

## **CPI *Unrestrained* Transcription**

Episode 52: Lexie Dryden

Record Date: March 15, 2018

Length: 51:09

Host: Terry Vittone

Terry: Hello and welcome to *Unrestrained*, a CPI podcast series. This is your host, Terry Vittone, and today I'm joined by Lexie Dryden of the Autism Association of South Australia, or Autism SA. Hello and welcome, Lexie.

Lexie: Hi, Terry. Thank you for having me.

Terry: Thank you. Let me tell you a little bit about our guest. Lexie Dryden has had a lifelong interest in autism and strives to learn as much as she can about the people who are impacted by this area of neurodiversity. She has worked for Autism SA for over 15 years and is currently a consultant in specialized life support services helping kids with autism at school and within their home environments. Her role includes direct one-on-one and small group support, joining with schools, families, health therapists, and the often-extensive teams working with children to increase their quality of life through evidence-based, person-centered practices.

Since March of 2013, Lexie has been training the MAPA® program, which stands for the Management of Actual or Potential Aggression. MAPA® is comprehensive training that teaches management and intervention techniques to cope with escalating behavior in a professional and safe manner. According to Lexie, training MAPA® is one of the best professional decisions she's made, and it has helped her to be more successful in her role both with kids on the spectrum and in supporting the team around the child as well as her family and other people in the community. Lexie also presents trainings and workshops for professionals, parents, and other caregivers, and she says presenting is a passion that allows her to share her knowledge to support a better understanding of autism.

All right. Lexie, let's begin. Could we start today with you giving our listeners a brief overview of your organization, Autism SA, and how you serve the community?

Lexie: Certainly. So, we've been around since 1964, and we also now support into the Northern Territory. But it was started by families who were driven by the desire to ensure that they had access to the best information, education, treatment, and support, and advocated for

acceptance and understanding and carried research and leadership in the community. So, people on the autism spectrum are at the center of everything we do, and we provide individualized and person-centered services and support for the people on the spectrum and their families and the team around the child.

And we have an extensive range of services from diagnostic assessment and planning, consultancy, therapy and support, social skill development, positive behavior support, support around anxiety and calming strategies, understanding autism, working on transition, toileting, sleeping, social development to provide respite and overnight support where we can. Day options, school holiday program, training for professionals, we provide conferences for families including recently having had Kari Dunn Buron, the creator of the Incredible 5-Point Scale come over, Peter Vermeulen who is from, I think it's Brussels, Belgium. That's the one. Michelle Garcia Winner will be coming over next year. And we're involved in the Asia Pacific Autism Conference and hosted that in 2013.

We also have an information line where parents can ring up and find information about autism, funding, services we provide, and provide a whole lot of other things such as public awareness sessions, expo, having autism ambassadors. We have an online library. So, our services are very extensive, and we are the main provider of support and the leader in that for South Australia.

Terry: You've got quite a large menu of services that you provide. How many people in a year would you say that Autism SA provides service to?

Lexie: That is a very hard question to answer because it does vary greatly from year to year.

Terry: Okay.

Lexie: But off the top of my head I can't remember. I should have collected the data on how many clients we actually have, because it's across the age spectrum. And I would have to look up the website. I know the school program has about 7,000 or 8,000 clients that we can service, that are registered with us, and that we have some adults as well. So, I think it was getting around 11,000 or 12,000 mark, but I would have to double check that one.

Terry: Mm-hmm. But in other words, if I'm a resident of South Australia and I have someone on the spectrum that needs special care, or I need some training about how to care for them, Autism SA would be the resource for me?

Lexie: It would be the best one in South Australia, I would believe. We get lots of really good positive feedback about our training and development series. We provide that at our clinic as well as out in the community and within schools. And so, because we're supporting the whole life spectrum, we service far more than just the clients that are registered with us.

So, to keep track of the data around how many people that actually access our services overall, it is thousands.

Terry: Wow, I see. So, let's talk about the MAPA® program, Lexie, the Management of Actual or Potential Aggression. I know that you started it, I think, I believe, in 2013 with the program. And why don't you talk about how it's influenced the program, the methods and the culture and your own approach to caring for people on the spectrum.

Lexie: We used to have a similar training that we undertook some years ago prior to moving over to what was then *Nonviolent Crisis Intervention*® [training]. And I'm looking at my certificate at the moment from when I first gained my certification, and it was actually October 2009. So, I know we've been doing NVCI [*Nonviolent Crisis Intervention*®] since at least then, if not before. So, some years.

I think that as far as our policies, which are very much least restrictive, hands-off policies, it fits beautifully within that. And with our Department of Education and the other education sectors are also very hands-off, and that fits within their policy. So, it is now embedded into all our policies and procedures, and it's become part of the culture of Autism SA.

It also has helped us to develop a more comprehensive plan based on evidence-based practices for staff, schools, families to utilize with the individuals, but also helps us to support the parents of the individuals with the diagnosis.

The staff, when they might be having a challenging situation or challenging day, it [MAPA® training] helps us to know what to do, when to do it, what to say, what not to say or do. And it really helps us to look at the underlying characteristics of autism and recognizing that contextually inappropriate behaviors occur as a result of that, and the anxiety that comes along with that, not understanding a social situation or the social context in which something is occurring. So, if we address the need, then we address the behavior, and de-escalation is the most critical aspect of that.

So, it helps us to have that plan and support schools and individuals supporting—and the family—to have that plan, but also to not respond reactively when things do go pear shaped and still have a plan for those circumstances.

So, that would be, I think, the main thing that it is something—it's a mandated training for all of our staff at Autism SA. And so, we are now moving over to MAPA® and hopefully by the end of this year, all of our staff will be fully re-trained in the new version of that.

Terry: So, it sounds like the MAPA® approach has shifted or informed the whole basic orientation of where someone who works with Autism SA would begin from. As you said, to look at

the person and read what they're trying to communicate rather than the behavior in the moment.

Lexie: Absolutely. And within our community staff, so those that are providing respite, short-term accommodation, one-to-one support, they actually now need to be trained in MAPA® before they can go out and support those clients, so that they have those skills ready to go when they need them rather than having to go out there and figure it out for themselves on their feet, which usually doesn't tend to end so well.

Terry: Well, an ounce of prevention here is coming into play, and I think that's one of the great things about the MAPA® program and the behavioral model is it gives people, you know, sort of a geography of where they are in a particular situation.

Lexie: Yeah, absolutely. And I think it's funny you say that, because I was presenting a training on Wednesday around positive behavior support, and one of the things we talked about in that is looking at the topography of autism, and the behavior and really mapping it in as comprehensive and factual a way as possible. So, I think that fits with what you said quite well.

Terry: You know, Lexie, during our pre-interview, you mentioned—let's get back to this idea of the basic orientation or the way a person approaches a task at hand or a person that they are charged to have a duty to care for. You mentioned that teachers could use MAPA® to break ineffective coping cycles, and that sounds really promising and really worth digging into. Could you explain how MAPA® helps teachers break ineffective coping cycles?

Lexie: We use it in conjunction with the Incredible 5-Point Scale a lot, but we do find that teachers often are trying to support multiple students. They'll have up to 30 in their class. They may not have another staff member in there; they're trying to support individuals from gifted through to those with some intellectual delay and other comorbid conditions. So, it can be very hard for them to try and really support everyone, and often they're quick to go to, I guess, the easy out, which is addressing the behavior and perhaps being punitive in that moment. And the evidence shows that, especially for those with autism, but for all people, that that doesn't actually work. And that's one of the things we stress the most when we even do the trainings: that this is not autism-specific training. This is training for people because people have anxiety. It is part of becoming or being human.

So, we talk a lot with them around looking at that maladaptive coping mechanism and the cycles that individuals have, whether they may be identified and registered with Autism SA, or perhaps just have some characteristics that they display that may warrant further investigations. So, we have asked a lot, "What do I do with this individual? They're not registered, but we think they show characteristics." And we always go back to looking at the anxiety and supporting them because the strategies will work regardless.

All of the Department of Education behavior coaches that are supporting individuals and staff at schools are trained in *Nonviolent Crisis Intervention*® [and are] moving over to MAPA®, and can support school staff to train in that. I'm recommending every time I'm going to a school that teachers be trained in it as it is one of the best trainings, and I think the most supportive for teachers to support students and the family around them.

But often what we see is that they're punished, or they're not looking at why their behaviors are recurring. And basically, if you always do what you always did, you'll always get what you always got. So, they're not looking more in-depth around why the behaviors are occurring.

So, we go in there and suggest that at certain points, to look at what is going on and maybe redirecting them or having that plan to know what to do using things like visuals of forced choice to show them what other options they have in that moment. Distracting them, knowing when to teach new skills or talk about or address the issues of concern, which is not when they're heightened, because then you will end up with that power struggle.

So, try and support them to be calm and break that cycle because, you know, I've been in situations where I've been severely heightened, and I know that logic goes out the window, and that's true for anybody. But I think with individuals, with autism, that anxiety and stress is there constantly. They come to school heightened. So, even though they may not show that, they're feeling that. And often we get the comment that the behavior of concern or the contextually inappropriate behaviors seem to come from nowhere. But if you can recognize that as a sign of stress and anxiety, break that cycle, support the individual to be calm, teach them the skills that they need to address the underlying characteristics of autism, then the outcomes for that individual and the staff are better.

It also means that the staff are looking more for the positives that are occurring rather than the negative because if you look for the negatives, you'll find them. And often that builds up a negative relationship with that individual regardless of diagnosis. So, if you're looking for the positives and helping them to be calm and really seeing that for what it is, the anxiety, then you're more likely to have that positive relationship and rapport with that individual and really support them to learn the skills they need.

Terry: Do you find that teachers are receptive or have become more receptive as time has gone on, as you have more experience with MAPA®?

Lexie: I feel that the majority of the time, more teachers are receptive. I think that they are under-resourced, underpaid, and overwhelmed. I think the need for teachers is huge, that they're certainly struggling and need a lot of support, but that their understanding generally has increased. I was even commenting at the training I did Wednesday, that one of the slides we put up is often around what is behavior. And a few years ago, when we

put that up, the most frequent comments were just going straight to the specific behaviors such as hitting, kicking, screaming, spitting, swearing, all those contextually inappropriate behaviors. And it took a while to pull from them that behavior is communication.

The training I did on Wednesday, one of the first comments when I said, "What is behavior?" This was a group of professionals and teachers. They actually said, "Communication." So, I think the understanding has certainly come a long way.

Terry: It's harder to list good behaviors, I guess, than it is those the problematic ones if you're a teacher, but to recognize that they're all forms of communication is sort of a paradigm breakthrough in a way, if you will.

Now, on your website it says . . .

Lexie: It is.

Terry: Oh, sorry, Lexie. Go ahead.

Lexie: No, you're fine. After you.

Terry: Okay, all right. Well, I was going to move over to the website for Autism SA. One of your quotes is, "Aims to improve outcomes for people on the autism spectrum." Could you talk about some of the ways that Autism SA helps you accomplish better outcomes for the people that you help?

Lexie: Because we provide such a vast array of services, it really is supportive of that. We try to be person-centered. We have that team approach. Everything we do is based on evidence-based practices, incorporating visuals. We make sure it's very much individualized because every individual, regardless of diagnosis, is just that. And one size would not fit all, so everything we do has to match that individual and the team around them.

When I'm supporting in schools, I always look at what is the teaching style of that staff member, what is the learning style of the individual, and how to meld that together somehow for positive outcomes and best outcomes. We provide strategies around supporting individuals to learn about calming strategies and breaks as well as providing staff understanding and families understanding of how to support them externally, because it needs to be that holistic approach. Looking at supporting improved communication for the individuals, so we have our speech pathologists and allied health team and psychologists that support the families and the individuals around any of those sort of things, looking at social pragmatics, supporting them with participating in the community and promoting community awareness and understanding via our events and promotions. We have family events that they can come to and just be part of the autism community and culture of autism.

We work very closely with the individuals themselves to try and get their input and perspective to support them to be happier. And I think that was one of the key things that came out of our recent conference with Peter Vermeulen, which is that happiness in autism is, I guess, underrated and not focused on or looked at enough. How do we support them in their self-esteem and those barriers so that when they become older, they are as successful and happy as they can be as an individual?

We try to help them around their environment by them having a bit more control of it, but not taking control of it, I guess, where possible from when they're younger and just supporting them through groups and community awareness—participation in the community when they're older to really reach their best life outcomes to be the best they can be and to try and fit into the community however they possibly can.

Terry: So, you really take a long-term perspective on overall wellness and self-actualization for people on the spectrum.

Lexie: We very much do try to do that. And I think the longer I've been with Autism SA, the more I've been able to see that, and really see some of those individuals I've worked with from when they've been in what we refer to as reception, when they first start school at about age 5 through to high school, now seeing some of them in the workforce as they've grown up, seeing them as adults. And I have one of my close friends who I've been friends with since I was eight. She has three children with a diagnosis as well as other comorbid conditions. And in finding out more about autism through her children, then was able to self-identify, and [she] has had one diagnosis so far.

So, I have had a friend since I was eight on the spectrum and to be able to see what's going on in her world, her struggles, but the triumphs and the way her kids are getting through that and now going on to study and work, and she's become a grandma, as have I, to be honest. It's really nice to be able to be part of that wider community.

And I think, in particular for me, my work, [and my] professional and social life, there isn't a big gap between the two. And I think I've found that more as I got older. There are more people in the community now being diagnosed, but I have friends with the diagnosis, and it's just such a blessing for me to be part of that culture and community.

Terry: Well, that's really a beautiful message, to have the length of service that you've had and to start to see these lives truly be impacted and changed and see people realize happiness in their life. So, what a great reward that must be for someone who has been dedicated as you have been.

Lexie: Yeah. We have a lot of times where things don't go as well as you would like them to. And I think we hold on to those positive when they happen, because they keep us going. We

know that with the right support, the right strategies, early intervention, and that team around the child really working together to create positive outcomes, but the quality of life for those individuals can be so greatly improved and that's what it's all about. That's why I do what I do and get up in the morning every day, just to try and support them, the families and everyone I can—not just myself, of course, everyone at Autism SA has the same values. And we just want to support them to reach the best outcomes they possibly can.

Terry: How many are you at Autism SA? I guess I should have started with that question earlier, but how big is your staff?

Lexie: It varies. We have a lot of casual staff in the respite area and day options and things like that, but I believe we're around the 200 mark.

Terry: I see. Okay. You mentioned that positive outcomes are something that sometimes are difficult to get to, and I know during our pre-interview you mentioned that you recently utilized a child restraint during a behavioral intervention. And I'm wondering if you could share that story with our listeners.

Lexie: I was working with the family of a boy who was about nine at the time, and he'd been off school for about a year due to extreme behaviors that were presenting at school. So, things like I was mentioning before—stripping his clothes off, when he was extremely heightened he would lose control of some bodily functions. It was hard to ascertain if that was accidental or intentional, or whether maybe it had started accidentally and become intentional, because it [those behaviors] got positive outcome for him, swearing, hitting, kicking on others, throwing things, very high levels of escalation.

So, this boy has an intellectual disability and was actually in a special school environment.

Terry: About what age are we talking about here?

Lexie: About nine at the time.

Terry: Okay, thank you.

Lexie: So, quite young, 9 or 10. So, quite high level of need. Family are in a rental accommodation, so, finding it very hard to deal with the property damage that went along with that when he was very heightened. So, there would be lots of kicking holes in walls, throwing things, damaging property due to that heightened escalation and his intellectual disability as well. So, they were barely coping and have since actually split up. They were having problems accessing the community because of the behavior. So, even just trying to get that student to school was—[he would act out] as soon as he would drive into the carpark of the school.

So, I was providing some support in the home environment and trying to find strategies and ways to de-escalate this individual, and he had an aversion to using visual support because they'd been used—I guess, for him, he perceived it as adversely in a school environment, but he referred to that as homework and had that compartmentalization that often goes along with a diagnosis of autism. I do this at home, I do this at school. So, the visuals weren't being successful in that moment as we were hoping they would be at home.

So, it was about 2:00 in the afternoon and I arrived at the house to provide some support, and as I . . .

Terry: Lexie, could I stop you there? Could we go back? Because I think when we got cut off. [The international call dropped and another call was placed to Lexie.] Did I miss something that as soon he got into the carpark he would start acting out?

Lexie: Yes. He would and then we were trying to work on a return to school program. And that might have been when we cut out, because there was a bit of a delay.

So, when we were trying to work on that return to school program, I was in a car ahead and he was being driven by his parents. And as soon as he pulled into the carpark, I could see him kicking and hitting and lashing out. So, they just turned around and went home again. We couldn't even get him into the carpark. So, it was a very, very stressful and challenging situation, and [we were] trying to work on ways to support that.

He is back in the school environment, but a different school and things are still a struggle, but we are working on it heavily. So, basically, when I arrived to do this at-home support for him this day, I could hear him the moment I opened my car door and could see mom at the front door waiting for me. And she said, it had not been a good morning. He's been like this since 6:30 this morning. That had been some hours. And there were holes in the walls. He had tipped his bed up. Toys had been thrown everywhere. And [his] mom dealt with it very, very well. She's maintaining calm, but was still very much struggling. And it's unfortunately something she was used to.

One of the methods they had used quite a lot to support him was to restrain him, but it wasn't in a *Children's Control Position*<sup>SM</sup> or anything that would be able to be maintained as he got older, or was particularly safe for anyone involved. But he'd also inadvertently learned that, "I can escalate; I don't know how to self-calm. I have deep pressure placed upon me by this form of restraint and I find that calming, without being able to cognitively process that."

So, I was trying everything I could to try and de-escalate him while he was in his room. So, I tried different sensory activities and strategies that I had tried previously. I did have one of

my sensory items thrown at my head. Luckily, this missed me, and hit the wall behind me and broke in two. So, I removed myself, tried to give him time and space to de-escalate. That wasn't effective. He would actually come out of his bedroom, come into the hallway and started tipping over furniture, trying to swipe things off, kicking, spitting, screaming—very, very heightened, not coping, not having any ability to communicate what the problem was, and I think was way past that at this point, anyway. I don't even know if he knew why he'd escalated at that point. I think there was a lot more going on than just his diagnosis of autism in that moment.

So, as he was in the hallway and I'm trying to think, "What else can I do? What else can I do? What else is going to work? What are some of the proactive strategies? What are some of the evidence-based strategies I could use?" Because nothing was working. He actually went to hit his mom as his mom went to walk past. And I was behind him, and as he reached back, I just instinctively went, "I know what I can do," and very quickly put him into the *Children's Control Position*<sup>SM</sup> so he wouldn't hit his mum, and just held him lightly. It wasn't a tight grip because it didn't need to be. Put him off balance, you know, with being on the side. I was able to keep my balance.

So, he's trying to head-butt me, he's trying to spit at me, he's swearing, he's cursing, he's trying to kick at his mom, but I was very easily and effectively able to keep him from kicking any of the kitchen equipment or anything else, keep him safe from his mom. His mom sort of secured the environment. And even though I'd never had a chance to discuss that with her as an option, I have that relationship with her. I know she trusted me enough that that was okay. And that's something else we're looking at within Autism SA, is policies and procedures around home visits, and should we need to actually engage in any of these holds and control positions, what we can do to support that in advance. But at least I had that trust with that mother that I knew that would be okay.

And because he was used to being put in holds, it took a long time for him to really regain control. So, at one point, he actually asked if we could sit down. And I am aware that once they're on the ground, generally speaking, we try to let them go. He was not back in control. So, I supported him in a crouched position while still in that *Children's Control Position*<sup>SM</sup>, but lightly. At any time, he could've easily got out of that hold. It wasn't tight or too firm. But he, I guess, was used to that, so it was calming for him. I talked him through, even though he was swearing at me, trying to turn his head and spit at me. I could see he wasn't back in control. Any time mom would walk past, he would again try to kick out at her and kick at her.

Eventually, after about half an hour, which was a lot longer than I was hoping and would have liked, I was able to suggest that he was calm enough for me to let him go, and he was able to agree. And once I did that, I gave him the direction to go back to his room to calm, which he was then able to do.

Mom and I then sat down and went through what had happened, why it had happened, what else we could do. So, in my head I'm going through the *COPING Mode*<sup>SM</sup>, going over that with her. So, what other options did we have? We did that later on as well in another home visit, going through every aspect of that, looking at the pattern, looking at what were the indicators and things like that that meant when he got to that point. Developing a plan for down the track, collecting data on that where we could, and looking at that plan for the future.

But also, as I left, I was still fairly heightened, and I got a little scratched but nothing too major. I was in no way really, really hurt. It was the first time I've actually had to use a *Children's Control Position*<sup>SM</sup> in a home environment or at all. So, as I drove around the corner, I pulled up ["pulled over, " US usage] and rang my senior to debrief with her and discuss it with her so that she was aware of what happened. I could talk it through, and felt that I was back in control again, to be able to continue to drive home.

So, the whole MAPA<sup>®</sup> principles were in my head, and I was able to use them even if it wasn't a formal process in that moment, but then we were able to sit down and go through it in a more formal way to really make sure that everyone involved was back in control, that we were orientated to the facts that we were looking at every aspect of that to ensure, moving forward, we could minimize that happening again.

Terry: Excellent. So, the MAPA<sup>®</sup> process really prevented much more drastic outcomes than you might have seen for everybody involved.

Lexie: Most definitely.

Terry: Thank you for sharing that with us, Lexie. And I'm glad that you're okay after a harrowing experience, and I mean, for a first time, it sounds like you really put the principles and the physicals into meaningful action. Congratulations.

Lexie: Thank you for that.

Terry: Yeah! Autism SA is a registered charity and I'm wondering if you would give us your opinion of how South Australian society views people on the spectrum, and if you would describe the general mindset as enlightened or supportive or the change that you may have seen in the several years preceding.

Lexie: I think, again, that it is a very individual perspective, and everyone has their own view on autism or the behaviors that might come about because of autism. And I think some people who are a bit older might still have that almost negative mindset around looking still at the behaviors that recur and the contextually inappropriate behaviors rather than why they're recurring and feel that sometimes the punitive measures are still the best. However, research shows that doesn't make positive behavioral change.

I think people have certainly gone from, "When I first started," "Oh, you work where?" or, "What is autism?" or, "I've heard a little bit about that." We used to have the very classic common one of, "Oh, that's like *Rain Man*, isn't it?" which, of course, is a very stereotypical view and not representative of the broader spectrum as well.

Nowadays, when I mention where I work, I generally get, "Oh, my cousin, or my brother, or my sister, my uncle, my friend has autism." So, the awareness has certainly increased exponentially with, I guess, the rate of diagnosis.

But I think that understanding and awareness and inclusion within the community has increased greatly as well, which is a really lovely thing to be part of and to see. So, with that increasing diagnosis from probably—I think it was 1 to 2 in 500 to 1,000 if not greater when I first started at Autism SA, to now being greater than 1 in 100. So, the worldwide stats from 2016 or 2017, were about 1 in 100, but I know in the UK and the US it's roughly 1 in 88. So, probably even higher, probably 1 in 68, but the stats we go by in Australia are 1 in 100. But we did do a study that showed that of school-aged children, it was probably around 1 in 42 because that's the cohort that's getting more diagnosed rather than the adults.

I do think that support needs have certainly increased, but I mean, the support mechanisms have increased. Our funding has increased to support individuals on the spectrum, but probably not much. It probably hasn't increased along with the diagnosis. It certainly is getting there. I think that there's always going to be families that have high needs that may not always be able to get the services that they need, but we are working towards that and I think Autism SA staffing has increased greatly to match that need as much as we can.

Our education system is struggling, and I don't know whether that would be similar in UK or America. But to meet the needs and that diversity, not just around autism, but around individuals is huge. I think there is a lot more success stories happening, and I guess because where individuals that are adults being diagnosed, they're able to convey how they feel, they're able to express what happened to them at school and be part of the change to see how the education system and schooling and support can really benefit individuals with a diagnosis from a lived experience, which is so vital.

And we have individuals such as a gentleman called Tim Sharp, who has created the world's first superhero with autism called Laser Beak Man. He's an amazing drawer, very vibrant black colors. And I think that there's a lot more of that. There's an individual called Wenn Lawson, who has a PhD, and does a lot of talks around his area of interest as well as autism.

There's a lot more people without lived experience, but who are then able to become mentors and support for individuals on the spectrum. So, it works so nicely. And I think that there are societal changes to really benefit all individuals and that diversity that comes with being human.

Terry: Well, that's very promising.

Lexie: It's still a long way to go, but it's certainly a good start.

Terry: But I think people maybe are starting to get accustomed, or if not accustomed, at least familiar, with the idea that rather than a disability, it's a different operating system, as my boss works with kids on the spectrum through an organization called Islands of Brilliance, ([Unrestrained Episode 23](#) is a CPI podcast interview with the founders) where he mentors as a designer with a kid on the spectrum and helps them to realize the art through computer programs. So, he has that sticker actually on his computer that says, "It's not a disability. It's a different operating system." [The sticker is misquoted here. It reads "It's not a processing error, it's a different operating system."] So, there is hope there, I think, for the way that people on the spectrum are viewed, and I think that's promising. I think you have done a presentation with Temple Grandin, who has really been a beacon of light about what people on the spectrum can contribute in their work with animal management, for instance.

Lexie: Absolutely, and that was one off my bucket list. I wanted at least to see her present and had missed out on two opportunities when she came to Sydney once and Melbourne once. And my friend on the spectrum was going to go for a road trip and invited me, and I was unfortunately going to be overseas for my first ever overseas trip at that point. I wasn't even able to see her. And then the next year I was able to present alongside her at an event in a place called [Tintinara](#). And I actually went to an agricultural high school, so I've got an interest in animal husbandry anyway.

But to be able to meet her, spend four days with her, go out to tea with her, see her in an animal husbandry environment, hear her talk about autism, get to know her as an individual, was probably one of the highlights of my career in the field, and just was amazing. She was just such an inspiration.

Terry: What an excellent kind of a chance that you got to meet her, and she had a chance to meet you as well.

Lexie: Thank you!

Terry: Yes.

Lexie: I've presented—I'm trying to think of the correct term because it was this event that I presented as keynote speaker with her. So, I presented, and she came up and presented, and I presented after her again. I didn't quite get the opportunity to share the stage per se, but very close.

Terry: Excellent, excellent. Now, when we spoke before the interview, you talked about something called the Incredible 5-Point Scale, and how you merged it with the MAPA® model to create a hybrid that now you use in training, and I think that's really interesting. Could you break that down for us a little bit?

Lexie: Sure. So, the Incredible 5-Point Scale was created by Kari Dunn Buron and Mitzi Curtis. And we've been using that at Autism SA for many, many years, and it's a tool that's really helped us to streamline the supports that we provide. There's many, many other practices that we use as well. So, this is one of many, and we are very eclectic. As long as they have evidence, then we are trying to use them, tweak them, incorporate them together as much as we can. But with that one, because it is so clear, and it delineates and breaks down any social situation or anything along those lines into very clear, systematic ways of describing behaviors or social situation or event, anything, that it fitted really nicely.

So, I'd been working very extensively with a high-needs individual in our northern suburbs, and was trying to figure out a way to present information more clearly for the school to wean them off my services basically, and to leave something behind that was easy to utilize and could be—data had to be collected on it, etc. It was factual, systematic, and to the point.

And I found that by using the MAPA® escalation or the *Verbal Escalation Continuum*<sup>SM</sup>, and looking at that anxiety, that did it quite well from a level two and up. So, level one is when a person is calm and in control for emotional regulation through to the five being "Too late, I've lost control." So, the one is the least amount of anything, and the five is the most amount of anything, or the greatest. So, in this case, it was looking at the least amount of escalation to the most amount of escalation, basically, one [meaning] calm, in control.

So, I looked at how I could meld the two. [Level] two would be pretty much the beginning stages of anxiety, when they might increase that questioning, increase movement, fidgeting, looking at the facts. So, what you see and what you hear for that individual might be tapping more or might be quieter. Some individuals become more withdrawn at a level two. Then the level three is that next level of increased anxiety. So, you might see that low-level refusal. The fidgeting increases, the pacing might increase, etc., straight to a level four which is that verbal release, that intimidation, low-level physical, but not generally directed at anybody, and placing that on the scale and putting it in a very factual form. And the five is that at-risk individual, the total loss of rational control, and incorporating that in what you see and what you hear. And with this, it also looks at, well, what do we do?

So, it has a plan for the individual as well as those that provide the support as two separate things. So, we use the 5-Point Scale to support the individual to have a plan about what he sees, what he hears and what he may feel, or she may feel, at each level of the scale that created one separate for the staff to have around, "What do I do when they're at each level?" and incorporating those MAPA® principles.

So, distracting and diversion, helping them—again, we've passed the level five, or wherever it may occur with that developing that therapeutic rapport with that individual when they're de-escalating, and referring to that as the recovery period where the data occurs after level three, four, or five, and really looking at building that rapport with them where we can.

One of the things that we like the most about it is that we were able to track data because you can have that predetermined [concept] about what each level looks and sounds like, and then just circle the number on the 5-Point Scale and track it, and for that individual to start with. We did that every 15 minutes. We asked that individual what level he felt, and then with time we actually did an observational level as well. And we knew, at a level four or five, not to ask that individual. You could see that with that level, and we would just circle it on the scale.

He, to start with, was only at school for two hours twice a week and with three-to-one support. So, two SSOs, or School Support Officers, and myself, and I was trying to upskill the staff on what evidence-based practices to use to shape his behavior and reward him, etc. After about a year and a half, he was at school pretty much full-time, and we had tracked that data. I was able to develop a little graph to show him how much more successful he was, how he'd only been getting to a level four pretty much for two terms, and his average behavior was between a one and a two for the majority of the time.

And we could also use it to figure out patterns of behavior. So, again, that *COPING Mode*<sup>SM</sup> and looking at when things occurred and provide plans and alternatives for what to do if he got to those levels. We did find that the only time it went pear-shaped was when the plan wasn't actually followed, and people misperceived a level four to be a level three, for example, and didn't follow the plan well enough. But it does work, and it does show improvement to that individual and also was able to prove to the powers that be that the funding that they were receiving was working, and it needed to continue.

Terry: I see. It really brings a whole other visual component to the *Verbal Escalation Continuum*<sup>SM</sup> that I think fits with it very well, and that you can use to show somebody what their progress has been or what stage they're at by that expression on a face, for instance, that the 5-Point Scale has. That's very nice, very nice.

Well, Lexie, let's close today with—I want to ask you about your dream advance in care for people on the spectrum, or where do you see real progress happening? I mean, in your heart of hearts, if it could be like this, what would that be?

Lexie: I guess because it is such a broad spectrum, it's hard to answer that simply and succinctly, but I'll do my best. My name does mean "word" or "languages" in Greek, so, I am known to talk. But I think one thing would be that we don't need to provide care or support for them, that there is just that community acceptance and understanding of autism as being part of the neurodiversity of being human. And it could just be an accepted part [of society], and that any support that is holistic is in place for everybody, because that would support the wider community. And those, especially in education, that are using visuals, using schedules, using structure, using ways to support de-escalation, calming strategies, are taught across the board for all people, not just those, regardless of their age, their ability, race, creed, or religion, but they are person-centered. They are individualized.

I guess the hard part, sometimes, is there *are* individuals with comorbid conditions. There are those that have epilepsy, Down's Syndrome, intellectual disability, or intellectual delay, and that it is trying to support those to get their needs met, that is probably harder, like [for example] the individual I was talking about before.

And that would be where just having all people understand autism and what it means, and what would work, and promoting happiness and being calm—I think is a huge area. I think that if we could provide training at a tertiary level for teachers coming out—I think at the moment autism is more of an elective than it is a compulsory thing—but the strategies, I think, are wider than supporting just the autism community.

So, I think if that was taught and really practiced more [it would be beneficial]. I think a lot of new teachers come out without the practical skills to support any individual at times with escalations. And it's those that have characteristics but perhaps not the diagnosis where that is not always put in place as best practice.

But I do think helping people to look at the underlying characteristics, knowing that suspensions and exclusions, etc., don't tend to work effectively for long-term behavioral change, and often they have the adverse effect to be counterproductive, but look at the anxiety and the stress, and supporting the skill training around learning social skill development, learning how to follow a schedule, how to be rewarded for doing the right thing whether that's verbal or tangible. But definitely having those proactive and positive behavior supports in place across the board for every individual who needs it, individualized to meet their individual needs.

Terry: Well, that's a beautiful vision of where we hopefully will get to. And I think it really is important, as you said, that teachers are provided more than an elective look at how to deal with behavioral issues with people on the spectrum, to support them, to support

better outcomes for people on the spectrum on a much longer-term basis as you have done at Autism SA. Thank you for sharing that with us.

Well, I want to thank my guest today. She's Lexie Dryden of the Autism Association of South Australia. She is currently a consultant of specialized support services, helping kids with autism at school and within their home environments. Thank you so much for joining us today, Lexie.

Lexie: Thank you very much for having me and allowing me to be part of the CPI community.

Terry: Thank you, and thank you all for listening.