

# **Oral Public Comments**

**IACC Workshop 2019:  
Addressing the Mental  
Health Needs of People  
on the Autism Spectrum**

**May 21, 2019**

## Oral Public Comments

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**Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.**

**Eileen Nicole Simon, Ph.D., R.N.**

**May 21, 2019**

Comments for oral presentation at the IACC workshop on May 21, 2019

Eileen Nicole Simon, PhD, RN

[PII redacted]

I decided to attend this workshop because providing for the lifelong needs of developmentally disabled autistic people is such a serious issue. Best will be when autism can be prevented. But in light of the epidemic that began in the 1990s, solutions must be found (and immediately) for providing appropriate life-long care.

Discussion of mental health services should be the focus of this meeting. Many more psychiatric afflictions (beyond anxiety, depression, suicide and aggressive behavior) need to be addressed. More inpatient (or residential) units are badly needed to provide the care and services needed.

I submitted a comment to the IACC a few years ago about a possible way to hire and house autistic adults. Marriott has a chain of Residence Inn hotels with a full kitchen, dining space, and living-room area in each unit. I asked for discussion of developing a possible plan for housing autistic adults in a few units of each Residence Inn hotel, and employing them to also work in the hotel.

I recently took a grant-writing course at UMass Boston. Looking for private foundations that seek to provide grants for worthy causes, I noticed that Marriott has several philanthropic organizations, including the Marriott Hotel Philanthropy.

The online link to the Marriott Foundation is [marriottfoundation.org](http://marriottfoundation.org).

I want to contact Marriott with my plan. I would like to find collaborators for this effort. I hope I can have more interactive involvement in this workshop, beyond making this brief presentation.

I would appreciate discussion of this idea by members of this IACC Workshop committee.

**James Williams May 21, 2019**

**Mental Health Issues Aren't Just Abstract Symptoms.  
They Are The Byproducts and Consequences of the Realities of Having Autism.**

Greetings. I am an adult self-advocate with autism who has experienced many mental health issues throughout my life, and my comment today is about several of these issues I have discussed.

On an abstract level, it's very easy for us to feel sorry for people with autism who are experiencing mental health issues. Depression, anxiety suicide, aggressive behaviors, and self-injurious behaviors are all very real and serious issues, and affect many people with autism. When we hear the statistics of how common they occur with people with autism, it's just natural to stop and think if there are ways that we can help people with autism cope with these issues.

However, although many mental health issues are genuine symptoms that people with autism face, they don't exist in a vacuum. They are often caused by genuine stressors and struggles that people with autism experience in their daily lives. Although I am aware that my mental health issues are symptoms of my autism, I also perceive them as the byproducts of the numerous other struggles that I live with due to my autism. I shall demonstrate this by explaining how many of my mental health issues are not just symptoms in their own right, but the consequences of other core symptoms I face due to my autism.

Like many people with autism, I have experienced many bouts of depression. I also cope with anxiety on a nearly daily basis. I have also had several episodes of aggressive and self-injurious behaviors while growing up, but do not engage in these behaviors today. Fortunately, I never got to the point of attempting suicide, but I have had many friends with autism who have done so at some point in time in their lives.

However, when experiencing many of these mental health issues, I have never just experienced them without an external cause. Every bout of depression, anxiety, aggressive, or self-injurious behavior was prompted by a consequence of another symptom of autism. My mental health issues are not just symptoms of my autism, they are *byproducts* and *consequences* of other symptoms of autism that I live with daily. To demonstrate this, let me share an overview of how many issues I deal with due to my autism contribute to my mental health issues.

First, I do not experience depression for the sake of feeling depressed. My depression is the consequence of living a lifetime in a world where being myself is seen by others as inappropriate. A world where the social intuition and instincts from my brain—the only brain I've ever known—continue to subconsciously tell me to behave in ways that are perceived as offensive and inappropriate, and are often not tolerated by most people, even other people with autism, because of how my brain is wired differently. A world where I have routinely been asked to leave numerous jobs and have been rejected and shunned by many people due to unspoken social rules I was expected to know yet was never openly taught. A world where societal mandates and sacred social rules in our culture aren't just hard to understand, but actually hurt me and hamper my ability to cope with my autism. All of these realities of life, and other things, contribute to my depression.

Second, I do not experience anxiety for the sake of feeling anxious. My anxiety is a consequence of living a lifetime of being rejected and shunned by formerly close friends for social violations that I was

unaware that I made until after I upset them. It is a consequence of having to wake up every morning in fear that a friendship you value, or a membership in a group or organization, can be taken for you at any time due to your autism offending people due to behaviors that you cannot control. It is the consequence of never knowing if the next social move you make is going to upset or offend a person you are interacting with, or having to deal with a social response by other people that was different than you anticipated because your differently wired autistic brain expected a social response. All of these realities of life, and other things, contribute to my anxiety.

Third, although I have not engaged in aggressive behavior for many years, the times I engaged in aggressive behavior while a child and adolescent was never for the sake of being aggressive to people. Internally, I have always tried to be a gentle, peaceful person, and have been known by many people as a “gentle giant.” But sometimes, constantly being misunderstood by the world and you, and the pain of having to endure unpleasant realities of life in a world that refuses to listen to your cries and pleas of suffering can cause you to feel so much anger and frustration that aggressive behavior can occur as a result. The episodes of aggression I had growing up were few and far between, but were almost always caused by feeling like I lived in a world where no one listened or understood the issues I was going through. Indeed, my aggressive behavior came to a permanent end when I finally found a social group of understanding friends during late adolescence, and it has never returned.

And finally, the self-injurious behavior I engaged in while growing up was not for the sake of being self-injurious, or because I actually wanted to seriously hurt myself. I engaged in such behaviors because I routinely felt as if life was so difficult to deal with that I often would hurt myself just to release the internal stress and tension that often built up within me. They were also often caused when I felt as if people refused to listen to how upset I was feeling in a situation. What enabled me to move beyond self-injurious behavior was improving the ability to communicate with others how much frustration I felt during daily living.

So what does this mean? Mental health issues aren’t just symptoms that are directly a part of the autism, they are the byproducts of the issues and struggles that people with autism face *as a byproduct and/or consequence* of these systems. If we really want to help people with autism with mental health issues, we have to pay attention to just how much the realities of living with the symptoms of autism can cause these issues. We also need to start analyzing just how much many “unquestioned” socio-cultural norms and social mandates in our society and culture can hurt people with autism, cause them social isolation, and can hinder their ability to access assistance from others when they need to.

In addition, when you have autism, you are often taught social skills that remind you daily that your natural way of thinking is wrong and inappropriate. You are often told that “your way of being” is the wrong way, while the way of the non-autistic majority is the right way. This in of itself can cause a person with autism to become severely depressed and anxious.

Don’t get me wrong—social skills instruction and the efforts of professionals and others to help people with autism understand essential social skills have helped people with autism like myself and others become functioning members of society. But it’s not always easy to live in a world where your natural way of being is inherently considered unacceptable. Where what makes you “you” is considered by people as intolerable and unforgivable.

If we really want to help people with autism deal with mental health issues, we can’t just analyze the statistics of how often they occur, or talk about them as abstract symptoms. We need to start looking at

the realities of daily life that can cause these issues to occur, and start brainstorming ways that we can help people with autism live with those daily realities. Only then, in my opinion, will we truly be able to fully help people with autism who live with mental health issues on a daily basis.