

Written Public Comments

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

May 21, 2019

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I was listening on the call today – My name is Stacey Hoaglund. I am the president of the Autism Society of Florida and trainer on a variety of topics related to ASD. I live in the same county as the Stoneman-Douglas School shooting this year, and have actually spent a great deal of time working in that school. As a result of the shooting, I have coordinated and participated in a mental health public presentation on recognizing mental health conditions in ASD, and the difference between aggression and violent behavior. It's a hugely misunderstood dilemma in our country.

Trauma is certainly a massive issue in ASD. Our kids (I'm a parent of an adult with ASD) not only deal with the obvious events that cause trauma, such as restraint by physicians, therapists, school staff, etc, but given that they are expected to live in a world where most of us are speaking a totally different language and have our own level of expectation that is supposed to be naturally "understood" by everyone, is quite traumatic in itself. Parents who have no prior knowledge of autism do their best to muddle through parenting their young child, teachers make the assumption that all kids learn the same and call upon their years of training to guide them to teach kids who learn differently, people in the general public expect all human behavior to follow their preconceived notions of what is expected, etc. All of this can leave a person on the spectrum with a great deal of anxiety, frustration and trauma.

There are certainly skills that we can teach people to help them overcome some of the side effects of trauma, but paired with that, I really feel that we need to spend even more time educating parents, teachers and the general public about autism and how they have the power to be a difference. If the world can get to a place where we recognize that conditions, such as autism, are part of the human race, I think that we can grow to be more inclusive, more supportive and more malleable in how people with autism are seen, treated and respected.

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 the IACC workshop on May 21, 2019

Eileen Nicole Simon, PhD, RN
[PII redacted]

The needs for seriously afflicted people on the spectrum are enormous. Public funded programs in Massachusetts are in no way adequate.

Following are descriptions of what I have encountered with my two autistic sons, Conrad and Anders:

Conrad:

In 1995 my son, Conrad, died in a group home managed by an agency contracted through the Department of Mental Retardation (Cooperative for Human Services). Staff at the house were minimum wage care givers. Most were in their early 20s. Conrad was 31 years old and often frightening to his young care givers.

A "facilitated communicator" was engaged to try to obtain information from Conrad, whose language was minimal. The facilitated-communicator reported that Conrad had been physically and sexually abused by me, his mother. She reported some of his echolalic responses in support of her conclusions.

"Want me to take your feet off?" may have been his most shocking remark.

My explanations were sneered at. I once asked Conrad to take his feet off the coffee table. He refused, which is when I asked him if he wanted me to take his feet off (the table).

I was prohibited to visit Conrad. I last saw him on Halloween 1994. I brought a bag of halloween candy for him. When a staff person saw me, she screamed at me, and told me to get out, "And, don't ever come back!" she yelled.

"I love you, Mom," were Conrad's last words to me, as he stood on the porch and watched me drive away.

What a shock to get to work on January 17 and receive a phone call from my husband.

"Conrad is dead," he told me.

Friends at work drove me home. Then I called to ask if I could see Conrad.

"His remains have already been bagged," I was told by the medical examiner.

My grief remains great. No one seems to understand this. Why???

See conradsimon.org for more on the lethal level of Thorazine in Conrad's blood, which was cited as the cause of death on Conrad's death certificate.

Anders:

Conrad's brother, Anders, was a patient at Westborough State Hospital at the time of Conrad's death. Anders remains in a state of grief as much as I do.

In 2003 Anders was discharged from Westborough, The social worker told me he was to come home and live with me and my husband. He was 40 years old, and my husband and I were in our sixties.

My husband refused to have Anders live with us. Anders had been taken to Westborough by the Lexington police after having stolen many cars. My husband feared we might be sued for Anders' criminal activity.

Reluctantly, the social worker found a community group home for Anders. Anders was very unhappy there, and often went missing. In 2009 he was gone for 7 weeks +2 days. He spent a few months at the Quincy Mental Health Center, but the Department of Mental Health (DMH) closed this inpatient facility, despite community efforts to keep this unit open.

My son returned to the group home. As in Conrad's house, staff are minimum wage workers, and mostly young. Many staff are not native English speakers. Anders has an auditory system impairment that makes it difficult for him to follow conversations even with native English speakers.

Anders reacts very badly to "strong redirection" given by staff in loud commanding voices. He covers his ears and runs out of the house.

Anders should have been encouraged to participate in training for employment, and to work toward achieving a GED high school equivalency diploma. No! I have repeatedly been told, "He's not ready."

Anders refuses to go to his day program, held in a large warehouse room with no windows. The primary activity at this program is coloring. Instead, he takes off every morning, and I have no idea if he is doing the things he tells me. He says he spends a lot of time in different libraries. He does enjoy reading, and he is a store house of information.

I think Anders needs a personal care companion (PCC). He maybe needs two PCCs. I am thinking about applying for a grant to see if I can pay for such assistance. Is this something participants of this workshop can discuss?

I am a 26 year old man with Autism, I am concerned about the current debates in the Autism community. Please protect the medical model of disability and Autism. I am diagnosed with Autistic Disorder (F84.0). Autism is not just some quirky personality type, nor is Autism disabling because of society. Autism is a lifelong developmental disability that disrupts every single aspect of my existence. Overly vocal, and largely "self diagnosed" persons with Asperger's Syndrome are bullying and screaming over low functioning, barely verbal persons with classic Autistic Disorder. I am in favor of eliminating the "spectrum" and each condition being recognized individually. I hardly relate to anyone with Asperger's. The neurodiversity movement does not represent me or my values. They are bullies who make threats to Autistic people and the parents of Autistic children. Please help end the pseudo-science. Please help find cures and fund research! Neurodiversity rejects cures & research, while favoring handouts from society, I would love to cure my self harming tendencies. My go to moves are head butting walls and choking myself with belts- "quirky personality" right? No. Severely disruptive developmental disorder that affects my life every second of every day. Defend the medical model, defend people with Autistic Disorder. I am not "normal", nor am I "a different version of normal". I am impaired in several areas, if I want to be independent I have to learn and practice skills that apparently come natural to most. The neurodiversity movement would have us "dumb down" what it means to have normal functioning- that is a dangerous precedent. Please defend this disability. Neurodiversity is out of hand, some proponents promote Autism as a gender and attack people who want cures. It's quite disturbing.

For those who attend mainstream education, the most critical need to prevent/minimize mental health problems is having friends or at the least, insuring classmates INCLUDE the individual in social events both in and out of school. This requires all teaching & administrative staff to be informed about the condition, how it affects the particular student, and how to support/coach the peers to engage with their atypical classmate. This must start in elementary school and intensify in high school. Kids need to be sensitized to be KIND to their schoolmates who are different, say hello, sit with them at lunch now and then, invite them along to group events and outings on weekends. As they get a bit older, they need to learn how to coach their classmate on social nuances in a clear, direct manner to insure understanding and praised for doing so. Having an ASD consultant in the workplace is often needed to inform co-workers on how to understand any 'odd' behavior and best engage with their affected workmate. Most young adults with ASD end up spending significant time alone in their rooms resulting in frightening mental health issues. Programs to get them out to the gym, in hiking, drama, gaming etc groups and activities related to any of their special interests are a critical need.

Sandy Krause

May 21, 2019

It is quite common for those diagnosed with ASD have a comorbid mental health diagnosis. It is also likely that living with ASD in an NT dominated world CAUSES anxiety for our ASD citizens. We need to make certain mental health services targeted to ASD clients is accessible



**Written Comment to the Interagency Autism Coordinating Committee Provided by SafeMinds
Executive Director Lisa Wiederlight**

May 21, 2019

I am pleased to present this written comment on behalf of SafeMinds for the 2019 IACC Workshop Addressing the Mental Health Needs of People on the Autism Spectrum. SafeMinds is interested in learning why such mental health issues as suicidality, depression, anxiety, self-injurious behavior, and aggression co-occur with autism so frequently. We ask the IACC to consider if the same biomedical factors that result in the development of autism also affect the development of these issues.

We believe that it is important to research appropriate treatment approaches for these mental health issues, and how they may be modified to address the needs of the autism community. Further, such advances should be distributed to practitioners via a clinical infrastructure so that people with autism and their caregivers receive best practices in mental health services.

Concurrently, mental health professionals must be trained to identify and treat mental health issues in people with autism and their caregivers. Waiting lists for mental health services are dangerously long in many cases. Further, as caregivers address the mental health needs of people with autism, in many cases, family-based therapy should be considered as a possible treatment modality.

We look forward to seeing the development of policy priorities with supportive research in the very near future on this urgent issue.

Respectfully submitted,

Lisa Wiederlight
Executive
Director

If not already addressed it would be helpful to discuss how CCS (Comprehensive Community Service-- Medicaid) and other services and support are available to individuals with Mental Health issues but once it is known that a diagnosis of Autism exists then they are typically excluded and referred to the autism benefit. This leaves individuals with autism and OCD, depression, anxiety and other mental health concerns struggling to access care and puts autism service providers in a bind as the capacity to help older children and those with these unique needs then requires additional PA requirements.