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.
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