00;00;09;25 - 00;00;37;00

Dr. Norrine Russell

Create space for your family's individual journey. Your journey isn't going to be like somebody else's and grieve whatever losses you have. Grieve those losses and find a way to create joy and happiness in in what your family does have.

00;00;40;22 - 00;00;52;14

Courtney Ringstaff

Welcome to Adjusting the Sales, a podcast for parents, caregivers and Service Providers for Children with Disabilities. I'm your host, Courtney Ring Staff, and this is my co-host, Melina Danko.

00;00;52;24 - 00;00;55;16

Melina Danko

Hi, everyone. We are so glad you've joined us.

00;00;55;25 - 00;01;24;29

Courtney Ringstaff

Melina is the assistant director of communications and marketing at the Center for Excellence in Disabilities and the project director of the West Virginia Family two Family Health Information Center. I'm a social worker in Morgantown, West Virginia, and I've created this podcast to be a platform where parents, caregivers and service providers can come together, exchange information, educate one another, and find support and connection through the relatable topic discussions.

00;01;25;22 - 00;01;40;27

Courtney Ringstaff

We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

00;01;42;07 - 00;02;16;28

Dr. Norrine Russell

I'm Noreen Russell, and I am, first and foremost the mom of two amazing teenagers. I have a son who's 16 and a daughter who's 14, and they both have some special needs. Actually, both of them have autism, ADHD and anxiety, and they actually both are very bright and academically advanced. So that's kind of our situation in our family and probably the most difficult thing.

00;02;16;28 - 00;02;39;14

Dr. Norrine Russell

And I know we'll get a chance to talk about this today, but in terms of sharing with other parents, I think the most difficult thing for us has been the mood dysregulation piece of the combination of those things with my son. He's really struggled with his moods and anxiety and depression. So that's a little bit about me as a mom.

00;02;39;20 - 00;03;05;17

Dr. Norrine Russell

We live in Florida and my kids have tried. They've been in public school, they've been in private school, they've been in charter school. And currently we homeschool using an online program. So that's another thing that I think is a good talking point for today's podcast is what are we doing and how are we making it work and what does making it work look like really for work?

00;03;05;21 - 00;03;34;28

Dr. Norrine Russell

I actually have a student coaching practice called Russell Coaching, and at the practice we help students who are very similar to my kids who are intellectually not impaired or delayed in any way, but they have executive functioning difficulties and school can be hard for them. And that's what we do at Russell Coaching for students. And in my spare time I like to cook and bake and read and travel.

00;03;35;09 - 00;04;02;17

Melina Danko

Those are all the important things that help us stay sane in the day to day lives, too, is there's there's fun, enjoyable things as well as our family. So thanks for sharing. I did want to ask you, did you have a career similar to what you do now prior to having your kids? Or did your family life impact your professional direction?

00;04;02;24 - 00;04;32;09

Dr. Norrine Russell

I have, I think, kind of an interesting story there. So I have a Ph.D. in psychology. And when I finished graduate school, I went into academia and I initially for several years taught at the University of Minnesota. And then I moved into doing nonprofit work because I had always done applied research and applied work in the community, having to do with kids and development and particularly girls in development actually.

00;04;32;09 - 00;04;58;27

Dr. Norrine Russell

And I had a career in nonprofit for several years, and then after my son was born, he was just complicated from the get go. And I'm sure there are parents out there listening who can relate to that. And I retired from my nonprofit career, which I had loved. And then slowly over the next few years, there were just a number of circumstances that happened.

00;04;58;27 - 00;05;18;09

Dr. Norrine Russell

I had a lot of psychologists in the community say, Could you mentor this student? You know, could you help this girl? And I'm not a therapist. So I was kind of like, What are you talking about? They're like, you know, she kind of needs what you were doing at the nonprofit just one on one, you know, some some life coaching, some mentoring.

00;05;18;22 - 00;05;41;07

Dr. Norrine Russell

So this was six years ago, and the field of coaching was in a really different place. But it started with these requests from the community to work with individual, often middle school girls. And I did that. And then as we went through the diagnosis process with my son, I just started reading a lot more and learning a lot more.

00;05;41;07 - 00;06;14;00

Dr. Norrine Russell

So my background is in developmental psychology anyway, but developmental psychology is really the positive psychology part of things. You know, what is healthy normative development? So I wasn't a clinician, I wasn't an ADHD specialist, I wasn't an autism specialist. And over the process of Ethan first getting diagnosed with ADHD and learning a lot about that, and then I started a parent support group here in the Tampa Bay area for parents of kids with ADHD.

00;06;14;00 - 00;06;42;03

Dr. Norrine Russell

And that was an incredible experience to learn from other parents and to learn from professionals in the community. And then, you know, started working with students with ADHD. And the practice has kind of grown from there. So yeah, much different career place. Then 20 years ago when I was teaching at the University of Minnesota or you know, 16 years ago when I was still working in nonprofit.

00;06;42;07 - 00;07;10;23

Dr. Norrine Russell

So Russell Coaching for Students is a direct outgrowth of having Ethan and then my daughter Lila and realizing that there are not a lot of resources out there for parents who have complex kids. We talk a lot about ADHD, we talk a lot about autism, we talk about anxiety, we talk about learning differences in giftedness and kids who are twice exceptional.

00;07;11;03 - 00;07;39;16

Dr. Norrine Russell

But what I was finding was because both of my kids had multiple diagnoses of neurodevelopmental issues, it was really hard to find a space where therapists understood us, where psychiatrists understood us. And that was kind of shocking to me. And so what I wanted to do was initially through the support group, bring parents together and provide support because that's what I needed.

00;07;39;16 - 00;08;08;12

Dr. Norrine Russell

Frankly, I needed support. And so I started building connections and building this group and things have sort of organic, fully grown from there. But I don't know that things are that much different now than, let's say, ten years ago when we were going through all of the diagnostic processes for Ethan. I think parents who are getting these diagnoses and they often kind of come one at a time, oh, there's autism there.

00;08;08;12 - 00;08;28;05

Dr. Norrine Russell

Oh, well, I think there's also ADHD there. Oh, now we have anxiety. You know, it feels in those years that you're just climbing a mountain without a guide or a backpack, and some days a son isn't even shining.

00;08;28;05 - 00;08;36;22

Courtney Ringstaff

Can you tell us a little bit about that diagnostic journey for your son and then how you then found out that your daughter was being diagnosed with the same things?

00;08;36;22 - 00;09;09;12

Dr. Norrine Russell

Yeah, so Ethan's story is and he wouldn't mind me sharing this, he was first identified with sensory issues at probably age two. And from early on this was a child who was extremely active, extremely hyper. And again, I had studied child and adolescent development, so I felt like I was reasonably well prepared, know when to know what to look for in terms of developmental milestones.

00;09;09;12 - 00;09;37;29

Dr. Norrine Russell

But he was just off the charts, hyperactive. And so our first kind of journey into the what's going on with Ethan was an O.T. and kind of sensory integration concerns. And then he was four when he was diagnosed with ADHD. And interestingly, I remember both his dad and I at the time saying, you know, is there anything else going on?

00;09;38;01 - 00;10;16;00

Dr. Norrine Russell

And the doctor told us, no, all of his symptoms really fit into ADHD. And, you know, that's all I see. And then it wasn't long after that, Ethan was five, five and a half when we got the diagnosis. Because of our ongoing concerns about his meltdowns and emotional dysregulation, that's when we got the diagnosis of anxiety. And we actually he has the diagnosis of DMD, which is the dysregulation, kind of a more severe form of anxiety and depression for kids.

00;10;16;13 - 00;10;39;29

Dr. Norrine Russell

And that helped us to make sense out of a lot of things because not every child with ADHD has such severe emotional dysregulation. So we worked on that for a few years and then still kind of around the edges of our minds, we were like, It feels like there's still something else going on. And nobody had ever talked about autism to us.

00;10;40;00 - 00;11;05;07

Dr. Norrine Russell

Nobody had ever brought up the possibility of autism. And I am in no way casting blame on anybody, right? Like I have a really complex child and we got good care. But when you have a kid who is so incredibly super complex and they're very bright, they're very verbal, I mean, he was reading at a college level in kindergarten.

00;11;05;16 - 00;11;38;18

Dr. Norrine Russell

You know, I think the pieces just don't automatically fall into place diagnostically. So we finally had him evaluated for autism when he was eight. Our diagnostic journey with Ethan was ADHD. Then the anxiety mood dysregulation piece, then autism. And along the way we did have an educational evaluation done testing his IQ, testing his academic abilities, and he has a very uneven profile there.

00;11;38;18 - 00;12;04;08

Dr. Norrine Russell

So he's just a really complex kid. My daughter does not have the same level of mood dysregulation, but I had her tested for ADHD when she was five because I could now I could see it, you know, I could see it. And she's less hyperactive, although she is hyperactive type. And I remember and there might be parents listening who can kind of relate to this.

00;12;04;08 - 00;12;27;20

Dr. Norrine Russell

I remember telling her teacher that she was going to be out for the day to get an evaluation. And the teacher who was a wonderful teacher, I mean, she was a terrific teacher. My daughter got a great kindergarten education. You know, she loved to read. She loved math. She was happy. And I remember her her teacher saying, but she's so cute, she doesn't have ADHD.

00;12;28;04 - 00;12;48;08

Dr. Norrine Russell

And I was like, oh, and at the time as a mom, you know, you're filled with so much doubt when there's so many unexpected things that are happening and these diagnoses are coming at you fast and furious. And I was like, Maybe she doesn't have ADHD. She really is cute and she's bright and she's doing well in school.

00;12;48;08 - 00;13;08;23

Dr. Norrine Russell

No, I think she does like so we went and had her evaluated. She had ADHD and then her autism diagnosis story is actually, I'm going to say, adorable, and I hope no one will take offense to that. So there is a book called All Dogs Have ADHD, and I had gotten it for my son because my kids both love animals with all their heart.

00;13;09;03 - 00;13;28;24

Dr. Norrine Russell

And so we got this kid's book called All Dogs Have ADHD, and my daughter is more of a cat person. She's like, Well, so Mom, what do cats have? Then? I was like, I don't know. So I went on Amazon and I looked at with their other animals. Was there a turtle, a horse, whatever? Come to find out that there is a book called All Cats Have Asperger's.

00;13;28;26 - 00;13;49;15

Dr. Norrine Russell

And so I ordered the All Cats Have Asperger's. This was back when that was still, you know, the proper diagnostic label. And she read the book and she's like, Mom, mom, I think I have Asperger's. And I remember her coming in and reading the pages to me, like on page seven, it says this and that's me. And on page 11 it says this and that's me.

00;13;49;21 - 00;14;14;05

Dr. Norrine Russell

And on page 14, this is exactly how I am. And I was like, Oh, oh, really? You know, in your mind is already kind of in amazement at what you're living anyway when you have your first one and they're super complex. And I was like, Oh yeah, okay. Lyla, way to nail it. Let's make an appointment for an autism evaluation.

00;14;14;05 - 00;14;40;23

Dr. Norrine Russell

And so I went in, had the autism evaluation, and she does have mild autism. My son is more moderate to severe with no intellectual disability. But yes, so that's her autism diagnosis story. And it just cracks me up because it does speak to how much we need to talk with kids about what they're feeling and what they're experiencing.

00;14;40;23 - 00;15;05;09

Dr. Norrine Russell

And I think it also speaks to the difficulty of being a parent with two kids with special needs or neurodevelopmental disorders and trying to understand each one of them. My kids, their personalities couldn't be more different. Their temperaments couldn't be more different, but they have the same three diagnoses. And that was hard to puzzle through as a parent.

00;15;05;09 - 00;15;32;16

Dr. Norrine Russell

So kind of a long answer to your question, but I think our story of kind of one diagnosis at a time, trying to figure things out, feeling like you still didn't understand your kid. I think that's a story that a lot of parents can relate to. And what I would say when I put my other hat on as a professional is keep advocating, keep asking the book that I wrote, asking the right questions about ADHD.

00;15;32;27 - 00;15;55;22

Dr. Norrine Russell

I really strongly recommend to every parent if you're getting an ADHD evaluation, please know that two thirds of kids with ADHD have a comorbid diagnosis and so ask be an advocate. But these are all things I've learned along the way. And it was I'm I'm going to be truthful because I think this is what your podcast is about.

00;15;55;29 - 00;16;00;08

Dr. Norrine Russell

It was hard and I was I felt very alone and lonely.

00;16;01;22 - 00;16;36;28

Melina Danko

How amazing that she basically diagnosed herself. And so when you think about it, that really does resonate with me, that it's really important to have these different types of exposures because it helps children and adults to be able to label what they're feeling. And maybe not be able to express that any other way until they see it in writing somewhere else and they can relate.

00;16;37;17 - 00;17;11;00

Melina Danko

And so I had never thought about that before, but I am definitely going to remember that Lila's story is going to be locked in my vault forever and thinking about the different ways that I can increase exposure and opportunities for people to relate and be able to express. Because sometimes you don't know. You just know you're not feeling right, but you don't know how to how to express that or how to to label that or what that even means.

00;17;11;00 - 00;17;23;05

Melina Danko

Or maybe it maybe it's that that's how you feel. And you don't realize that that's not right until you see it in a book and you're like, Wait, okay, this sounds familiar, so thank you for sharing that.

00;17;23;29 - 00;18;06;10

Dr. Norrine Russell

There are so many great books about neurodevelopmental disorders, whether it's ADHD, autism, anxiety, dyslexia. There really are terrific children's books out there, and I hope that they are making their way into every school library, every doctor's office, not just therapist's office or families who have a kid who have already been identified. One of the biggest blessings of our lives was friends that we had when the kids were little, who the mom was a teacher and her two children were about the same age as my two children, and they learned a lot about ADHD and autism because they loved my kids.

00;18;06;10 - 00;18;15;00

Dr. Norrine Russell

And so it's a great thing for all families to have some books about kids with special needs in their home library.

00;18;15;24 - 00;18;33;15

Courtney Ringstaff

You said you felt very alone and that led you to starting a support group. So what were some of the support systems and networks that you identified or that you had to create in order to kind of start to feel just like you were navigating your your space and your life a little better?

00;18;33;15 - 00;19;04;18

Dr. Norrine Russell

One thing I want to say is that for me, it was a long process and it was difficult. And so if there are people out there who are still going through this process and you're feeling depressed, lonely, overwhelmed, those are all really normal feelings. They are to be expected when you are getting this kind of evaluation and diagnostic process going through this kind of diagnostic process.

00;19;05;01 - 00;19;43;01

Dr. Norrine Russell

And one of the things I wish I could say to myself ten years ago is you were doing a great job. You were doing a great job because at the time I felt like a failure. And I hoped that as our awareness of these kinds of disorders grows, that moms and dads won't feel so alone for me, you know, I created the Tampa Bay ADHD Parents Support Group, and what we did every month was bring in a speaker from the community.

00;19;43;01 - 00;20;07;13

Dr. Norrine Russell

And I just did everything I could to find all the local experts from the school that helps kids with learning disability goes to psychiatrist who developmental pediatricians and I just kept trying to learn and to network. And so that piece was great because every month I would find a speaker for our group and, you know, we would learn something more.

00;20;07;13 - 00;20;39;15

Dr. Norrine Russell

And we had, you know, a great turnout and a great group, very consistent. And so you also learn from other people whose kids are a little bit further ahead in their journey. But I will also say that we were very much alone as a family. We live in Florida. We did not have extended family near us. We did not have cancer uncles around who were struggling with the same issues.

00;20;39;15 - 00;21;13;14

Dr. Norrine Russell

And so nobody really could relate to what we were going through. So we were geographically isolated, but also very much psychologically isolated. And so I think for me, I just kept reaching out to experts and building my network and throwing myself into work so I could feel like I was making a difference in every client that I had and every new professional I met, I felt like I was learning something and being able to better understand what were my options for helping my own two children.

00;21;13;29 - 00;21;35;07

Dr. Norrine Russell

But even though my kids both had plans at school, you know, there's a limited amount that schools can do. And I'm not salting them. That's the system. And so we've had some great teachers through the years, we've had some not great teachers through the years. We've had some school environments that worked for either one or both of my kids and some that didn't.

00;21;35;15 - 00;22;01;19

Dr. Norrine Russell

Unfortunately, my story is a story of a mom really kind of figuring it out on her own. And I really hope and this is part of why I built the practice into a national practice. I really hope that we can reach as many parents who feel like I did ten years ago. Is this ever going to stop? Are we ever going to be emotional, regulated?

00;22;02;06 - 00;22;25;25

Dr. Norrine Russell

Is my kid ever going to be able to sit through a whole day at school? Am I going to get called from school several times a week for the rest of his educational life? You know, and I want parents to have a roadmap and have hope and it's just really hard when you're doing this journey mostly on your own.

00;22;27;13 - 00;22;52;19

Dr. Norrine Russell

So, Courtney, I wish I had a more beautiful answer for you about support systems, but I had a lot of really kind people in my life, my college roommate, my kids, friends, mom. But in terms of a really robust support system, it was kind of like one person here and one person here and one person here, and it wasn't school or family.

00;22;53;27 - 00;23;14;10

Courtney Ringstaff

I feel like that is a common experience and that's why we're all working to provide more of a supportive network for families who are navigating those systems now. But I feel like we hear that repeated on this podcast that families are like, Nope, there was no support system. I had to make my own or I had to navigate this by myself.

00;23;14;27 - 00;23;29;22

Courtney Ringstaff

And that's unfortunate. But I think that's also why we're all doing what we're doing. So what are some strategies that you're using for fostering that positive and supportive environment that's really made a difference for your kids and your all's way of life?

00;23;30;24 - 00;23;56;09

Dr. Norrine Russell

It's a really good question and I'm glad you asked it. So one interesting part of my pre kids career was I did a lot of work around strengths and developmental assets that kids have and that communities have. And so because my nonprofit work was very strong space and positive psychology and how do we help kids to build all of the skills and qualities they need?

00;23;56;28 - 00;24;25;06

Dr. Norrine Russell

I think that ended up integrating really nicely into parenting. Like what are the strengths my kids have? Yes, they have autism. Yes, they have ADHD. Yes, they have anxiety. But what are their gifts and talents? And that has definitely carried over into what I do professionally too. And it's usually an essential part of coaching, even coaching with students, which is very unusual and hard to find.

00;24;25;06 - 00;24;48;07

Dr. Norrine Russell

But we are a strengths based practice and we are strengths based family. So my kids from early on have known, what are you good at? You know, what are your strengths? We say to my son all the time, Your strength is your love and your compassion. You were born with a heart. We use this kind of take off of a line from the Grinch.

00;24;48;07 - 00;25;07;23

Dr. Norrine Russell

And in the Grinch movie it talks about his heart growing two sizes. And I tease Ethan and I say, You were just born with a heart that was two sizes bigger than everyone else. And so it's just a cute little funny thing that relates to Christmas. And and he just has all of this love and compassion, both for people and for animals.

00;25;07;23 - 00;25;33;01

Dr. Norrine Russell

And and so we've always focused on that. We've also and I'm so very thankful for this not experienced academic difficulties. And so one of their strengths is that both of my kids love learning. They are curious about things. Their autism kind of manifests itself often in very scientific interests. And so that's been a strength that we can capitalize on.

00;25;33;01 - 00;26;08;21

Dr. Norrine Russell

And so I think as a family, having a strengths based perspective has been one of my guiding principles. I think normalizing the messiness, right? Like just we're going to have some hard days and every family has hard days. Every kid has hard days, every mom has hard days and just sort of normalizing that, even though on the inside I had to kind of fight my inner perfectionism, I still really tried to be clear with the kids about we can do hard things.

00;26;08;21 - 00;26;37;18

Dr. Norrine Russell

There was an author who had written a bestselling book at the time that I was parenting, and then when they were younger and, you know, one of her mantras was, we can do hard things. And that kind of became our family mantra. We can do hard things and love wins. And so we had these kind of family values and family sayings that I think helped us get through the emotional meltdowns or the calls from school or the times when I felt like, Gosh, Ethan needs all of my attention right now and I'm feeling bad about my parenting balance.

00;26;37;25 - 00;26;57;29

Dr. Norrine Russell

And then we just created rituals and routines that worked for us. I would say that's the third thing, you know. So Friday afternoons were always fun. Friday, my son, since he was six months old, has been fascinated by the profession of firefighting. And so when he was in elementary school, we drive around a different firehouse and take tours, do creative things on Fun Fridays.

00;26;57;29 - 00;27;15;05

Dr. Norrine Russell

So that was always our okay, we got through the week. We're not doing anything tough. We're having fun Friday. We might not be able to have sleepovers, we might not be able to go to certain community activities, but we can get in the car and go have fun or we can do something fun at home that works for us.

00;27;15;05 - 00;27;27;06

Dr. Norrine Russell

And so creating rituals and routines where we could celebrate life and have fun in a way that works for my kids and their autism and ADHD.

00;27;27;06 - 00;27;52;02

Courtney Ringstaff

Thank you. I love that idea. And and like Molina has mentioned before, I like when we give our audience and our listeners something concrete that they can potentially implement to improve their situations, could potentially help their children and their families. So thank you for sharing that. I'm curious about what IEPs looked like for your kiddos, because I know we have family sometimes get some pushback from the schools not wanting to implement IEPs that they're doing well academically.

00;27;52;02 - 00;27;59;29

Courtney Ringstaff

What type of accommodations do you have to advocate for so that your children were successful, or did they need accommodations?

00;27;59;29 - 00;28;24;17

Dr. Norrine Russell

Yes. So this is another challenge that gets put on you when you have a child with a neurodevelopmental condition. I didn't know anything about five or fours or IEPs. Right. I mean, I didn't I never worked in a school. I didn't know a single thing. And I remember who my kids were at the preschool age going, well, what's the difference?

00;28;24;17 - 00;28;44;28

Dr. Norrine Russell

The first question that every parent asks, what's the difference between a504 and an IEP? I think I had to ask that question ten or 20 times before I even understood what those plans were and what they were designed to do. And I am a pretty smart person and I still had a lot of trouble understanding how is this all set up, how does this work?

00;28;44;28 - 00;29;14;00

Dr. Norrine Russell

And so I do want to say to parents who are listening, be patient with yourself. This is complicated, this is difficult. And while the schools and the laws are set up for your involvement, it's not always easy to navigate. And that's not on you. That's just a really complex system of federal laws that is hard to learn. And so be patient.

00;29;14;08 - 00;29;45;13

Dr. Norrine Russell

Find someone who can help you find your people. Usually it's another mom. So Ethan actually had an IEP in preschool through like early find or, you know, child find, whatever it's called in the state where your listeners are at. And then when we went over from his private preschool into public school, we had to update that. I remember at the time, you know, hearing from school will spread.

00;29;45;13 - 00;30;13;27

Dr. Norrine Russell

He's not intellectually delayed. Maybe he doesn't need an IEP. And because his challenges have always been the self-regulation and the emotional regulation, but he presents as this not atypical for for autism kids. You know very bright kind of little professor will talk your ear off oh so smart. He's so smart and so right from the beginning, I was like I was the one who was having to help them understand what his needs would be.

00;30;14;08 - 00;30;39;29

Dr. Norrine Russell

And that's not what you expect. Going into elementary school. You expect school to be the expert. You expect them to guide you. You expect them to bring all this information to you. And so I was just completely taken aback in those early years of, wait a second, school is supposed to be the one telling me what to do and how they can help.

00;30;39;29 - 00;31;16;02

Dr. Norrine Russell

And so that was a huge shift to make. And thankfully, I have kind of an advocate personality by nature and had gotten to practice those skills with some earlier experiences in life. So Ethan had an IEP that had been started in preschool and he had his IEP all the way through. He has it today, even though we are in Florida technically home schooled and I think what was most difficult was realizing that he was going to have an entirely different educational experience than I had.

00;31;16;02 - 00;31;53;18

Dr. Norrine Russell

He loves school, he loves learning, but the emotional dysregulation was so difficult. And and that's not something that a whole lot of schools are able to address. And and at the level that he needs it while also receiving a standard level of education. Right. He didn't need to be in a special classroom or a special program. So we were very lucky in the first few years of his elementary school experience, he was in a co-taught classroom where there was a special ed teacher and a regular teacher, and it was just wonderful.

00;31;53;29 - 00;32;26;28

Dr. Norrine Russell

My daughter has a504 plan and even after she got her autism diagnosis, we got pushback from the school like, she's really doing fine. She doesn't need an IEP. And in some ways that's true. And in other ways she would have benefited from some services at the time. I think the tides were turning a little bit and schools were much more likely to try to provide services using a504 than to actually go ahead with an IEP.

00;32;27;12 - 00;32;52;08

Dr. Norrine Russell

So she has a504. That is a really long, long answer to your question. But there are so many complicated pieces of this IEP and 504 for parents who are at the beginning of their journey, just learn. Just, just learn, ask questions. Put everything in writing. Don't ever take a phone call from school. This is my personal advice to you.

00;32;52;21 - 00;33;17;17

Dr. Norrine Russell

Put everything in writing, get it in email or in a letter so that you have all of that documentation. Because a year from now, two years from now, three years from now, you're not going to remember all of those phone calls and be patient with yourself and be patient with school because they are trying their hardest. They too are working in a system which is complicated to navigate.

00;33;17;17 - 00;33;39;12

Dr. Norrine Russell

So if you're at the beginning stages, keep advocating, keep asking questions, get everything in writing, and then as you get further, I would say trust your gut. There were a lot of decisions I made that were decisions that I never thought I would make. I wanted my kids to be at their elementary school from K through five. I wanted them to go to our neighborhood middle school.

00;33;39;12 - 00;34;05;24

Dr. Norrine Russell

I wanted them to have that neighborhood, community, school experience, and that's not what we ended up doing. And I had to trust my gut and my instincts for my kids and make decisions that I didn't see. A lot of parents around me making. And eventually I came to peace with that. But it was another point of feeling lonely and alone.

00;34;05;24 - 00;34;37;13

Melina Danko

I did have some questions about where they are now because at 14 and 16, it seems like you're we're in those teen years. Right. And so from your previous work experience, you said that you worked with middle school primarily girls. We hear often that particularly for individuals with disabilities, when those hormones kick in, those teen years can can be really, really tough.

00;34;37;26 - 00;35;02;03

Melina Danko

And then I can only imagine throwing in the mood dysregulation that it's even more tough. So can you tell us a little bit about how things are maybe are you pulling in any tips from your previous work experience or does all that go out the window when it's your kid and you know, all of these other things?

00;35;02;03 - 00;35;36;05

Dr. Norrine Russell

They're both doing terrific right now. I'm incredibly proud of them. And I feel at this point, I finally feel like, you know what, I've done a good job parenting. I have been a good mom and I can look back and see where I put the hard work in to educate myself, to build connections, to ask questions, to keep learning, to take time and just go lock myself in the bathroom, you know, which I think is a great coping strategy.

00;35;37;07 - 00;36;01;18

Dr. Norrine Russell

So Ethan right now is 16 and he does online school from home. And we do have a teacher who comes to the house three times a week to work with him and that really helps me to stay out of the mess of it. Right. Like we know our teenagers want autonomy and we know it's important for them to be developing autonomy.

00;36;01;18 - 00;36;30;08

Dr. Norrine Russell

Right. And it's not good for parents to be micromanaging high school. And so we have a teacher who comes to the house three times a week to work with him. And he's doing beautifully in school. He's he's taking a a regular course load of honors and a couple of apps and doing well. He is also receiving services through vocal rehab and they have helped him to get a job.

00;36;30;08 - 00;36;51;07

Dr. Norrine Russell

So he has a part time job at a vets office, which is wonderful. I had a moment, not a moment, a long moment. Many moments of pushing to become a bagger at Publix, which is our kind of biggest grocery store chain here in Florida. And he was adamant with me that he did not want to go back groceries at Publix.

00;36;51;07 - 00;37;08;12

Dr. Norrine Russell

And I was like, you'd be so great bagging groceries that Publix. You're so kind and you're thoughtful and you're helpful and you're a little bit chatty and all the moms would love you all the people would love you at the public. No, mom, I don't want to work at Publix. And again, I had to learn the same lesson over again.

00;37;08;12 - 00;37;30;14

Dr. Norrine Russell

Listen to your kids. Listen to your kids. Because he kept saying to his vocal rehab counselor, I want to work with animals. I want to work with animals. So his job coach eventually found the right placement for him. He works at that office here. Shout out to Gregory Vet. They have been absolutely wonderful. So he has a part time job at Gregory Vet and he's doing well.

00;37;30;14 - 00;37;58;29

Dr. Norrine Russell

We do struggle because of the extent of his mood dysregulation in autism. We still struggle socially. So there is a terrific camp program here that he attends weekends and during the summer, and I think that's really been his social outlet, but that's still an area of struggle. He was invited to homecoming this year and went to homecoming. So that was like just adorable to me.

00;37;58;29 - 00;38;23;21

Dr. Norrine Russell

And he was really excited to be asked and just so cute to see, you know. And I think that, you know, he started dual enrollment this year, so he's taking a couple of college classes. I think he's just going to be a typical kid with neurodevelopmental disabilities. He's going to mature a little bit later. He's going to need a little more support for a little longer.

00;38;24;01 - 00;38;45;03

Dr. Norrine Russell

I'm going to need to remember that that support should not be me. When when we can find the right professional and that he's on his own journey and that he has strengths and gifts that he has to offer the world. I'm going to need to be patient. It's not going to be my journey. He's not going to go off to live in a residence hall at 18 the way I did.

00;38;45;17 - 00;39;19;06

Dr. Norrine Russell

And that's okay. Lyla is also doing great. She has a lot of social anxiety and so being at home for her really works. She interestingly, has really come out of her shell socially, and she has this group of other teenagers that that she hangs out with. And it was so fascinating to watch her become the leader in that she, like, kind of identified one girl from a school she had attended, one girl from a camp she had attended, and then a girl she went to school with in her early years.

00;39;19;12 - 00;39;47;07

Dr. Norrine Russell

And now the four of them have this group chat and they have so much support they offer each other. I'm like, wow. Like, so fascinating that my, my daughter has this group of girlfriends and she's just in many ways a typical teenager in that way, doing school from home, you know, kind of a regular course load again, like Ethan and hanging out, doing a little bit more, socializing.

00;39;47;07 - 00;40;15;00

Dr. Norrine Russell

One of the things that I've noticed with Ethan is that our sensory challenges have gotten easier as he's developed. So you're asking me about, you know, kind of the hormones and the teenage years, what's better, what's worse? One of the things that got significantly better were the sensory issues. I mean, this was a kid who you couldn't take anywhere because if he could even hear that automatic toilet flush, we were in meltdown mode for the next 2 to 3 hours.

00;40;15;00 - 00;40;45;02

Dr. Norrine Russell

I mean, his sensory issues were severe, and now we can go places and he can have different fries at different restaurants without us having to take his food. So a lot of that has eased up. I think he has also been very fortunate to have some really gifted therapists who have worked with him on coping strategies and he now has the ability to kind of self-regulate in stressful situations.

00;40;45;02 - 00;41;11;06

Dr. Norrine Russell

Like even this morning before we started the podcast, our dog had a seizure this morning and he was able to come over and be calm with the dog and not get disregulated. Another interesting kind of benefit of having kids who are delayed socially and emotionally is kids with ADHD and autism are is I'm really yet had to deal with a lot of things that we associate with adolescence.

00;41;11;06 - 00;41;41;20

Dr. Norrine Russell

You know my kids are not interested in parties they haven't been exposed to vaping, to alcohol. They haven't even really been exposed to seeing other kids engage in dating much less sexual activity. So in some ways, that's been a little bit of a blessing. Even though they're behind still, you know, I'm not worried that my 16 and 14 year old are vaping or drinking yet because they're just naive and immature for their age.

00;41;41;20 - 00;42;12;17

Dr. Norrine Russell

And so that piece has been really good. And oddly, I think that our experience continuing, what of course, has been our experience all along, has been a little bit atypical when it came to hormones. I have enjoyed this time of parenting. It's fun to watch them growing into young adults and I would say that both of them are happier now as teens than they were in elementary or middle school.

00;42;12;17 - 00;42;45;09

Dr. Norrine Russell

So I'm going to just hope that that is the experience of some of your listeners, that adolescence doesn't create hormonal chaos because some of the maturation that's happened as they've moved into adolescence has been really beautiful and really helpful to me. And so days go by, sometimes weeks go by without tears around here, which was not the case, you know, during childhood.

00;42;45;09 - 00;42;53;04

Melina Danko

Thank you for sharing that. That's a a unique side that that I hope others can relate to.

00;42;57;08 - 00;43;18;25

Courtney Ringstaff

Or it can just give parents who are in those middle school and elementary school days some hope that things are going to be easier and they might be dreading teen years, but it could get better and regulation could get better. So it can also give some hope. Is there any message that you would like to share or that we haven't touched on yet?

00;43;18;25 - 00;43;22;14

Courtney Ringstaff

Before we kind of move on to our last question.

00;43;22;14 - 00;43;51;24

Dr. Norrine Russell

I think we've talked about some of the important themes. You know, be an advocate, create space for your families, individual journey. Your journey. Is it going to be like somebody else's and grieve whatever losses you have, grieve those losses and find a way to create joy and happiness in what your family does have. Like we weren't at community events all weekend long.

00;43;51;25 - 00;44;25;27

Dr. Norrine Russell

My kids didn't play sports. We were in many ways on our own, but we found ways to have joy and happiness in that. And so in thinking about our story and and what I would say where I'm at now, you know, be an advocate, accept that your journey is going to be your journey. And whatever it is, accept it and look for it and then take delight in the moments of joy and happiness that you do have.

00;44;25;27 - 00;44;41;16

Dr. Norrine Russell

Because you will. You do. We all do. Regardless of the struggles and the tears and the meltdowns and the IEP meetings and all those things.

00;44;42;14 - 00;44;58;02

Melina Danko

This podcast is sponsored by the West Virginia Department of Health and Human Resources Office of Maternal Child and Family Health, Children with special health care needs program and. The West Virginia Family two Family Health Information Center and produced by the West Virginia University Center for Excellence in Disabilities.