Micah Levenson, MSW, LICSW

[micah@micahlevenson.com](mailto:micah@micahlevenson.com)

206.715.1762

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Improving Health through Trauma-informed Approaches for Individuals with Autism Spectrum Disorders and Other Developmental Disabilities, their Families and Caregivers

Question One: Tell us about your experience seeking support/treatment (for yourself and/or your child) in the health care setting, school setting and/or community and how it affected you?

In my lived experience as an autistic person, I feel I am very privileged. Some people tell me my experience as an autistic person and therapist working with autistic people and their loved ones might be fairly unique. After psychological testing, I was diagnosed with autism in 1981, a couple months before I turned six years old. Autism was a 1 in 10,000 diagnosis around this time. I was born into a family of clinical psychologists and New York City psychotherapists running institutes and treatment centers. I was profoundly developmentally disordered, didn’t start speaking until I was five and a half, couldn’t function in any measurable way in my early schooling, and to this day suffer from notable disabilities and challenges, even if I mask them well. After my testing and diagnosis, nothing happened on professional support or treatment levels at home, at school, or anywhere until my later adolescence. This consisted of trying multiple psychiatric medications that did not work for me and gave me side effects, and a few short-lived rounds of cognitive-behavioral therapy. As an adult, I’ve engaged in very long-term, insight-oriented psychotherapy.

Public school was very challenging without any support. I always did well on writing assignments and tests, but suffered from severe school avoidance. I still graduated from AP classes with an A- high school average. I also averaged about fifty days of school missed a year and rarely handed in homework. If I was a kid today I think I would be destroyed by the public- school system in Washington. The sheer volume of homework, compulsive behaviors of monitoring grades and assignment completion through online systems… I see family after family driven crazy by this constant monitoring of school. Autistic people in school often report feeling pretty traumatized by the experience. For some, simply being in the school environment is experienced as a stress reaction, on neurological levels, that feels awful and is toxic on a chronic basis. I was lucky, I wasn’t bullied, teachers liked me and tried to inspire me, I had a friend or two at times, but sometimes having autistic wiring means certain environments themselves feel horrible, trigger stress, and make our amygdalae light up like a Christmas tree.

My autistic lived experience led me to become a clinical social worker who has sat down and communicated with hundreds of people all over the autism spectrum and their family members. These experiences have taught me traumatic life experiences are common for the autistic and their loved ones. Chronic minority stress and marginalization leads many autistic people to experience a life that could be described as a traumatic state of being. When macro traumas, sexual or physical assault, major accidents, or abuse occur in the lives of the autistic, the impact of trauma can be very different from that which is typically researched. The vast majority of my clients have shared stories of trauma. Not just the autistic, but also the vast majority of parents, siblings, and other family members. When I start working with an autistic person and their family members, everyone often tells me how traumatized, overwhelmed, lonely, and underserved they feel. As a human being I have been deeply affected by this, and this facet of my life experience has been a factor in my decision to speak publicly about the autistic experience.

Question Two: What has helped you in the past and what would you want community professionals and policy makers to know?

I’ve devoted my adult life to trying to help autistic people and their family members, and I definitely have some things I’d like community professionals and policy makers to know. I

have many intakes with people who were already diagnosed with ASD and have had all kinds of treatment interventions. I ask if any professionals have explained what a neurodevelopmental disorder is in the first place. Or if any professionals have discussed how ASD is a lifelong condition that seems to change throughout the developmental stages of life. If the person has a diagnosed intellectual impairment or high levels of required support needs, I ask parents if that significant factor is emphasized or even discussed. Most seem to be very uninformed regarding neurodevelopmental conditions, and information provided in some settings is often outdated or one-size-fits-all. If you lurk on online communities and social media groups for the autistic or their parents, you’d think feeling confused and uninformed is almost universal. Unfortunately, this lack of evidence-based information and big picture, understandable perspectives, leads many autistic adults and parents of autistic people into maelstroms of internet disinformation, inappropriate treatment methods, whacky diets, and headfirst into the greedy claws of charlatans and snake oil peddlers, some remedies and cures quite toxic and horrific.

Continually up-to-date psychoeducation and linkages to healthcare, education, and community resources must be put on the pedestal. It should be customized to the diagnosed individual. The DSM-5 diagnosis now has two extensive categories of deficits, with three different levels of support needs per category. What might work amazingly well for one family or autistic person might be contraindicated, or harmful, for another. Family members of those with cognitive challenges or high support needs require additional education on these aspects of the condition. Studies are finding the average autistic life span to be around 36. Reasons for this include drowning, accidental death, and myriad medical problems. Very poor diets, sedentary lifestyle, self-care challenges, and difficulties in effectively communicating medical symptoms contribute heavily. These safety, physical, and medical needs of the autistic must also be prioritized within treatment. I strongly recommend policy-makers support specialized intensive case management as a tool to provide education and oversight of big picture, long-term healthy development for those diagnosed with neurodevelopmental disorders. Intensive case managers could provide psychoeducation and case coordination within all settings. Intensive case management would have a reasonable chance to guide the autistic and their families to appropriate, and cost-effective, treatment or resources based upon their specific needs. When only behavior or symptom reduction is emphasized, it robs us of focusing on both the basic human biological needs and long-term existential needs of the autistic. The autism spectrum is too broad to claim any treatment method recipe can work for any majority of those on the spectrum. Therefore, a systemic approach based upon educating people about their, or their child’s, diagnosis, evaluating the specific needs of someone on the spectrum, and long-term management of that individual’s case is necessary.

Question Three: What would you change if you had a magic wand?

When one has neurodevelopmental challenges with social communication, attempts to truly express oneself can sometimes be a beautiful and magical thing, like waving a wand. With heritable genetics and fetal environmental factors, being autistic should be considered a “born this way” condition. One change I’d like is much more acceptance of what I had to personally accept. The lifelong neurodevelopmental process we’ve been calling Autism Spectrum Disorder for the last five and a half years seems to be extremely hardwired. There is no fixing it, no curing an entire central nervous system that is wired differently. In my middle age, I’ve had to accept there is no changing this, I’m wired this way, and I can’t fix it. No one can. It just has to be accepted and if there are any problems, they have to be managed. The DSM-5 diagnosis itself now speaks in a language of required levels of support. Autistic people and their loved ones need to be treated with human dignity. We feel like any other human being, and we hear and deeply feel what is said and felt about us. Many parents and families are just as traumatized as we are. Too many ideas, statements, and even treatment methods are depressingly dehumanizing.

I am far from alone in having concerns about what I’d call “deficit-only” treatment models that fixate on the symptoms, functional impairments, and all the bad things. Most autistic children, adolescents, and young adults I meet tell me how every person in their life is focusing on their problems. They tell me it feels bad. This should be changed, and it shouldn’t take a magic wand to do. A study just came out connecting social stigma to mental health problems for the autistic. Earlier, I brought up how research is indicating the average autistic life expectancy is in the mid-to-late 30s. Suicidality is a notable factor in this short life many chronically, and macro-, traumatized autistic people live. We have a severe depression and suicide crisis in the autistic community. In my autistic life experience, I was lucky enough to be exposed very early to, and later formally trained in, a strengths perspective. I’m very happy to be fixated on a perspective focused on discovering an autistic human being’s strengths, talents, and positive capacities. It helped me to survive and get to where I am today. If I could wave a magic wand it would be to make many in the autism spectrum professional and policy worlds fixate on strengths perspectives, it can give a traumatized autistic person reasons to live and function out in the world. There should be much more study of those autistic people who have overcome significant obstacles to achieve a fulfilling adult life. You should listen much closer to what we have to say. More and more autistic adults have decided to stop waiting for professionals and policy-makers to ask us questions, we are speaking up instead. A revolutionary change is coming to the understanding of the autistic experience and how to live the best life possible, throughout the lifespan. We grow up. Autism is speaking, louder and louder by the day.