

**Compliance is not the goal: Letting go of control and rethinking support for autistic individuals
(A TEDxURI Talk Presented on 23 February 2019)**

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And

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Amy Laurent (Primary Presenter):

Twenty years ago, I was a newly minted occupational therapist and I took a job working with children diagnosed with autism. Now I had never worked with an autistic child before and to my knowledge I had never even met an autistic individual. So I did what you do in those times when you have no idea what is going on and I started to read. And as I did - I encountered many concerning themes: children with autism are like empty fortresses, you have to break down walls to reach them. They are unfeeling. They live in emotional blindness. And there was one concerning theme that I kept encountering over and over again and it was put forth by Dr. Ivar Lovaas, who was considered to be the preeminent authority on educating children with autism at the time using behavioral principles. And this theory, was that when you were working with a child with autism, you were starting from scratch - you had a child in the physical sense; hair, ears, nose, yes; but not in the psychological sense. YOU HAD TO BUILD THAT CHILD! And often to build that child and scaffold development you had to strip away interfering behaviors.

Now... you can imagine, that I was quite concerned and wondered what I had got myself into... and I was also extremely curious as to what my qualifications were as a new grad were for ..child-building. So there was some trepidation when I went to my first day of work and I was about to encounter my first client. I look across the waiting room and there sits Cory. Surprising looking like a whole child. Now before I can even say HI to Cory, I'm whisked to the side of his room by his behavioral therapist and handed a

behavioral management plan. And in this plan is a list of all the things he is not allowed to do. Jumping, spinning, flapping his hands, silly talking? And all I can manage in that moment, is... WHY? Why can't Cory do these things. And the answer comes back at me super-fast. They are autistic behaviors. They are stims. They are nonfunctional and they are disruptive. We actually use this token board to encourage him not to engage in them.

She handed me the token board, she handed me the behavior plan and we went into our session. Now what you NEED to know is that this environment we entered was like a giant playground. There were inflatable cushions, there were slides, swings. We're having fun. Cory and I started to play, and as we played, we jumped, we crashed, we spun, we laughed... and it was really apparent that I was NOT good at inhibiting "forbidden behaviors" [Audience Laughter], when I was actually engaged in them myself. Because I was lost in play. It was also really evident to me that every time Cory got excited, he would jump and he would flap and he would jump and he would flap and he would giggle - every single time. And I would say, "you look sooo excited!" And the behaviorist would say "quiet hands." And I would go "but his hands ARE quiet, this doesn't make any sound [*jumping and flapping hands*]."

Okay - so it should come as no surprise that I was relieved of the token board and the responsibility for implementing that behavior management plan before the session even ended. I left my first encounter with an autistic child with two thoughts. Two: The first one was... I was really, really bad at behavior management plans. The second was a question. The question of WHY. Why did Cory engage in these behaviors? They appeared functional to me. Now as I settled into my new job, it became apparent to me that this question of why didn't just apply to Cory, it applied to all the children on my caseload. So every time a behavioral therapist would come into the session with me, I'd ask the same question: "why does the child engage in these behaviors?" And the answer was always the same: "because they have autism." And I would counter with, "well that's pretty circular, because they only qualify for a diagnosis of autism because they engage in these repetitive, restricted, and "stimmy" behaviors.

This focus on extinguishing - on getting rid of autistic behaviors - formed the bedrock of almost all of my clients' educational programs. This was pretty uncomfortable for me, because as I said, while they look slightly different from the norm - like Cory jumping and flapping every time he got excited - they appeared functional. And this idea that you could "fix" a child or these behaviors were problems harkened back to that early reading I did that viewed autism as something different - something deficient.

Now the voices of autistic adults are very clear in telling us this approach to extinguishing autistic behavior is flawed. In fact, you can't change underlying neurological differences by simply getting rid of some behaviors. You can't uncover a hidden, neurotypical child by extinguishing hand flapping. So we have mounting evidence that tells us that these behaviors are the result of differences. Differences in sensory processing, differences in social communication and neurophysiological differences. They're risk factors. And these risk factors are best understood in listening to the voices of individuals with autism. So I am going to invite you to do just that now.

Stephen:

Let's talk about some risk factors for dysregulation for those of us with sensory issues. They include: noisy restaurants and other places, tags on clothing, and also lighting fixtures that overly bright - and especially recessed lighting fixtures that we find commonly in ceilings. Social environments - certain social environments can also be dysregulating. Any activity where social interaction is the primary goal, rather than the activity. Executive functioning - thinking about thinking - for example, having to keep track of too many things without a schedule or something to refer to.

Dena:

Just not having a plan, not having things be predictable. The assumption of knowledge that I don't just automatically have. Just not having control over my environment. And - You know - and then there is just the whole cumulative cognitive rain barrel. How much energy have I utilized from moment to moment in my day.

Patti:

Whether it's sensory, or it's social, or it's task performance and task demands, or it's language processing demands that is just too much to me, a lot of the times I'm just saying, "this environment is overwhelming."

Amy Laurent (Primary Presenter):

We have research that validates these sentiments. Research that not only validates it, but extends it. Studies that show that the average resting heart rate of an individual with autism is much higher than a neurotypical peer. Studies that demonstrate elevated cortisol levels in the context of social interactions with other people. And studies that clearly show under and over responsivity to sensory information in the environment. And in this context we begin to understand these risk factors and their impact on the experience of an individual with autism. They result in heightened reactivity, heightened states of arousal and sometimes behaviors that can appear as explosivity. So again, we need to ask the question why. Why does this occur? And when

we ask that question, it becomes very clear that the risk factors result in an intensity of experience which cannot be contained.

Patti:

My internal state is not really reflected in a way that neurotypical person might recognize as joy. Umm...But I will say, a lot of it can be things like hand flapping and um...like the bouncing and swaying - things like that.

Neal:

...[Programming AAC device]...

Hey I am Neal Katz and I am thrilled to share my story. I feel stress and anxiety everyday when I feel out of control of my life. I experience tight tenseness throughout my body and others see this as me not listening and being compulsive.

Jacquelyn:

Experiencing stress is overwhelming... but in the worst of ways. It's like - it cannot be contained; it has to come out. And not in words. In fact, I don't really think or experience words when I am stressed. It's a very physical experience. In the midst of it - in a moment where I am highly stressed - you know, I pace, I grab my head and I scratch my scalp, I bite my cuticles and my hands um more and deeper and harder than usual. It feels like I am in this chaotic mayhem, and like I need to throw myself full force into a wall or smash things. And in my most stressed times, I - I do that.

Amy Laurent (Primary Presenter):

Some of these behaviors sound very familiar to us - things that we might engage in in times of intense stress and anxiety - some of them are less familiar, but they are all grounded in neurological development. It is human nature to seek out repetitive rhythmic actions, especially paired with pressure when we experience extreme stress and extreme excitement. We start to understand that the intensity of the experience of an individual with autism calls on these explosive behaviors occurring much more frequently. Given this knowledge - it is time for educational practice to reflect what we know.

We know better - we understand risk factors and intensity of experiences - we, actually NEED to be doing better. Again, adults with autism are crystal clear. They challenge us to rethink the status quo of behavior management. Trying to make them appear indistinguishable from the neurotypical population despite the fact that they have a unique neurology. We need to understand the behavior but understand it within the context of autism.

Michael John:

The behavior in question was more than just a behavior to me - it lay at the very core of who I was. And I don't know why I had that instinct, but I just did. And so it made the hurt doubly worse, because they weren't just criticizing behavior, they were criticizing the very fiber of who I was.

Patti:

So as we communicate our emotions, these behaviors may then be squelched, and trained out of us. The sense that mom, therapist, or society wants to fix me um - and not really seeing our personhood.

Jacquelyn:

To control those emotional experiences and how they look is to control me and who I am. It doesn't just feel "yucky" or tiring or boring. It isn't just unpleasant - it feels like living hell. Like total confusion and a feeling of being lost or incompetent.

Amy Laurent (Primary Presenter):

Again - the weight of these sentiments and the rawness of them cannot be ignored. It's time for educational practice to reflect our knowledge. Our knowledge from the research, and our knowledge from the voices of autistic individuals. And when we do that, we need to rethink this focusing on extinguishing behavior - on control and compliance. Because the voices of autistic adults are also very clear about the very real, dangerous and damaging outcomes of such a focus.

Dena:

Instead of focusing on making them indistinguishable from their peers - which means making it so that they just go along to get along - and that can result in very tragic outcomes.

Stephen:

Another area that is important to address is behavior plans; token economy; focus on compliance-driven programs and how they can be potentially dangerous and damaging and, in some cases, creating post-traumatic stress syndrome to autistic individuals.

Patti:

Two results emerge: One - anxiety increases, and Two - there is internal damage due to our communication not being honored and strong emotions like rage, SIBs, room destruction and suicidality.

Amy Laurent (Primary Presenter):

These lived experiences of enduring educational programs that focus on behavior management and focus on trying to make someone appear indistinguishable despite their unique neurology need to become a thing of the past. We need to move forward. So the question becomes - what's the shift? If behavior management isn't the way, what is? The shift is one from behavior management to emotional regulation [*PowerPoint Slide depicting "behavior —> emotional; Management —> Regulation"*]. We're going to take the focus off of that observable autistic, stimmy behavior and focus on the unique, underlying experience of the individual with autism. Fraught with those risk factors and that intensity of reaction and we're going to embrace that neurodiversity. And we're going to move away from management - this external locus of control - where I am putting some arbitrary plan in place to control your behavior, to make it look like you "fit in" and I'm going to shift that to regulation.

Regulation is a developmental construct where we teach individuals with autism new tools and strategies to be able to navigate their day successfully. To regulate those strong emotional reactions. So we move away from management - this external locus of control to emotional regulation - a focus on skill development within the autistic individual, and in that way we empower them. We empower them to navigate their day successfully, and when we do so, we maximize their potential.

Stephen:

It is vitally important to remember, that autistic people are not a collection of behaviors to be modified, but rather, individuals to support so that we can use the strengths that they have to lead fulfilling and productive lives and to make that the rule, rather than the exception.

Dena:

Well I just think that we need to be focusing on helping kids and adults maximize their potential and become the very best people they can be... Including their disability.

Michael:

Um - in all my years of running the world's largest membership organization for adults on the spectrum, I certainly got it that this was all a two-way street - that the rest of the world had a lot of work to do, and that we had some work to do as individuals on the spectrum. I don't know what that percentage is between the two of how much work needs to be done, but I do believe firmly that from our end, that 90% of our problems as adults in life

are caused by an inability to manage our challenges for emotional regulation.

Amy Laurent (Primary Presenter):

So as we make this shift, this shift to emotional regulation, we form a partnership. A partnership in which we help scaffold skills and abilities so that individuals are able to regulate their emotions and deal with the risk factors they have. But also a partnership that recognizes that we need to make accommodations to the environment so they're not so overwhelming...or activities. And it's within the context of this partnership that our question starts to transform. It's not just a question of why anymore, but a question of HOW?

Michael:

And starts the conversation with the individual by asking, "how can I help?" And I think that a lot of emotional regulation strategies really can benefit from that very concept.

Patrick:

But it's hard feeling tense...it's hard feeling mad and stuff. Sometimes it's hard for me to take deep breaths when I'm really angry. It would be key if we had some space, and stuff and had some time alone in our rooms and relaxed and did some good things, and...

Patti:

But I think that the help that would benefit me most from someone is to recognize that all of these behaviors (Flaps) um, are just communication, and they ARE valid messages, valid communication, and it's not just a part of autism.

Amy Laurent (Primary Presenter):

So in the shift to emotional regulation, we form a partnership and we honor and we acknowledge and we empower. We teach new strategies and we also make accommodation for the unique neurological differences. And it's a shift, a paradigm shift, which starts with that question, why?, but it reflects that we have SO much more knowledge now and that we need to leave educational practice, behavior management - that is rooted in limited understanding - behind. We need to move forward.

And in this context we understand that it was never about building a child or inhibiting behaviors when I was interacting with Cory, but about me helping him learn new and different ways for emotional expression and to manage those risk factors. And in that partnership it's also about me

accommodating him so the world isn't so overwhelming for him. And in the partnership it is also critical to acknowledge that we have SO MUCH to learn from individuals with autism. For instance, Cory taught me that autism is really just a different way of being, and honestly...the best lesson? Was that jumping and flapping is an AWESOME way to let joy run through you! *[Jumping and flapping/ audience laughter]*. Like really! Try it after you're through here *[Audience laughter]*.

Now, given that this is a partnership and that I have been joined by seven AMAZING autistic adults, that I am extremely fortunate to call my dear friends, I would like to step aside and let you listen to them and learn from them, one more time...

Michael: Let go of control.

Patti: Don't try to change us.

Neal: Listen to me.

Stephen: Learn from us.

Dena: Respect us.

Patrick: Support us.

Jacquelyn: Empower us.

Amy Laurent (Primary Presenter):
Thank you very much.