



AUTISTIC BURNOUT: WHAT IT IS AND HOW TO PREVENT IT

Presenter: Katie Oswald

WHAT YOU WILL LEARN

- Autistic burnout characteristics and causes
- High cost of masking
- Mental health outcomes in autistic adults
- Preferred mental health interventions
- Tangible inclusion strategies to improve quality of life

WHAT IS AUTISTIC BURNOUT?



DEFINITION

- “Autistic burnout is a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus.”

CHARACTERISTICS OF AUTISTIC BURNOUT

- Chronic exhaustion
- Loss of skills
- Reduced tolerance to stimuli

CAUSES OF AUTISTIC BURNOUT

- Life stressors
 - **Masking**
- Cumulative overwhelm and stress
- Barriers to support
 - **Lack of empathy and dismissal of struggles**
- Not able to get the help we need
- Eventually expectations outweigh our abilities until we collapse under the pressure.

BARRIERS

- Lack of acceptance and inclusion in society
- Access to mental health supports is lacking for autistic adults
- Lack of empathy, misunderstanding, and dismissal of our challenges by medical professionals

MASKING

- Masking our identity in an attempt to avoid stigma and survive in environments where we suffer from severe overwhelm
- Resisting or holding in natural responses to emotional experiences
- Observing, memorizing, mimicking, and acting-out social scripts
- Participating in activities and conversations that are not of interest
- Resisting one's own needs and preferences
- Attempting to control all aspects of a social situation

HIGH COST OF MASKING

- Higher rates of depression and anxiety
- More frequent PTSD symptoms
- Shorter average lifespan (research varies from 36-54 years)
- More frequent suicidal ideation
- Higher rates of suicide (5-9x higher than general population)
- Misdiagnosis
- Autistic burnout

THOUGHTS FROM MY PEER SUPPORT GROUP

- Intense anxiety
- Depression
- Feelings of hopelessness
- Feeling misunderstood
- PTSD
- Suicidal ideation and even attempts.

MY AUTISTIC BURNOUT STORY



ELEMENTARY SCHOOL

- Didn't like being away from home/my mom
- Pre-school – liked art but mostly stood in a corner watching other kids
- School wanted to put me in special education
- IQ tested and put in program for academically talented instead
- Liked learning, hated socializing
- Days were way, way too long for me and I “faked sick” a lot to stay home with my mom

MIDDLE SCHOOL

- 6th grade went to the combined middle school/high school
- Struggled to make new friends initially, but did have a small group of close friends
- Emotional struggles began
- Grades plummeted
- Depression and anxiety worsened

HIGH SCHOOL

- Started drinking and smoking
- Continued struggling with length of the school day and additional social expectations
- Started self-harming
- Many therapists and medications – still no diagnosis
- Anxiety and depression worsened
- Accommodation: reduced schedule senior year

COMMUNITY COLLEGE DROPOUT

- Barely graduated from high school
- Started an associates degree in broadcasting
- Switched majors (to banking, I think?)
- Failed and dropped out

AUTISTIC BURNOUT

- Sometimes couldn't get out of bed
- No longer enjoyed any of my old interests and hobbies
- Unable to start any projects
- Often stayed up all night playing solitaire and watching reruns on TV
- Slept much of the day so I didn't have to "engage in the chaos"
- Didn't help around the house
- Everyone thought I was lazy

RECOVERY

- 4 years
- I was able to keep a fast-food job during these four years, but I didn't do anything else
- I was 19 when I quit college and 23 when I went back
- Took one class at a time for three years to raise my GPA
- Transferred to Michigan State University as a sophomore in the statistics major

POST-BURNOUT ACCOMPLISHMENTS

- Statistics Major, second major in Russian, and Actuarial Science Specialization; Dean's list
- 3 study abroad programs, actuarial science club, student advisory council
- MS in Applied Economics and Statistics from Clemson University
- 2 years in Uganda as an Economic Development Specialist for the U.S. Peace Corps

ALL AUTISTIC PEOPLE DESERVE THE OPPORTUNITY TO
LIVE THEIR LIFE IN A WAY THAT WORKS FOR THEM,
SET THEIR OWN GOALS, AND TO DEFINE AND ACHIEVE
SUCCESS IN A WAY THAT WORKS FOR THEM.

INTERVENTIONS AND STRATEGIES



PREFERRED INTERVENTIONS IDENTIFIED IN THE RESEARCH

- Peer-led support groups
- Meditation
- Exercise
- Trauma informed care
- Art therapy
- Animal-assisted therapy
- Preference for interventions to be peer-led!

SOCIETY INTERVENTIONS

- Stigma reduction
- Education of society about autism
- Learning about the experience of autism
- True acceptance and inclusion
- These are things that YOU can do! Let's look at specific ideas.

ACCESSIBLE SPACES AND ENVIRONMENTS

- Fragrance free
- Sensory friendly - no bright or flashing lights, low noise, etc.
- Frequent breaks between activities or during long activities
- Limited number of activities and events
- Quiet recovery room available

ACCESSIBLE COMMUNICATION

- Incorporate different communication methods.
- Allow text chat for group communication.
- Provide space and materials for people to draw or write.
- Allow for extra time to ensure nonspeaking people can participate.
- Leave time for people to process/organize thoughts before responding.
- Provide written agendas to help people follow group discussions.

EDUCATE YOURSELF ABOUT THE LIVED EXPERIENCE OF AUTISM

- Read blogs by autistic writers.
- Read books by autistic authors.
- Follow autistic people on YouTube and social media.
- Interact with autistic people in your community.
- The more people you talk to, the more you will learn.

ESTABLISH AND HONOR BOUNDARIES

- People with sensory processing and communication challenges have different needs than most.
- If someone says they need a break, believe them; allow it without threat of punishment.
- Some people may not make eye contact or shake hands. Don't judge them for that.
- Everyone's boundaries will be slightly different. Trust the individual.

IDENTIFY AND COMBAT ABLEISM

- Discrimination and social prejudice against people with disabilities or those perceived to be disabled.
- Ex 1: Assumption that everyone is able to work in an open office setting without getting overwhelmed and providing no alternative.
- Ex 2: Wearing perfume or scented lotion in a fragrance-free environment.
- Ex 3: Prioritizing the voice of speaking individuals over non-speaking individuals

BEST WAY TO COMBAT ABLEISM?

- Question the status quo!
- It doesn't work for everyone.

RESOURCES



BLOGS

- Neuroclastic: <https://neuroclastic.com/>
- Thinking Person's Guide to Autism:
<http://www.thinkingautismguide.com/>
- The Art of Autism: <https://the-art-of-autism.com/>
- Different Brains: <https://www.differentbrains.org/category/blog/>

AUTHORS

- Temple Grandin
- John Elder Robison
- Cynthia Kim
- “Sincerely, Your Autistic Child”: <https://awnnetwork.org/publications/>

FOLLOW AUTISTIC SELF-ADVOCATES ONLINE

- JR Reed at Not Weird Just Autistic:
<https://www.notweirdjustautistic.com/>
- Paul Micallef at Autism from the Inside:
<https://www.youtube.com/c/AspergersfromtheInside>
- Autism Personal Coach/Doug Blecher:
<https://autismpersonalcoach.com/>
- In case you need more, check out:
<https://themighty.com/2019/08/actually-autistic-instagram/>

FULL SPECTRUM AGENCY FOR AUTISTIC ADULTS

- Website: <https://fullspectrumasd.org/>
- Meetup group: <https://www.meetup.com/Ann-Arbor-Autistic-Adults/>
- Facebook: <https://www.facebook.com/FullSpectrumASD/>
- Contact: Katie Oswald, katie@FullSpectrumASD.org