wouldn't change it. She needed those qualities because even though her surgery and her recovery was smooth, it's still a lot. She's still been through more than most adults.

## ACT 2

[00:09:44] **Hannah** Tricia and her team were inspired by what they'd heard from the parent survey. Families needed mental health support so that they could better support their kids. Tricia knew of a program at Cincinnati Children's Hospital called I-InTERACT. It's an online parenting course for families of brain injury patients. There was already a lot of good evidence that it worked. When parents applied the practical parenting tools, their children often did better. Plus, the program was virtual when virtual was still a novelty. Tricia and the team could quickly deploy it for SickKids families.

[00:10:23] **Tricia** So why we looked at this program is for several reasons. We didn't have a lot of money. It was something that was already made. And practically, why reinvent the wheel? So it was worth piloting in our population with some key adaptations.

[00:10:38] **Hannah** With Cincinnati's support, Tricia and the team piloted, I-InTERACT in 2018. Initially, it was for brain injury families and parents of congenital heart disease patients who experienced similar behavioral issues. When Engy joined the program in 2020, it had expanded to epilepsy and other neurological disorders, which are also associated with inattention, impulse control and anxiety.

[00:11:07] **Engy** Of course, I was on board. I'm like, yeah, let's do it, like I just wanted to do anything that would help me deal with him. Because I could see he's so anxious. He wants to communicate. And I don't know if what I'm doing is right or wrong.

[00:11:21] **Hannah** As a baby, Jacob had suffered seizures for nearly 18 months before being diagnosed with epilepsy. He's now five. With medication, he is seizure-free. But there were challenges. He'd been slow to talk. He learned words and forgot them immediately. He was often agitated.

[00:11:42] **Engy** He wasn't a very loud baby. Like he was quiet and sleeping more. That's the first sign that I noticed. And then the older he got, and now he wants to express himself. He can't. So, he was going a lot "ah ah." And like he would like, scream a lot and cry a lot. Even now, he still cries a lot. That's one of the huge issues that, you know, we're trying to work on to calm him down. He has a high level of anxiety. But the medication also has a little bit of contributing factor to it, right? So, he can be very challenging sometimes to deal with. Like when he's also very stubborn and when he wants something, he'll scream and scream and scream until he gets it. He's much better now that he's finally verbal. Much, much better. But way before that, it was so, so hard.

[00:12:30] **Hannah** As part of the program each week, Engy and her husband would study course materials covering the principles of positive parenting. It's a wide-ranging parenting philosophy that emphasizes proactive praise, consistency and self-compassion. It can be a helpful approach for any family, but positive parenting has been particularly effective for kids with early medical conditions.

[00:12:54] **Tricia** Positive parenting is not perfect parenting. We've talked about this among a lot of families and stuff, there's kind of this ideal like, 'Oh my gosh, you can just go on this website and find, you know, how to do it.' There's no such thing as that. Positive parenting is one way of building warmth, consistency and predictability in the home. That is the principles of positive parenting. And we know that these elements are protective factors contributing to optimal outcomes in many at-risk children and youth.

[00:13:26] **Hannah** One of the main strategies Engy learned was to compliment Jacob for very specific things.

[00:13:32] **Engy** So you say, Oh, I like how you're sitting so quietly. Oh, I like how you're not ripping because my son loves to rip things. He just cannot help himself. So, anything that can be ripped, he will rip it. So, thank you, Jacob. I like how you're helping me open the door. Like specifics. You're telling him what you like. And things that we don't like, we don't even give it attention. That helps a lot with their confidence, with my confidence it makes me feel like they're hearing the good stuff, not the bad stuff.

[00:14:01] **Hannah** Engy found that praising Jacob's good behavior encouraged more good behavior.

[00:14:06] **Engy** Because now he knows, Oh, mom likes when I opened the door when she's carrying something heavy for her. Oh, my mom likes when I'm not ripping things. Or my mom likes when I'm not putting things in my mouth. Because you're telling him what you like, so he wants to do what you like because now we have an understanding.

[00:14:24] **Hannah** Stephanie had the same aha moment with Faith.

[00:14:27] **Stephanie** So I would say my biggest takeaway from that program was learning that Faith does so much better with praise than she does with discipline or getting into trouble for doing something wrong. And I learned that if she does something good, like

make her bed and I say, Wow, you made your bed, you did a great job. She just lights up from the inside and you can, you can see it. So there is, it's like, you know, immediate gratification when I know that I change what I'm doing and it works right away.

[00:15:10] **Hannah** Along with studying the course materials, parents also meet virtually once a week with their parenting coach, Tricia or one of her colleagues. It's a nice check-in for parents. A chance to ask questions or vent frustrations. And it allows coaches to observe parents interacting with their kids and applying what they'd learned. With help from her coach, Stephanie discovered the power of careful observation and undivided attention.

[00:15:38] **Stephanie** So it was a lot of having playtime, one-on-one. Now with three young kids, I realized they don't often get one-on-one time with me. There's always somebody else around. So this was important. So we kind of scheduled our sessions in the evening and my husband would take the other two when he was home, he would take the other two away and then Rivkee, our therapist, she would watch us play together. And it felt unnatural because it was not a way I was used to playing. Was learning how to interact with her in a different way. And it took me a bit of time to get used to it, but I saw a shift in her like immediately. So one of the techniques is that you talk about what your child is doing. You just vocalize it. Oh, you are playing with the truck. And then if they're speaking, Oh, you think that is funny? And it feels strange because it's just not a natural way of speaking or interacting with your child, but she would like, oh, like make this face like mommy's really paying attention to me. I saw like immediately the way she reacted to having my full attention. And we had so much fun playing together.

[00:17:08] **Hannah** That was in 2019, pre-COVID, pre remote work. Virtual was not a thing, especially in health care. But being online has been a major triumph of the program. Even though initially there were doubts. Here's Tricia.

[00:17:25] **Tricia** There was this real like virtual doubt that virtual could actually reach families, and that was surprising to me, and especially because we started to see the uptake around families and the appreciation. And then also the richness, I guess. You know, certainly virtual is not a cure-all and not, you know, a perfect solution. But to actually work with parents and children in their own home and to practice skills that they then have to practice but in the same environment versus coming to my office and the stress about coming to my office and all of that, and it's a bit artificial. That, to me, was also a lovely surprise because of the hesitancy in some ways that we faced with trying to launch something virtually. But then the parents, even themselves reflecting on how natural and how wonderful it is that the therapist really can come to your home and give you that support.

[00:18:18] **Hannah** Then in spring 2020, COVID hit and everyone was going virtual. SickKids, like many hospitals, scrambled to shift outpatient care online, where possible. Since Tricia and the I-InTERACT team were already set up to be virtual, they received a small COVID grant from the hospital to ramp up the program. The money allowed the team to create their own I-InTERACT website called I-InTERACT North. They were able to extend support to even more parents and more medical conditions. At a time when community supports were shutting down, I-InTERACT North became a lifeline.

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### ACT 3

Four years after the first pilot, I-InTERACT North continues to expand to a range of conditions that can affect child behavior or parent mental health. For example, ADHD and autism spectrum disorder. Since the COVID grant, the program secured a few bigger grants, which allowed the team to grow from four coaches to 12. They've started taking referrals from the community, and Tricia is working to get I-InTERACT North into other children's hospitals and study it in a larger trial. The team has published about the program's impact, adding to the growing evidence that parents supports not only work but are critical to patient outcomes.

[00:20:22] **Tricia** We've had evidence, you know, not just in our work, but in decades of work internationally, in other different types of at-risk scenarios that has shown the importance of parent stress, parent mental health in predicting child's outcome.

[00:20:39] **Hannah** In other words, the healthier the parents, the better their children would do. For Engy and her son, Jacob, this has been palpable.

[00:20:48] **Engy** He's doing great, like amazing. Like, I couldn't even tell you he can even say hello. Now he's speaking. Tell me how he feels. That's like, like, it makes me want to cry sometimes, you know. You're just trying to help to connect with your child. You know, you feel we all have that connection with our children. We know even if we can't understand each other with words, you just feel when something's wrong with your child. Like, and I felt he was really like suffering. He wanted to connect and he wanted to communicate with me. And this helped both of us communicate.

[00:21:23] **Hannah** Many parents, like Engy will tell you that through the process, they've been able to let go of their guilt and learn to be kinder to themselves. Broadly, that's the point. By getting the right tools and support, parents are set up for success. They're empowered to be more effective parents, and the impact on their child can be immediate and noticeable. Also, there's a lot to be said for feeling heard. Here's Engy talking about Tricia as more of a therapist than parenting coach.

[00:21:55] **Engy** She definitely helped me before she helped him. You know, we're all a bit broken, and at that time I was very defeated. It was nice of her to coach me how to deal with my issues or how I feel, and all that's overwhelming. Like that sense of being overwhelmed and going through my own issues too, and trying to help my son and she helped with that. Like she was able to understand and make you feel it's OK that you have those feelings. You know, don't dwell on it because, you know, it doesn't make sense to dwell on it. Just keep going. Moving forward.

[00:22:31] **Tricia** We all strive in some ways to be the best parent we can be. And sometimes the work we do with parents is because a lot of them have had this extra stress and they want to do every single thing they can do to make their child as resilient as possible. And it's OK to have times when there's tantrums and it doesn't reflect on you as a parent but how do you manage and cope.

[00:22:52] **Hannah** Tricia uses the analogy of putting on your oxygen mask in a plane before helping others. Engy puts it this way.

[00:22:59] **Engy** I had my own trauma to deal with. So, you know, like she, she helped me through that too. Just making me feel like I shouldn't feel guilty and I'm doing the best that I can for him. So then when I'm feeling better, I'm able to help him. Because if I'm feeling bad, how am I going to help him or help anybody?

[00:23:19] **Hannah** From SickKids Foundation, this is SickKids VS. Thanks for listening. If you want to support work like this, visit [SickKidsFoundation.com/podcast](https://SickKidsFoundation.com/podcast) to donate. And if you like this podcast, please subscribe and rate us on Apple or Google Podcasts, Spotify or wherever you listen to SickKids VS. SickKids VS is produced by me, Hannah Bank, Neil Palmer, Jasmine Budak and Gillian Savigny. This episode was written by Jasmine Budak. Sound Design and Editing by Quill. Production Support by Ayesha Barmania. For behind the scenes extras and show notes visit [SickKidsFoundation.com/podcast](https://SickKidsFoundation.com/podcast).