Interview between Speaker 1 (Meg) with Speaker 2 (Amy) and Speaker 3 (Jacquelyn)

[Introductory music]

Welcome to the Two Sides of the Spectrum Podcast. A place where we explore research, amplify autistic voices, and change the way we think about autism in life, and in occupational therapy practice. I'm Meg Proctor from learnplaythrive.com.

Meg: Before we get started, a quick note on language. On this podcast, you'll hear me and many of my guests use identity-affirming language. That means we say, *'autistic person,'* rather than, *'person with autism'*. What we're hearing from the majority of autistic adults is that autism is a part of their identity that they don't need to be separated from. Autism is not a disease, it's a different way of thinking and learning. Join me in embracing the word *'autistic'* to help reduce the stigma.

Welcome to Episode Seven. So this episode is going to be a little bit different. The beginning of January, I hosted the first annual Neurodiversity in the New Year Summit, where I interviewed a variety of incredible speakers on topics relevant to occupational therapy and autism. Today, I'm going to replay for you one of the talks from that summit. In this talk, I was interviewing the two women behind Autism - Level UP! Jacquelyn Fede is an autistic self-advocate, developmental psychologist, and program evaluator. She's an assistant research professor at the University of Rhode Island, and Jacqueline is the co-founder of Autism - Level UP!, along with Amy Laurent, who is both a developmental psychologist and a registered pediatric occupational therapist. In addition to being the co-founder of Autism - Level UP!, Amy is a co-author of the SCERTS model, which is an empowering model of autism intervention focusing on social communication, emotional regulation, and transactional supports.

The original interview was a video, not audio, and Amy and Jacqueline are not just brilliant and innovative, they're also tons of fun. I think I must have edited out 15 minutes of laughter and onscreen banter, just to make the interview

podcast ready. So if you hear a hint of laughter in the clefts, just know that they have just said or done something hilarious.

All right, in the beginning of the interview you'll hear me mention the *'Energy Regulator Program'*. I'll link to it in the show notes at *learnplaythrive.com/podcast*, but before we get started, I'll explain it so you can picture it. *'The Energy Regulator'* is a tool that's all about how much energy a person has at the moment, how much energy would be optimal for the activity they're engaged in, and what activities might help get them to the optimal energy place for that given activity. They label the different energy levels *'Maxed out and Frenzied'*, *'Amped up and Fidgety'*, *'Focused and Purposeful'*, *'Settled and Calm'*, *'Sleepy and Still',* and *'Asleep'*. Amy and Jacquelyn will talk about the tool a lot more in the interview and you can check out the show notes or their website, *autismlevelup.com*, to get the tool absolutely free. Did I mention that? They create these amazing resources and give them away for free.

Okay, here's the interview. And just to help you tell their voices apart, Amy talks first, and then Jacquelyn talks about her experiences as an autistic person. Welcome, you guys!

Amy: Thanks for having us.

Jacquelyn: Thank you so much.

Meg: Thanks for being here. So everyone got a copy of your *'Energy Regulator Program'* this morning, and I can't wait to talk about it, and what it is, and how to use it. But before we dive in, can you fill us in on why you guys focus so much of your work on energy regulation strategies, and what your work is, also?

Amy: Well, so as part of the SCERTS model, many of you know emotional regulation is a huge component of the model, because we know that regulation is a huge challenge for many on the autism spectrum. And as I started to work more closely

with Jacquelyn and many other individuals, I realized that sometimes emotion is a very difficult concept for individuals, but this concept of regulation is still equally as important for them. And so we kind of landed in this idea of energy, because it's something you [Referring to Jacquelyn] can identify with.

Jacquelyn: Yeah, throughout my life, people asking me - you know, seeing that something is up and asking me, *"What's wrong? What's wrong? I want to help you, but you have to tell me what is wrong."* I never had the words for that. It was kind of like a language barrier for me. I don't tie what's going on internally to some arbitrary word, maybe like *'happy'*, *'sad'*, *'mad'*. But an energy state is something that resonated with me. I can tell you if I'm feeling amped up, or if I'm feeling sleepy. But tying those things to emotion became a layer of really not seeking help and avoiding asking people because I knew. I knew the questions that would come. So I avoided that. So we really wanted to try to take away that language barrier and bring it back to that more raw concept of just internal energy and around us all.

Amy: When I think one of the things that we know from the developmental literature is these arousal states are the basis for emotional experience for many individuals. And so, really, any emotion can happen at any energy level, if that makes sense. So you can be sleepy and happy, or you can be amped up and happy. So, this whole idea of stripping away that language and just taking it back to that basic level of what's happening internally in your body, and how does your body actually feel, what's your energy in your body, is really taking it back to the essence of regulation.

Meg: That's really interesting. So yesterday, one of the things we were talking about was how autistic people don't differ from their typical people and their ability to experience empathy. But the idea of the subset of people who have alexithymia, or a challenge with identifying emotions in themselves and others. So I don't know, Jacquelyn, if that's something that you identify with, but it sounds like that's a really effective way to connect to that subset of people.

Jacquelyn: I do, I do connect with that. And I often think and tell people, *"If I don't understand how to label it in myself, there is no way I am going to be able to think about it in someone else and understand what they're experiencing, and be able to respond to it."* It's not that I don't feel strongly that something is going on for the people that I care about. But that whole process — I mean, if I can't identify it for myself, there's no way that I could think through this empathy process in that way. So yes, definitely.

Amy: Right, but you often talk about — and you are an extremely empathetic person in terms of, like you'll be overwhelmed by somebody else's energy, but you won't relate it to their emotional experience.

Jacquelyn: Right. I call it like a *'deer-in-headlights empathy'*. It's so overwhelming, it's — Freeze. That's all I can do.

Amy: Yes, that's what you do. [Laughs]

Jacquelyn: [Laughs] Yeah.

Meg: That is so interesting. That really adds a layer of nuance to what most of us think about when we think about autism, and identifying emotions, and energy regulation. Can you tell us a little bit about *'The Energy Regulator'*? What's it for, and how did it come to be?

Amy: *'The Energy Regulator'*, which everyone's received a copy of, it kind of is this range of these six bio-behavioral states — which starts at this maxed out, frenzied, high, high, level and goes the whole way to deep sleep — is really based on the work of developmental theory and developmentalists like T. Berry Brazelton. So we're going back into the 60's, 70's; we're digging deep into understanding early experiences in terms of regulation. Again, stripping away that emotional piece, because in infancy, we're not regulating emotion so much.

We're regulating internal energy when we're supporting individuals. And so, even in SCERTS — and so, to kind of step back, in SCERTS we often talk about physiological arousal. These six bio-behavioral states and emotion being interchangeable are intertwined. And so, for a long time I've been thinking about, writing about, talking about the six bio-behavioral states and how important they were. But again, it wasn't until really kind of working with and supporting Jacquelyn and other autistics who were able to tell me that that emotion piece wasn't meaningful for them.

And again, working with some kids for a couple of years, and figuring out the emotional states just weren't sticking, that we stripped away the emotion label and went back to that basic of bio-behavioral states, which are consistent with the developmental literature. And then what we wanted to really focus on, in the sense that you can experience any energy level and any emotion at different energy levels, we wanted to look at what's the energy needed for the task, or the activity, or the context, and what is your current energy state. Because it's not always about, *"What level am I at,"* it's, *"What level am I at, and where do I need to be. Where do I want to be."* So the meter is really a measure of, are we in a match, or a mismatch for the given situation. It's the basis that kind of launches us off into, *"Well, what can we do next."*

Jacquelyn: And that's a really important concept too, in terms of if you look at the words that we've chosen. So if you look at Brazelton's language around those six bio-behavioral states, he has things like that highest state which we've called *'Maxed out and Frenzied'*, which he says is extremely dysregulated, right. And then the step down, which we have is *'Amped up and Fidgety'*, is agitated. So the words that he used are really awesome, and very reflective of internal energy, but as a society we've layered on a lot of negative connotations with those things. When people hear *'extremely dysregulated'*, they automatically go to this place of, *"Oh my gosh, the child's melting down. They're like throwing — you know, out of control."*

Amy: Right. So we wanted to make sure that the language was as neutral as possible, so we could capture those places where it's good to be maxed out and frenzied. Like, the playground is a great place to be maxed out and frenzied. And if I go out on the playground, and I see someone in a focused, purposeful state, they're not engaging at the place where we want them to. So there's a mismatch, which was what you were talking about there. So the language that we've chosen is purposely trying to let people say, *"Ah, there places where high energy is appropriate and matters, and we want it, and there places where it's not."* And we want to know where there's a match, and where there's a mismatch.

Jacquelyn: That is such a good reframing. I think most of us are familiar with models where there is a good kind of *'green'* zone, there's a *'not enough energy'* zone, and there's a *'too much energy'* zone. But I think that's a really important thing to say, that are you in the right place for your context and your activity? And that probably would make a lot more sense to the folks we're working with rather than, *"Are you in the right place? Are you in a good energy place?"* Are you in a good energy place *for* what you're doing right now.

Meg: I love it. So how do you, or how does an autistic person or a person supporting them use the energy regulator then?

Amy: So, really it's about helping identify that state. So we can use this energy meter with individuals with all different language and cognitive developmental levels. Some of it is just helping us as partners, frame our understanding of where they are in terms of their energy level in the context of the activities that they're in. As Brazelton said, is it a match or a mismatch. And then it's helping give that individual feedback so that they can start to self identify. So, it can be something that can be used on an individual teaching basis, but it can be used for a whole class as well. So if the teacher wants to help the entire class understand that the expectation for the class right now is *'Focused and Purposeful'*, or maybe it is that *'Amped up and Fidgety'* — we want you up and moving, we want you doing report, whatever — she sets that meter so that kids can start to figure out that

they're in a good match for that situation or not. So it can be used individually and in a direct teaching format where we're really helping people identify their own state, but it can be used in these larger formats as well.

Jacquelyn: It's taking away a barrier to begin with. So someone like me and many autistic people who perhaps would not ask for help, it may be really hard for someone who doesn't know us to know when we are getting amped up and maxed out, or when something is different. I would just, you know, slide under the radar. So stripping away that barrier and putting it in terms that are comfortable for me and that makes sense to me, it increases the likelihood that I actually will go to my partner and indicate where I am. And it's nice to have it written out on paper in front of me so that if I am not able to speak — if I'm so amped up and frenzied that words are not a possibility for me at the time, all I have to do is place an arrow there. And even regardless of that situational rating, it can be an indication of, *"I need some kind of regulation."*

Amy: Which is true now. So this vocabulary has really become kind of a core part of how you express yourself, especially with me. So I will just get texts from her with her level in them, so I kind of know if she needs some support in that moment. Because it's almost like her way, her bid, to say, engage me to give her some avenue to kind of offer some sort of support. And so that's been really helpful, I think, for me.

Jacquelyn: Yeah, it really opens the conversation for me in ways that I would never attempt, or think to attempt before having this kind of vocabulary available to me.

Meg: That is very cool. It's so cool to hear about how you guys are able to use that in those tough moments when language doesn't come easily. So you guys have other programs other than *'The Energy Regulator'*. Can you talk about what they all are and how they tie together?

Amy: So one of the other ones that they have in the link that you posted — so we actually included — well, there's a couple of tools in the handout that you posted,

or the freebie that you posted. The second page behind that energy meter — which is just the six bio-behavioral states and that match/mismatch framework so people can start to identify that — the second page behind that is a tool called *'My Energy'*. And that one is extremely useful. And I'm going to give her the floor to talk about it. And I'm just warning you. Because we know for autistic individuals that their energy expression might look different than what we expect it to look like. So a *'Maxed out and Frenzied'* for me might be really predictable in terms of my kind of frenetic energy, and my vocal volume, and my facial expression, and those kinds of things. But it's not consistent for everybody. So, the *'My Energy'*, allows us to look at those six bio-behavioral states again with a brief description what each of them are, and some kind of characteristics that you might associate with it. But on one side there's a column that says *'What it looks like to other people'*, looks like, sounds like, and what they may observe, and the right hand column says *'How I experienced or what I feel'*. And so, it's a way to really tailor our understanding of those six days for one person that we're working with, as opposed to just kind of having this global interpretation of what we think it looks like.

Jacquelyn: Yeah, when I filled this out, I found it to be incredibly empowering. Because after a lifetime of, *"Tell me what's wrong, tell me what's wrong. Use your words."* This is really the first time that I got to say, *"This is what it looks like for me when I am amped up, and this is what it feels like for me."* And that's really validating, and it goes a lot further in a partnership and establishing trust, when someone wants to know, *"How does it work for you,"* rather than, *"This is how you have to make it look when you are happy."* So it allows me to put really nuanced information in there about myself, like when I'm *'Maxed out and Frenzied'*, I can look like that deer-in-headlights. I can be really still, have no words whenever I'm experiencing some kind of intense energy state, the only outward expression I do is smile. I broke a bone in my foot and I went into the doctor's office, and I said, *"I think I broke my foot."* And I walked out without them even X-raying it.

So, for people to know this about me is really critical, right. You know, I've had

people say, *"This is not funny, why are you laughing?"* I carry actually an ID card that says, *"I smile in intense situations,"* in case I'm interacting with police and I'm like — if I saw that, I would get assaulted. Yeah, and so it's really just — it's a safety, it's validating, and it goes a lot further in allowing partners to provide regulatory support for me if they know that just because I'm smiling, doesn't mean all is well and good, and that in fact could mean it is really not.

Amy: And then you dig deeper. One of the other things, I think, that came up really strongly when you fill this out for yourself, was how closely some of your states can look to one another. So, when you are in that kind of drowsy state, you often get a frenetic energy about you. So it actually looks like she's amped up, but she's tired. And so what she needs to do in that moment is very different if it's a mismatch with the environment.

The same thing is, when you're maxed out and frenzied. You can have very explosive energy, like very explosive energy, and she's very strong. But you can also shut down.

Jacquelyn: Right.

Amy: Which can look like someone who's kind of bordering on this real low arousal level. So being able to tease that out and actually hand that to somebody, and help them understand that about you, I think is really powerful. It's actually helped you a great deal to kind of navigate relationships with different people, even at work.

Jacquelyn: Yes, it's basically a list. We give you a lot of ideas of some of the tools and strategies you can try out, and it gives you spaces to indicate what this does to my energy, and is it soothing, is it alerting? And it also gives you a space to say, *"Do I like it?"*

Amy: Because if you don't like it, you're not gonna use it right.

Jacquelyn: Right, exactly. I'm not going to access it. And that can be very helpful when you're trying to think about those mismatches and energy. That kind of stuff at the frontline, and strategies you can try out and use in those situations where there's a mismatch. And though those strategies in the regulator are all sensorimotor in nature, so they're broken down by the different sensory systems, and again — so if you get into a situation where there's a mismatch where your energy is too high, you're going to look to that and say, *"Who brought something that can bring me down,"* or if your energy levels are too low for the situation and it's inhibiting active engagement*, "What's something that's going to increase my arousal level."*

[Intermission begins]

If you're a professional working with kids on the autism spectrum, I'm sure you set out to work in a way that reflects your values. But far too often in our work, we don't realize how big our blind spots are. We may find that our model is medical rather than social, neurodiversity is suppressed rather than celebrated, our language is outdated, our interventions are compliance-based rather than strengths-based, and we may not be contributing positively to our clients sense of autonomy and identity.

That's why I created the free Five Day OT and Autism Challenge. When you register for the challenge, you'll get daily e-mails for five days with articles and videos that are absolutely paradigm-shifting, and you'll get access to the most incredible private Facebook community where everyone reflects on their takeaways from the learning assignments. It takes fewer than 30 minutes a day, and you'll be surprised to find what changes it inspires in your work. Is your work aligned with your values? Are you ready for the challenge? Visit learnplaythrive.com/challenge to register.

[Intermission ends]

Meg: Next, you'll hear Amy and Jacquelyn talk about a different tool called *'The Person in Context'*. Again, you can grab this tool for free in the show notes at *learnplaythrive.com/podcast*. Or you can grab it from the Autism - Level UP! website. *'The Person in Context'* is a worksheet with three columns. On the left,

there are different factors to consider — physiological, interoception, sensory, motor, cognitive, communication, and social. In the center column, they give really specific subcategories for each of these to help you think more concretely and more thoroughly. And then in the right column, there's a place for you to work through your case study. First you work through each category from the person's own experience, then you work through it considering the environment, and then considering the activity itself. So in the end, you'll have a really detailed analysis that considers so many factors that would be forgotten without the structure of this form. Here are Amy and Jacquelyn to talk more about it.

Amy: So *'The Person in Context'* kind of builds on these other tools that we've been talking about. And what it does is it really allows us to build a profile for the individual according to their sensory preferences, as well as kind of their reactivity profile, and also has places for us to understand them in terms of their communication style, their cognitive strengths, and areas for growth or opportunities for growth. There's places for social. It basically built a very comprehensive profile of what we would consider both risk and protective factors for regulation, but for us to really understand who that person is and what they bring to the regulation equation in their active engagement.

Once you build that profile for a person, we have the same categories for environments and activities. And you kind of go through an activity and an environment, you build the same profile, and you can look across for matches and mismatches. And again, it gives us a really good indication of where we need to provide support, because sometimes — I mean, we know as OT's people come at us and they're like, *"They need a weighted vest,"* or, *"Can you get them on a sensory diet,"* but if we do *'This Person in Context'* and you look at where their risk factors are and what's happening in the environment, maybe it's not a sensory solution they need at all. Maybe it's a language, or speech and language, or expressive communication, or—

Jacquelyn: Or a literal diet. Like, they need to eat.

Amy: [Laughs] That whole interoception thing, like you.

Jacquelyn: Yeah.

Meg: Yeah, I think that's especially important for OT's to hear. We can get stuck in one framework. It's often sensory, sometimes it's behavioral. Neither of those covers everything, right. So I think it's so nice that you have this tool that can encourage us to look beyond just one framework, one solution, one type of strategy to help folks get to where they need to be for that particular situation.

Amy: So just to give an example in context for you, but again this applies widely to anybody working through early intervention through school years or whatnot, but a lot of your go-to strategies for regulation or sensorimotor — I mean, I'm sure people can see that we're standing to talk because sitting is not a good option. She's doing calf raises and moving around and doing all sorts of isometrics while she's standing here. I'm dancing a little bit more than she is, but she's got a lot going on. So a lot of your go-to strategies are sensorimotor, and you know that. But you also get into situations because of your interoceptive difficulties where you don't eat. And you don't think to eat, and you don't know that you need to eat.

So you could be going into a meeting, like a high level meeting at two o'clock, and think, *"Oh, I need this burst of physical activity,"* which is only going to deplete her from a caloric standpoint further, and probably amp up her energy further if she does that, when what she really needs to do is stop and eat. So it's when you put all of those pieces in context that you start to understand what intervention at what time makes the most sense, as opposed to just saying, *"Oh, this strategy will always work for this person."*

Jacquelyn: And when I filled out *'The Person in Context'*, I was like, *"Oh, I'm so aware of my needs,"* and everything. I did it for a meeting at work — I have one day per week

where I have a lot of back-to-back meetings. And I was like, *"Oh, I wake up at like two in the morning. I go to the gym and workout for like two hours, because when I wake up I'm super amped, almost frenzied every day."* So I go through that and then, you know, I'm done with that by five or six a.m., something like that. And I don't sense hunger. And I hate the thought of taste and texture in my mouth, especially early on. So, the idea that maybe I should eat doesn't really cross my mind.

And so I'm filling this out and I'm seeing all these things I do, and all these proactive physical activity strategies that I have in there, and then I'm realizing, my meetings start at one p.m. and I probably haven't eaten anything up to that point. And when I people say to me, *"Well, don't you see other people eat lunch at the office, and that would remind you?"* I say, *"No, I try to escape that because their lunch smells horrible and I have to get out of there."* That's my only thought. And I have this meeting that is people waiting on me, because I don't do well in these meeting situations. So I'm even less likely to think about eating. And so filling this out, I was like, *"Wow, this is a real risk. Like it could get to the end of my meetings at 3:30 and I have not put anything in terms of fuel in my body."* And even if I don't sense hunger, I'm gonna respond in some way and I'm gonna have less ability to be...

Amy: Tolerate people?

Jacquelyn: Yeah, exactly. And so when we come to the end of that meeting agenda and the agenda is done, yet people continue to talk about random things that don't matter like, the Patriots lost. And I'm like, *"The agenda is done, I need to go. I mean, why are we still here."* If I'm hungry, that's just gonna be worse.

Meg: So the structure of the form is kind of cueing you in to consider strategies that aren't necessarily your go-to, or aren't fully at the front of your awareness, right?

Jacquelyn: Right. Putting it in writing in front of me and explicitly, *"You're not eating."* Because we have a physiological section and it's something that a lot of people forget, so.

Amy: So you set Google calendar reminders after that.

Jacquelyn: Yes. I put in Google calendar reminders to try to make myself remember to consume some food before these meetings begin.

Amy: So one of the things that's really important to think about with all of these tools, because obviously we're talking about her experience with them, and on our Facebook page, she actually has done many videos where she talks about her experience filling them out, and kind of her *'Aha!'* moments with them. But they can be used at all different developmental levels. You can use these tools with very young, pre-verbal children, or developmentally young individuals. It just gives us a framework, so you can kind of conceptualize and understand. So if they can participate, if they can fill them out, we invite that. We want that, we want to build that self-awareness. They're just going to build self-advocacy and self-knowledge in the long run. But even if we don't have a person at that cognitive and linguistic level, we still want to be using this framework to understand how to provide comprehensive support around regulation.

Meg: So, okay, let me see if I'm understanding this right, because this is definitely a question I had, and it's a question I'm seeing in the comments too — that for your younger or more concrete folks, or folks who don't have as much insight, or simply aren't speaking and aren't able to share what insight they have in a way we can understand, you are using this process to sort of trial and error see what works, see what helps people, and when it helps them, and to help them move towards identifying where they are and what they need? Is that right?

Amy: So, yeah, in a sense, yes. So it would depend on the individual tool, how we would answer that question, because it's a little bit different for each one. But for, say,

the *'My Energy'* one where it says, what other people observe, or see, or hear — we really want a team, or people closest to that child to sit down and kind of come up with an understanding of who that child is, and then consensus so that everybody is on the same page with how that child's experiencing that environment at that time. What we're going to miss out on for that kiddo, or that individual, is the *'What it feels like to me'* because we might not be able to get that information. But if we get everybody around that child conceptually understanding these six levels and what they look like, it gives us a lot more consistency in our response which brings a lot more predictability to the interaction, which provides a lot more support for the individual.

So that's where we would start something like the regulator which we were talking about, which is these different kind of, *"Let's try these vestibular strategies, let's try these proprioceptive strategies,"* we would do that trial and error with a more concrete learner, or a learner who's not yet using symbolic forms of communication. And we again will be watching really carefully to figure out what does this do to their energy level. Does it increase it, does it decrease it? Is it something they're seeking more of, or are they trying to get away from it? And that gives us information about, *"Is this a tool or strategy that we want to introduce when they get into those places where there is a mismatch and we need to help them shift their energy?"*

So, again, it's gonna really depend on the tool. But if we get those things started, something like *'This Person in Context'* where we build the profile and understanding, it's such a powerful thing for a team to sit down and really say, *"Who are we holding at the center? Who are we supporting? Why are we here in the first place?"* And getting that accurate profile of who that individual is, it's so powerful because it shapes everybody's view and how they move forward in supporting that individual.

Jacquelyn: And I would just add that doing *'The Person in Context'*, just explicitly putting in front of a team that that person is just one third of the equation, we're looking

at the environment and the activity too. I think too often it all falls on the person, the autistic person, to change or adapt, and we need to look at how can we modify the environment and how can we change this activity if we see these mismatches. And then, how can we empower the individual with knowledge and understanding of their own risk and protective factors when they're in these situations. I like that it lays out specifically that there are other things to focus on besides, *"What does the person need to do differently."*

Meg: I hear so many things and what you guys both just said that we miss! One, using the whole team, right. Therapy is often between me and a client, ideally not, but it often is between the therapist and the client, and you're talking about getting everybody around them, and getting their insight, and what they've observed. You're talking about not coming with a cookie cutter set of regulations strategies; of really using informal assessment and observing; and letting a child, even if they're not speaking, teach you about what is meaningful and helpful for them. And then, Jacquelyn, about not putting all of the impetus to change on the person. That we can shape our activities and our environment in so many ways to support optimal engagement. We all need to hear that, I think, over and over and over again.

So I wanted to head in the opposite end, too, because one of the things that came up yesterday was how we can teach self-advocacy to our folks who have the language or the tools to do that. And Jacquelyn, I feel like you hit on this a little bit of saying, *"When I lose my language, I take my finger and I point to this to show people what I mean."* Can you all talk a little bit more about how we can use your tools to help folks identify and ask for the things they need when nobody is there doing that for them, or with them?

Amy: So, I think any of these tools are — I mean, if you look at their design, they're purposely designed the way they are, to be able to be accessed across a large age range. They don't look childish in any way, but yet they can be used with younger individuals. But they're definitely appropriate for adults to access and use, and

that is certainly by design. So, these tools, even if you're using them and you're self-identified, and you want to be able to start to have conversations with people about some of these concepts, you just need to be able to fill them out and have that hard copy to take to someone to talk about those things. It's a really powerful place to start.

One of the tools that we didn't talk about which is the last one, and it's released in the suite, is actually called — sorry, I stepped on her foot — it's called *'The Power Plan'*. And there's a plan for powering up, so increasing arousal level, and there's a plan for powering down, so decreasing arousal or energy level. And basically what it does is it collapses all of these supports that we've talked about. So things like considering the physiological piece and making sure that that's addressed and taken care of, and the interception piece, but then sensorimotor strategies that increase arousal level, and different intensities of increasing arousal level, as well as what we would call language-based or reflective and thinking strategies — I'm like, which terms did we use where? — reflective language-based thinking strategies, and how they increase or decrease arousal level at different intensities.

And it kind of gives one plan that that person can kind of build for themselves and refer and reflect on, and use those strategies, and also share with other people.

Jacquelyn: Well, I just — I always emphasize with these tools, that it leads you to self-advocacy. If you don't understand yourself, if you don't have a set of terms that you're comfortable with, or that are meaningful to you, you're not going to be able to get it out to someone else. You might not even be able to think about the fact that it's possible to get it out to someone else or to advocate for yourself. You know that my energy sheet that really asks about, *'What does it feel like for me'*, and all these forms that talk about *'What are the things that work for me'*, and where are my matches and mismatches in an environment. I like to say, you

know, *"My brain is different. So, to expect that what I look like and how I am will be the same is not accurate."*

If someone has a different brain, we should expect that things are going to be different, and things that look different are likely exactly what is needed for that person. So, just that self-understanding. I mean, sometimes I hear from you and from others when we talk that, is people's diagnosis is withheld from them. So they don't even have the knowledge that they are autistic. And if you don't know that, everything that you judge about yourself, and everything that you're looking at is already like, *"Why can't I do it like everyone else?"* You have no knowledge that a difference may actually be needed. So, I think — I mean, I don't know how to tell people to self-advocate, but if you give people the tools, and a language, and something that is real to them. It goes much further in building trust in relationships and building confidence in themselves. It's just a different world to me.

Amy: Well, it's made a huge difference for you in terms of being able to express what you need and the support that you need as well. And I think one of the things that is important to think about all of our tools is they really are grounded in the developmental literature and developmental psychology, as well as influenced by the fields of OT and several others, speech, language, and pathology. So you've got tools that are built on a very strong theoretical and evidence base. So if someone's saying like, *"What are you coming at me with?"*, you can look at these things and go, *"Oh, these are these are solid, they're not just somebody's, like, whimsical ideas."*

Meg: Awesome, thank you for sharing that. One of the questions that came up in the comments was, *"Can you guys elaborate on what your collaborative relationship is between the two of you?"*

Jacquelyn: What we really are is a team that is a combination of a neurodiverse neurotypical perspective, and an autistic neurodivergent perspective. And I think what makes

us effective together is, yes, I have my own end of one experience. I also have a developmental psychology background, so I think about things more broadly than that as well. But some of my specific experiences can overlap greatly with much of the autistic community. And then Amy is in schools and working with a wide variety of individuals, and she's worked in many different fields as well. So I think we're able to take this combination of general knowledge, and interdisciplinary knowledge, and personal experience, and tie it all together to make things that are applicable for what is going on in classrooms, and in homes, and in OT sessions. And for adults in the workplace, and living on their own, and living with others. So I think we just somehow cover a lot of bases together.

Amy: And on a more practical operational level, we do a lot of lecturing together. Being able to bring these concepts to life together, we create all of these tools which we make available for free, that are posted on the website, so people can download them because we are all about access and helping people gain access to good information that's going to make a difference. So, we do that as well. Program evaluation stuff. So we've got a variety of different services that we offer and work on together different types of projects and things, but really it's about leveling up in any way that we can. So, whether it's through creation of tools, or whether it's through education, our goal is to bring that combined perspective. And we've found that the power of the combined perspective is just something you don't have, if it's just one of us, right.

Meg: Yeah, that comes through crystal clear. It's amazing. I love what you guys create together, it's awesome. Okay, to wrap up, a lot of our audience today and watching the replay are OT's working with autistic folks. There are other types of therapists and their parents but, if speaking to the OT's, if there was one or two things you would have us do — do differently, start doing, try to do after listening to your talk today, what would that be?

Amy: So I've got a couple. I think the first one is for OT's to think really broadly about the types of supports that we can provide in terms of regulation. So many times,

like you've said, we get sucked into one framework or one silo of intervention. And we really need to think broadly about the types of supports we're providing. So sometimes there are sensory motor strategies for sure, but we can also, and we are skilled at providing information and language-based strategies, we're also very good at thinking about forward thinking and reflective strategies, that metacognitive piece. So we need to think broadly about how we intervene and what type of intervention makes sense at what time, and be able to advocate for that as OT's. So that's one of my big pushes, is for us as OT's to be able to really say, *"This regulation thing is big, and it's foundational, and we've got the tools to be able to address it from a lot of different angles."* I have another one.

Jacquelyn: Go ahead.

Amy: My other one is that *'well regulated'* does not mean somebody is calm. Well regulated is their energy level matches the environment and the activity that they're in. So if they're on the playground, and they're amped up and fidgety, that's a good match. I do not want a calm child on the playground, right. If we're coming back in and it's silent reading in the library, maybe I do need a focused and purposeful child. And now if they're amped up and fidgety, there's a mismatch, and I do need them to come back down. But the percentage of our day that calm, or focused and purposeful, actually applies? Is very small. And we need to be realistic and honest about that. Think about if we were calm this entire interview. All of your audience would have left. They would have been bored, right? So many times we think that calm is well regulated, and is not. Well regulated is your energy state matching the environment in the activity. Those are my two. What do you got?

Jacquelyn: I love those two. And I would just say, empowerment. Some of these tools, like we said, not every autistic person is going to be able to fill them out for themselves, either because of developmental level or insight, self-awareness, anything like that. And teams, and parents, and OT's, you can get it wrong. You might have some things that aren't right. But I guarantee you that presenting this

kind of information, and thinking about it in this way where you're really trying to focus on what does it look like for them. Like, *"We want to understand you,"* rather than, *"We want you to look like this when,"* will go so much further in building that relationship with someone than just getting them to be able to say that they are happy because it's some goal somewhere, right. So I think the empowerment of validating their true experience — don't be afraid to make mistakes because it will be far more empowering this way than some of the other techniques that can be used.

Meg: Okay, I could seriously sit here and hang out with you guys all night, or at least until Jacquelyn's 8pm bedtime. [Laughs]

Jacquelyn: [Laughs] You guys can carry on.

Meg: Y'all are awesome, thank you so much for being here tonight. I think we're all gonna get off of Facebook and go to your website, or go to your Facebook page and spend some time digging in. Thank you so, so much. This was truly enlightening for me, and I'm sure for so many other people.

Amy: Well, thanks for having us.

Jacquelyn: Thank you.

Meg: All right, we're all gonna level up in 2020.

Amy: Whoo!

[Ending music]

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