

AUTISTIC BURNOUT: “MY PHYSICAL BODY AND MIND STARTED SHUTTING DOWN”

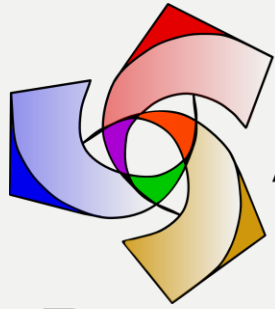
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Portland State University / Academic Autism Spectrum Partnership in Research and Education

Introduction: Dora Raymaker

- Research Assistant Professor, PSU Regional Research Institute for Human Services, School of Social Work
- Transition-age and adult populations (autism, mental health, developmental disability)
- Social services intervention research (systems scientist, not a clinician—though clinicians are on our team!)
- Community based participatory research approach
- Co-director Academic Autism Spectrum Partnership in Research and Education (aaspire.org)
- Autistic and disability rights (self-)advocate
- Science for social change!





AASPIRE

Academic Autism Spectrum Partnership in Research and Education

- Research group founded in 2006 by Christina Nicolaidis, MD, MPH and me
- Christina used “Autism Journal Club” to lure me into a social interaction
- Lots of complaints about autism research:
 - *Not relevant / useful to autistic people*
 - *Issues with research design*
 - *Stigmatizing questions, language, dissemination*
 - *Potential harm to autistic people*
- ...just like other marginalized populations
- **Stop complaining and do something!**

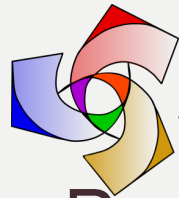
Community Based Participatory Research

Emancipatory approach to research developed in public health

Community members are co-researchers in every phase of the research

Lived experience and community knowledge is respected on the same level as academic expertise

AASPIRE community partners involved at all stages of this project



AASPIRE

Academic Autism Spectrum Partnership in Research and Education

- 12 years later...
- Team made up of academic researchers, autistic individuals, family members, healthcare providers, and disability services professionals.
- In partnership with PSU, OHSU, Autistic Self Advocacy Network, Autism Society of Oregon, Syracuse University, Indiana University, and members of the Autistic community at large.



aaspire.org



Currently Active AASPIRE Areas of Study



Autistic burnout (this talk)

- Exploratory study to understand and define experience of autistic burnout
- Begin creating a measure of autistic burnout



Autism and professional employment

- Exploratory study to understand facilitators of success
- Intervention to facilitate employer autism-friendly culture change
- Intervention development to improve professional employment outcomes



Healthcare

- Healthcare disparities study / understanding hc experiences
- AASPIRE Healthcare Toolkit and Autism Healthcare Accommodations Tool
- Adaptation of Toolkit for emergency / hospital

autismandhealth.org

Agenda

1 “Autistic burnout” and why it needs research

2 AASPIRE autistic burnout study

3 What we’ve learned so far about autistic burnout

4 Implications/recommendations for people on the spectrum, families, clinicians

5 Wrap-up and questions

1. “AUTISTIC BURNOUT” AND WHY IT NEEDS RESEARCH

Background



What Is “Autistic Burnout”?

- Term used in the autistic community, typically for a feeling similar to professional burnout?—only applied to all areas of life
- Sometimes called “autistic regression?”
- Autistic adults report times when they can no longer cope, lose skills / function, start acting or feeling “more autistic,” lose jobs / school / relationships / mental and physical health; sometimes leads to permanent disability or suicidal behavior
- Something is happening but many questions, like
 - *Is there an unambiguous definition of “autistic burnout?”*
 - *Is it different from professional or other well-explored kinds of burnout?*
 - *Is it different from depression?*
 - *Why does it happen and how can it be relieved or prevented?*

Autistic Experience vs. Current State of the Science

- Much discussion on blogs, social media, community spaces about autistic burnout
 - *Source of distress*
 - *Factor in poor life outcomes*
 - *Factor in suicidal behavior*
 - *Connected to stress, masking (having to “pass” as non-autistic)*
- High priority for autistic adults

#askingautistics I told my therapist I think I'm having #autisticburnout. She agreed and that's as far as we got. What helps? Help me.
#actuallyautistic



Autistic Experience vs. Current State of the Science

- Published research for autism and burnout is on family, teacher, caregiver burnout
 - *Little is empirically known about burnout in autistic people themselves*
- Burnout, in part driven by masking, may mediate suicidal behavior in physicians and medical students whose suicide rates are 1.5-2x higher than general population
 - *Could similar mechanisms contribute to the 35% rate of suicide plans or attempts by autistic adults?*
- What's the answer to the question of "what helps?"
 - *We have to start somewhere*



2. AASPIRE AUTISTIC BURNOUT STUDY



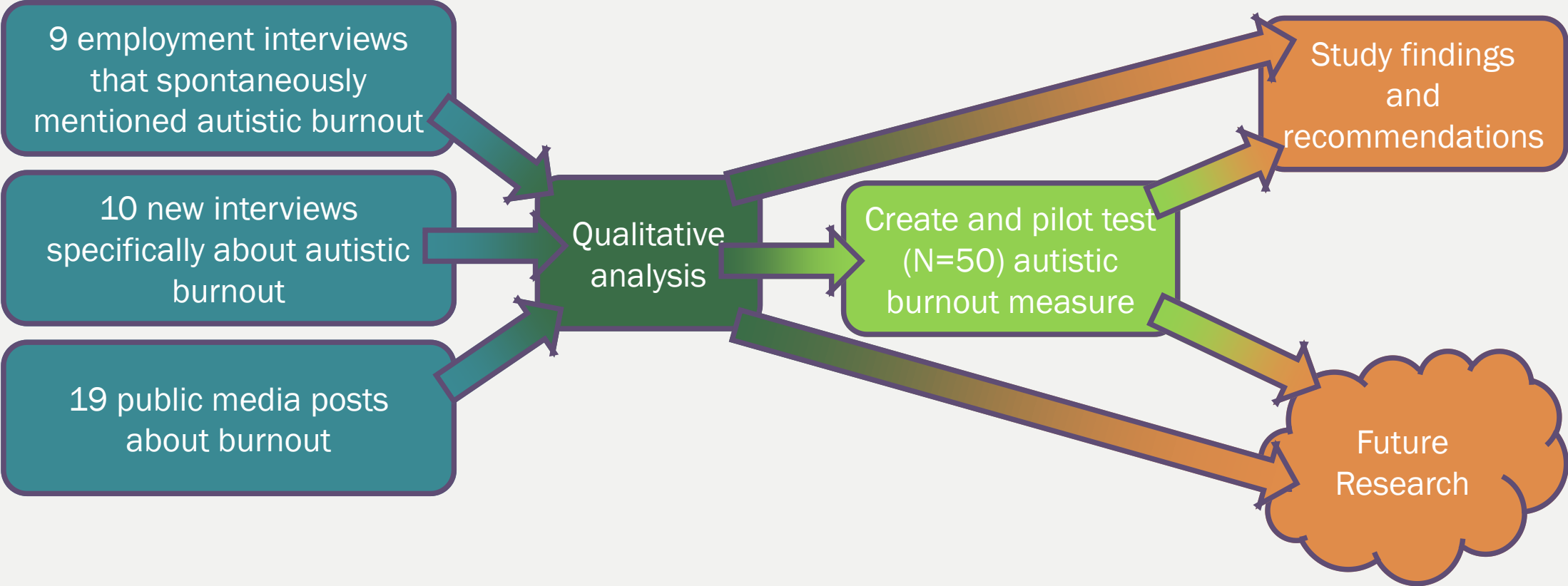
Aims and Methods



Study Aims

1. To characterize autistic burnout, and qualitatively understand people's experience of it and strategies for preventing or recovering from it
2. To develop and conduct initial psychometric testing (content, construct, and congruent validity, internal reliability, and acceptability) of a measure of autistic burnout based on what we learn in aim 1

Study Design



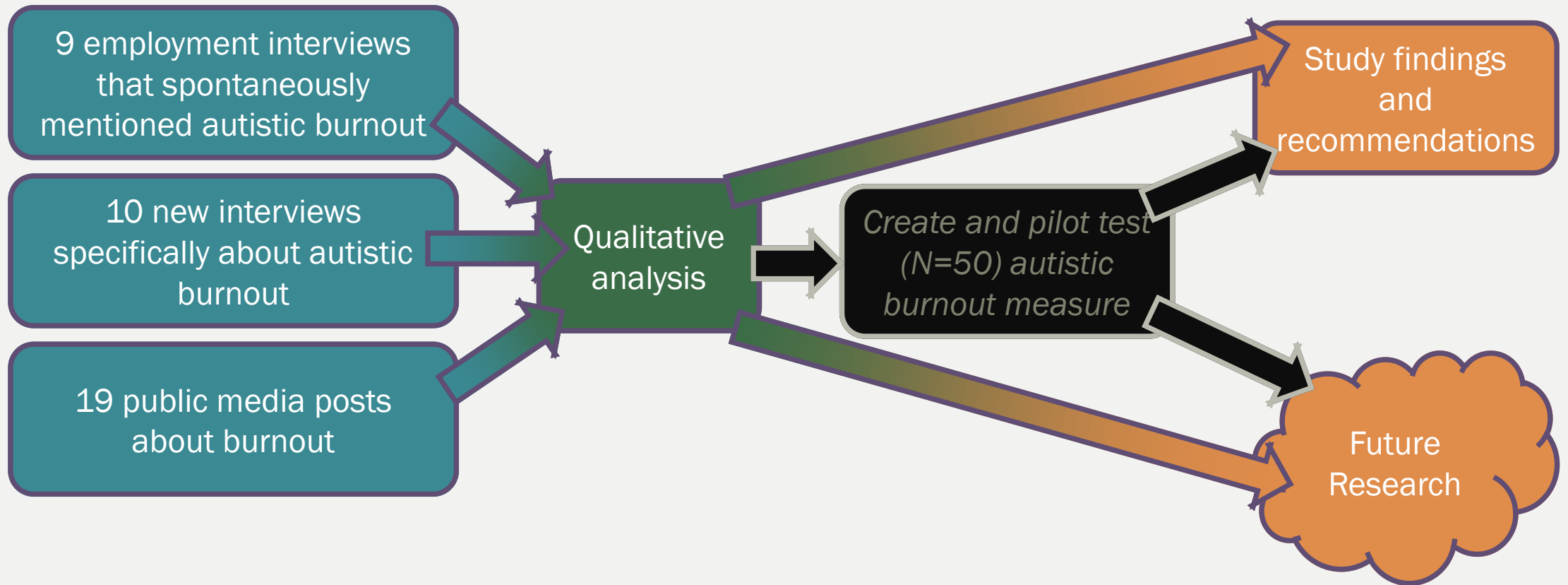
Qualitative Data Sources

- 9 employment interviews that discussed autistic burnout spontaneously (from interviews with 45 autistic adults with professional training) national sample; community-based recruitment
- 10 new interviews focused on autistic burnout; national sample; community-based recruitment; purposively sampled to fit demographics not covered in the employment interviews;
 - *Tell me the story of your experiences with autistic burnout*
 - *Definitions / characteristics of autistic burnout*
 - *Strategies / advice / resources to prevent or relieve autistic burnout*
- 19 key public online media sources (blogs, videos, twitter, Instagram) compiled by the AASPIRE Autistic community partners and recommended by study participants; threads followed from the initial list

Qualitative Analysis

- Thematic analysis – look for recurrent, strong, and pervasive ideas across interviews
- Semantic and latent levels – both taking words at face-value, and inferring underlying meanings from narrative and broader context
- Critical paradigm – “reality” as represented by qualitative data is a product of an interaction between participant and researcher, positioned within a broader context
- Verification
 - *Multiple coders, double-coding, meetings to discuss and converge codes*
 - *Member checking with our CBPR team*
 - *Triangulation with other data sources*

Current Status





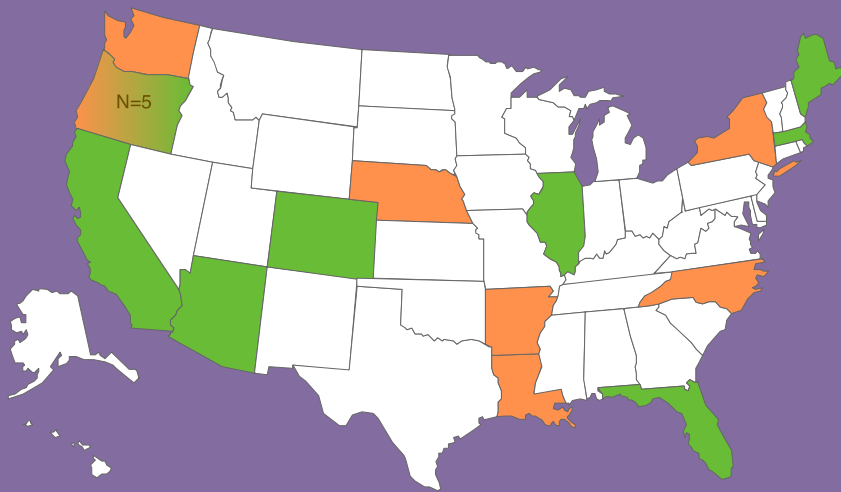
3. WHAT WE'VE LEARNED SO FAR



Results



Demographics and Data Characteristics



Primary public social media / blog sources N=19

Burnout (N=10)		Employment (N=9)	
Degree		Degree	
HS/GED	33% (3)	HS/GED	
Assoc.	11% (1)	Assoc.	
Bach.	44% (4)	Bach.	
Masters	11% (1)	Masters	89% (8)
Doctorate		Doctorate	11% (1)
Gender Identity		Gender Identity	
Female	36% (4)	Female	67% (6)
Male	64% (7)	Male	11% (1)
Other		Other	44% (4)
Race		Race	
Asian		Asian	11% (1)
Black/Afr. Amer.		Black/Afr. Amer.	11% (1)
White	100% (10)	White	67% (6)
Multi		Multi	11% (1)
AAC Use	20% (2)	AAC Use	44% (4)
Disability Service Use	50% (5)	Disability Service Use	33% (3)
Age		Age	
Mean	41.2	Mean	33
Std.dev.	12.2	Std.dev.	31.1
Range	24-65	Range	21-65

“So this combination [of stress, masking, social isolation, loss of an important support person], along with the overwhelming confusion of what was 'wrong' with me, why I couldn't really connect with anyone, why people singled me out or played tricks or used me, of what the hell was wrong with me and why i [sic] just kept hitting this wall over and over again, was what led me to crash and burn out - my physical body and mind started shutting down. I could feel each system in my body closing off as gravity got heavier than it had ever been. I didn't know what to do - did not understand what was happening to me - I had no way to communicate this. It was like a switch had gone off, my verbal ability to convey what was going on in my mind and body was gone. I did not want to die, I've never wanted to die. I needed to step out. I needed to remove myself from the environment and take myself elsewhere; I needed to escape. But the only way I knew how to do that was to die. So I tried.”

Kieran. An autistic burnout. *The Autistic Advocate: Autistic People Have a Voice*. Vol 2018:

<http://www.theautisticadvocate.com/2018/05/an-autistic-burnout.html?m=1>; 2018.

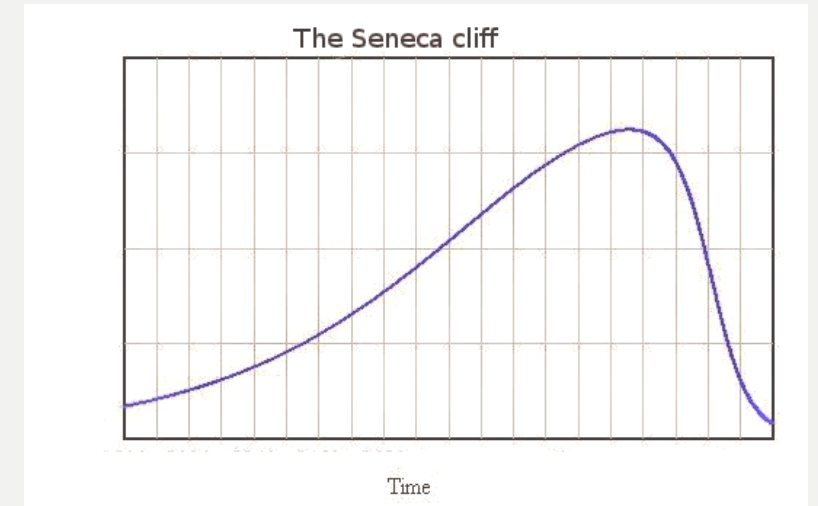
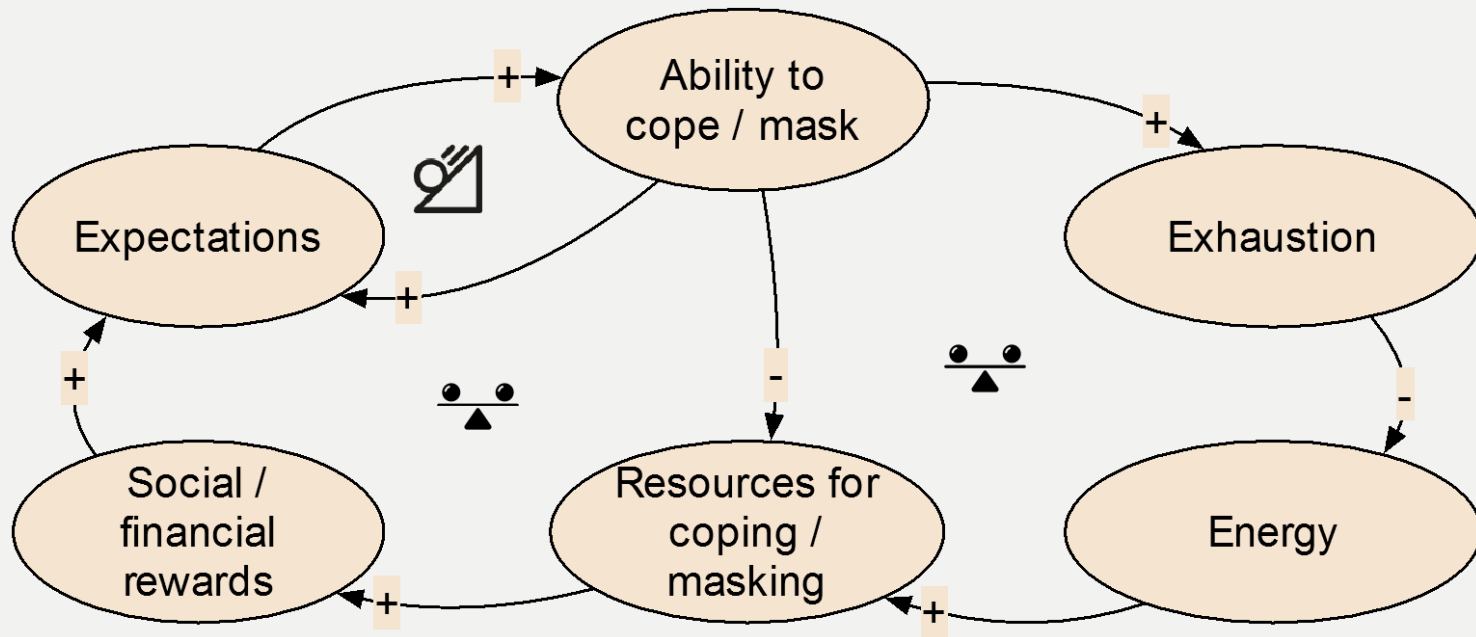
Components or Features

- Loss of skills: cognition, executive function, memory, speech/communication, ability to cope, ability to do things once could do
- Increased sensitivity: to sensory stimulus, to sensory overload, to change, to social stimulus
- Increased autistic behavior (e.g., stimming, speech difficulties)
- More frequent meltdowns / shutdowns
- Chronic exhaustion

Causes

- External expectations chronically outweigh abilities to meet them
- Chronic masking, struggle to “pass” as non-autistic and/or repress autistic behavior
- Change, stress from change, stress
- Inability to recover quickly enough from the strain of pushing to meet external expectations / mask / cope

Possible Dynamics?



- Leads to a “growth and collapse” type behavior
- System grows faster than available resources can keep up

Impacts on Life

- Loss of job, social standing, sense of belonging
- Lack of understanding from others
- Reduced self-esteem and self-efficacy
- Increased depression, anxiety
- Self-injury and suicidality

Onset and Course

- Timing throughout life
 - *Puberty, post-puberty*
 - *Points of increased independence (e.g., starting high school or college)*
 - *(then a period of stability?)*
 - *Points of increased stress*
 - *Aging*
- Collapse and retreat to recover
- Often (especially later in life) incomplete recovery

“Types” of Autistic Burnout?

- Low-level and constant
- Intense / acute
- Social burnout (only coping with / tolerance for social interactions is exhausted)

Autistic Burnout vs. Professional Burnout

- Professional burnout is characterized by
 - *Exhaustion*
 - *Depersonalization*
 - *Reduced self-efficacy*
- Much evidence in data for exhaustion and reduced self-efficacy
- Little evidence for depersonalization

Autistic Burnout vs. Depression


- Some overlap; for example, feelings of worthlessness, exhaustion
- Likely insufficient overlap to be the same
- Autistic burnout did NOT include, for example, slowed or speeded movement, hypersomnia/insomnia, etc.
- Notably did not include anhedonia (not caring/feeling); if anything there was a pervasive frustration because people continued to care and feel but felt incapable of taking action on their feelings
- Some participants who had a diagnosis of depression took care to differentiate it from their burnout

Working Toward a Definition

- *“Autistic burnout is a state of physical and mental fatigue, heightened stress, and diminished capacity to manage life skills, sensory input, and/or social interactions, which comes from years of being severely overtaxed by the strain of trying to live up to demands that are out of sync with our needs.”*
- *“It's like promoting a [neuro-typical] person beyond their own skill level...until they flop...only times 100...and sometimes far more.”*
- *“Having all of your internal resources exhausted beyond measure and being left with no clean up crew.”*



4. WHAT DOES IT MEAN AND WHAT CAN BE DONE ABOUT IT



Implications and Recommendations



#askingautistics I told my therapist I think I'm having #autisticburnout. She agreed and that's as far as we got. What helps? Help me.
#actuallyautistic



“WHAT
HELPS?
HELP
ME.”

Fitting in... Autistic Burnout



What is it? .

1. Late onset loss of functionality due to sustained monumental efforts.
2. Happens to MANY young ASD adults and many more all the way up into 50-60 years.
3. Often directly related to failing at "fitting in" with NT social skills despite faking it all the time to make it

ASD Adult NEEDS:

1. Know basic polite skills
2. Acceptance.
3. Protection.
4. Friends who "get" him..
5. Education on awareness and advocacy. .
6. Mentorship.
7. Vocational training in a strength area.

NEVER:

1. Assume social skills learned in a classroom will work outside of the classroom.
2. Under estimate how hard it is to be someone you are not neurologically meant to be.
3. Assume that NT social skills are the only way to success and/or integration in society.
4. Under estimate the importance of "like" people/friends for social interactions and practicing of ASD social skills .
5. Believe the books have all the answers. Ask about Autistic Burnout on forums where there are autistic adults.

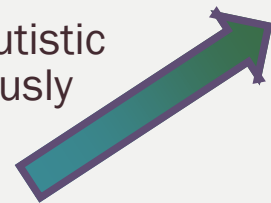


No ASD book or NT professional references Autistic Burnout. Only ASD adults talk of it.
Please treat this as a real and serious threat until it can be disproven as a threat.

Visit Karla's ASD Page for more information

Rapidly Evolving Topic in the Community

- For example, see the list of strategies for avoiding or coping with autistic burnout at: <https://queenofthedrowned.com/2019/05/26/resource-s-for-burnout-recovery-featuring-the-autistic-social-network/>
- And **What is Autistic Burnout? A guide from Autism Women's Network** (fine print at bottom: Sources: "Autistic Burnout – Are You Going Through Burnout?" Anomously Autistic. Endow, Judy. "Autistic Burnout and Aging." Ollibeau. "Help! I seem to be getting more autistic!" American Asperger's Association. Kim, Cynthia. "Autistic Regression and Fluid Adaptation." Musings of an Aspie. Schaber, Amythest. "Ask an Autistic #3 – What is Autistic Burnout?" Thanks to Lindsey Allen, AWN Nebraska for compiling this guide. © Autism Women's Network 2017)



What is AUTISTIC BURNOUT?

a guide from Autism Women's Network



signs



- Lack of motivation (hard to care about goals when everyday life is overwhelming)
- Loss of executive functioning abilities (decision-making, organization, etc.)
- Difficulty with self-care
- Easier to reach overload or meltdown
- Loss of speech, selective mutism
- Lethargy, exhaustion
- Illness, digestive issues
- Memory loss
- Inability to maintain masks or use social skills
- Overall seeming "more autistic" or stereotypical
- May have period of high energy before collapse

causes



- Passing as neurotypical / suppressing autistic traits
- Doing 'too much', too much stress
- Aging: needing more downtime, having less energy
- Changes, good or bad (relationships, jobs, living arrangements, belongings, environment, routines...)
- Sleep deprivation, poor nutrition, dehydration
- Illness
- Sensory or emotional overload

strategies



- Time
- Scheduling breaks, managing spoons
- Leave of absence
- Stimming, sensory diet
- Exercise
- Massage
- Reminders and supports
- Routines
- Better environment/job/etc.
- Boundaries, saying 'no'
- Dropping the mask/façade
- Solitude
- Absolute quiet
- Creative projects, passions, special interests
- Paying attention to reactions and your body

Sources: "Autistic Burnout – Are You Going Through Burnout?" Anomously Autistic. Endow, Judy. "Autistic Burnout and Aging." Ollibeau. "Help! I seem to be getting more autistic!" American Asperger's Association. Kim, Cynthia. "Autistic Regression and Fluid Adaptation." Musings of an Aspie. Schaber, Amythest. "Ask an Autistic #3 – What is Autistic Burnout?" Thanks to Lindsey Allen, AWN Nebraska for compiling this guide. © Autism Women's Network 2017

Strategies and Recommendations for Autistic People

- Time off from school, job, life
- Reduced self-expectations
- Stimming, time with special interests
- Sensory and/or social withdrawal
- In general, time spent without the “mask”
- Passage of time; time to recover

Strategies and Recommendations for Families and Friends

- Reduced expectations
- Acceptance of the person even when they don't "pass" for non-autistic / acceptance of autistic behavior
- Emotional support, empathic connections
- Direct support for instrumental activities of daily living
- Accommodations at work / school / community

Broader Systems-Level Considerations

- Discrimination and stigma around autistic behavior and disability encourage people to mask – anti-discrimination / anti-stigma work may have long-term, indirect impact?
- Therapy with normalization goals may need to be reconsidered?
- System-level changes that normalize disability may be beneficial in reducing overall risk of autistic burnout?
- Professional, clinical, family, and self-advocate communities all could benefit from further understanding and discussion around autistic burnout

Considerations Around Transition Age

- Many adults report their first autistic burnout around transition age
- May be a particularly vulnerable time due to increase in expectations, number and scope of life-changes, and general stress of that developmental time
- Young people may not understand what is happening to them if it is their first experience of autistic burnout

Transition Age Narratives

“I was intellectually gifted, but emotionally and socially way behind my age. I burned out completely at age 14 from stress, socializing issues, and the start of an erratic puberty...Only now do I see it as burnout...”

“It actually started in middle school, my sensory issues got a lot worse, then I started socially withdrawing...like hanging out in my room and going into shutdown and...then my parents were really concerned because...they thought I was depressed, and for that [instance of burnout] afterwards...I never got to the point where I was before, like, I couldn't deal with sensory issues the same way I went from having no diagnosis of autism to have a diagnosis of autism so it was a significant point in my life....I think that [instance of burnout] was caused by the social differences and interaction of a teenager versus pre-adolescent years.”

A Caution About “Reduced Expectations”

- NOT MEANING reducing expectations about a person’s ability to achieve their goals in life!!! They should have the same opportunities as anyone!
- ONLY talking about expectations of how close to a non-autistic person’s path theirs should look
- In other words:
 - DO EXPECT US to be able to achieve our dreams!
 - ...Just don’t expect us to always achieve them in the same way a non-autistic person would 😊



Key Points from the AASPIRE Research Team for Family and Professionals

- The more people need to mask the more likely they are to experience burnout
- Educate yourself about disability rights, and cultivate positive autistic or disability identity in young people
- Teach young people to pace themselves and set flexible boundaries for themselves
- Focus on autistic strengths and preservations to reduce the risk of burnout; for example, choose activities or employment in alignment with special interests
- Be sensitive to the possibility that decreases in function (when someone can do something at one time but is unable to do the same thing at another time) may be a sign of autistic burnout

Limitations

- Small, qualitative study, convenience sample, burnout-specific interviews missing important demographics
- Designed to get an in-depth understanding from experts, not to generalize to a population
- Preliminary, exploratory work
- Analysis and interpretation presented here is still developing and has not been finalized

Next Steps

- More research is needed
 - *Measure development*
 - *Increased understanding of underlying causes and associations*
 - *Understanding of role in suicidality*
 - *Programs to relieve or prevent*
- More conversation is needed
 - *Autistic people have been talking about this experience amongst ourselves for a long time*
 - *It's time to broaden the discussion outside of the community so it can gain more potential for action*



5. WRAPUP AND QUESTIONS



Thanks & Questions

- Thank you to the AASPIRE team, and to all of our research participants who shared their wisdom and experience with us
- Autism in Adulthood journal
- Contact me! draymake@pdx.edu | <http://doraraymaker.com>
- Happy to answer questions on: autistic burnout, community-engaged approaches to research, AASPIRE's employment or healthcare studies
- This research supported by National Institute of Mental Health award number 1R21MH112038, and by Oregon Health & Science University / Portland State University Collaboration Seed funding. It is the responsibility of the authors and does not necessarily represent the views of NIMH, OHSU, or PSU.