



Supporting Autistic and Neurodivergent People

Zack Siddeek, MSW Johnathan Martin, MA





Who is Zack? (He/Him)

Grew up in Western Colorado. Mix of Italian, Iraqi, and German.

Diagnosed with PDD-NOS at 11.

B.A. from Evergreen in everything 2013.

MSW from UW in 2018.

Disability Systems Navigation Coordinator, The Arc of King County

Organizer of the Square Pegs



Who is Johnathan Martyn? (He/Him)

High School Social Studies Teacher for Everett Public Schools

UW Seattle Instructor

From Kent WA

Diagnosed ADHD at 26, self-realized Autistic at 29. "AuDHD".

Former primary prevention specialist for King Country Sexual Assault Resource Center, Education Coordinator for Seattle Against Slavery, and founder of Men's Accountability Community

Community organizer for ending gender-based violence and disability rights advocate



Johnathan Martyn (right) and family

The Agenda

For our time together, we will cover:

What neurodivergence may look like and how do we define it

How neurodivergence may impact a person's experience with receiving care

Sensory differences and executive functioning

How to best support neurodivergent students or clients

We Don't Want This To Be A Long, Boring Lecture

We're sure y'all have been through lots of long, boring trainings - we will try to spare you from that.

We want this to be as interactive as possible. Please ask questions.

This is everyone's space. If you need to take a break or use the restroom, we won't mind.

Please let us know if there is anything we can do to make things more accessible.



Who Are You All? (If we have time)

We would love to hear:

Name, pronoun, role, etc.

What is your connection to Neurodiversity?

What are you looking to learn from this experience?

Is there anything we can do to make this presentation more accessible?

Our Mission:

The Arc of King County advocates for the right of individuals with intellectual and developmental disabilities to live, learn, work and play in the community - improving the quality of life for all of us.



Contact us:

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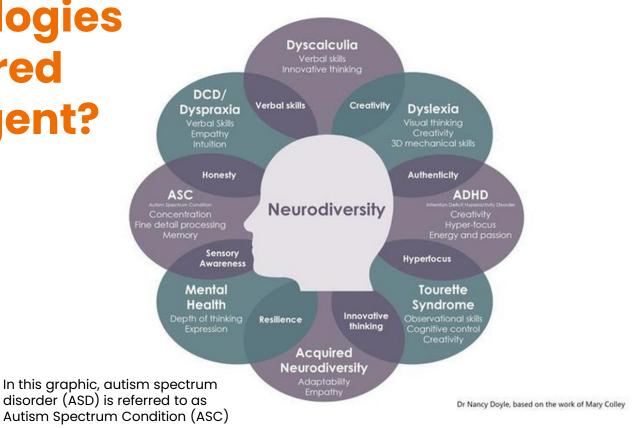


Brief Description of Autism

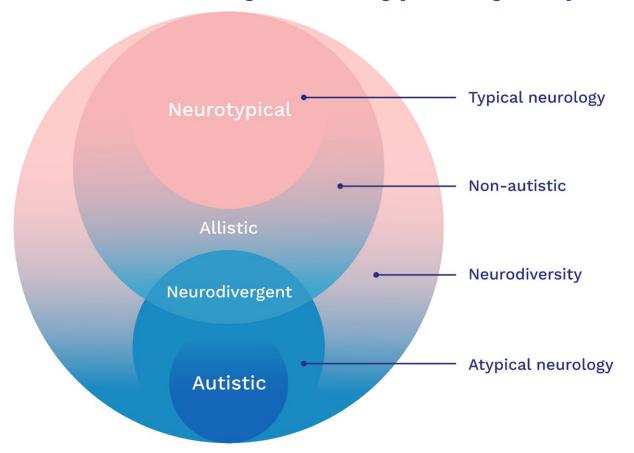
- Autistic people make up 2ish% of the population
- Sensory differences
- Meltdowns and shutdowns
- Social communication and interaction differences
- Executive functioning
- Impact of trauma



What neurologies are considered neurodivergent?



Neurodiversity-neurotypicality map



Person First Versus Identity First

Person First: "Person with autism"

- Autism is only a part of a person, and not a defining feature
- A person should not be defined by their disability
- Typically used by professionals and people with intellectual disabilities or Down syndrome

Identity First: "Autistic person"

- Autism is an inseparable part of one's identity, like ethnicity, gender, or sexual orientation
- Having to see "beyond" someone's disability to be seen as a person is dehumanizing
- Preference of most Autistic people

"Models" of Disability

| Moral | Capitalist/ Economic | Medical | Inspiration | Social |
|---|---|---|--|---|
| Thoughts: Punishment / sin Perpetual child Pity /tragedy Menace / threat "Freak" / undesirable Burden | Thoughts: Inability Undesirable Burden Cost too much Not worth it | Thoughts: Broken Incomplete Not good enough "Special" | Thoughts: Gift from God "Special" Exceeding expectations Death is better than disability | Thoughts: Disability as diversity Social perceptions Strengths-based Part of identity |
| Action: o Isolation & segregation o Containment & control o No support o charity | Action: o Isolation & Segregation o Containment & Control o No support o Discrimination | Action: o "Fix it" o "Be like everyone else" o "Hide it" | Action: o Demeaning o Non-human o Focus on the non-disabled | Action: o Empower o Accommodate o Person-led |

"MEDICAL"

Thoughts:

- Broken
- Incomplete
- Not good enough
- "Special"

Action:

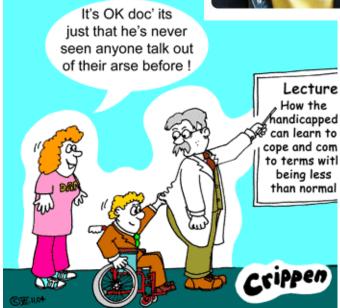
- o "Fix it"
- "Be like everyone else"
- o "Hide it"



Let's wipe out cancer, diabetes and autism in his lifetime.



Research Institute





Push yourself!

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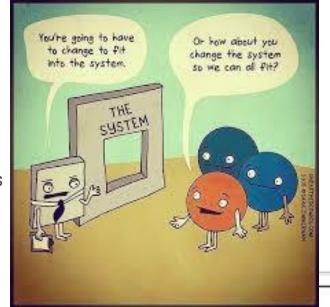
"SOCIAL"

Thoughts:

- Disability as diversity
- Social perceptions
- Strengths-based
- Part of identity

Action:

- Empowerment
- Accommodate
- Person-led











Neurodiversity Diagnoses for Adults

The process will depend on the specific thing being assessed.

ADHD can be diagnosed by PCPs, although some may refer out to neuropsych tests.

Autism will usually require an ADOS, ADI-R, DISCO, or 3Di.

These tests can be very expensive out of pocket, \$2,000 to \$3,000.

No providers in WA currently accept Medicaid for Autistic Diagnostic Assessments for adults.



Self Diagnosis

Self Diagnosis is an accepted practice within the autistic community, due to:

- High costs and long waiting lists for assessments
- Lack of understanding in clinicians to what autism lookings like in people who aren't white men.

The vast majority of people who do self-diagnose do so after an extensive amount of research and self reflection.

"You can't be Autistic because" ...

"You have a psychology degree. You can do a better job faking it."

"You can't be autistic. You get straight A's."

"You are not smart enough to be autistic. Your IQ is too low."

"You have too high of an IQ to be autistic."

"You're too pretty to be autistic."

"You don't look autistic."

"You have a college degree; you can't be autistic."

"You can't be Autistic because you can talk."

"You can't be diagnosed with autism over the age of 8."

"You can't be autistic because you want friends."

"You can't be autistic because you make eye contact."

"You can't be autistic because you dress normal."

"You're too extroverted to be autistic."

"You can't be autistic because you are good with perspective taking."

"You can't be autistic because you are drawn to humanistic therapy."

"You can't be autistic because you are married."

Masking

Masking is the practice of hiding your autistic traits for the comfort of others around you.

Masking is directly linked linked to anxiety and depression in autistic folks.

One study showed the masking was the biggest predictor for suicidal ideation in autistic adults. (Cassidy et al. 2018)

How do expectations around "professionalism" lead to or discourage masking?

Masking is also directly linked to autistic burnout.

Autistic Burnout

Prolonged periods of intense masking and stress seem to be the biggest factors.

During burnout, Autistic people can lose the skills and abilities they could count on, like cleaning the house, driving a car, working a 40 hour job, or even speaking.

Autistic burnout is a state of prolonged mental, physical and emotional exhaustion.



All of this has an impact

The suicide rate for the autistic community is 9 times the general population's rate.

31% of autistic people report sexual assault/rape at least once in their lifetime.

Autistic people may be likely to engage in substance use as a coping mechanism.

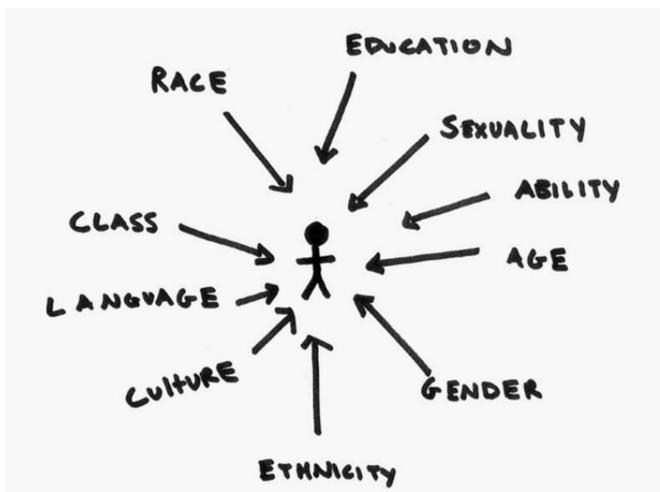
Autistic people are more likely than the general population to have experienced homelessness.

Autistic people on average die 16-30 years earlier compared to non-autistic people.

What Services Exist for Autistic Adults in Washington?

- DDA: Provides services like case management, community residential services, supported employment and day services for those who qualify. Around 20% of autistic people qualify for their services.
- Alyssa Burnett Center: Seattle Children's Alyssa Burnett Adult Life Center offers lifelong learning for people 18 and older with autism spectrum disorder and other developmental disabilities.
- Square Pegs: A Series of meetup groups for autistic adults, both virtual and in person.

Disability Does Not Happen in a Vacuum



Autism and LGBTQIA Intersection

From my survey:

Heterosexual - 80 (58.39%)

Bi/Pansexual - 31 (22.63%)

Homosexual - 12 (8.76%)

Asexual - 5 (5.11%)

Heteroflexible, ginosexual, demi-bi, queer, variable/uncategorized, Grayasexual Prefered not to answer - 1 in each of the above (.73%)



Autism and LGBTQIA+ (cont.)

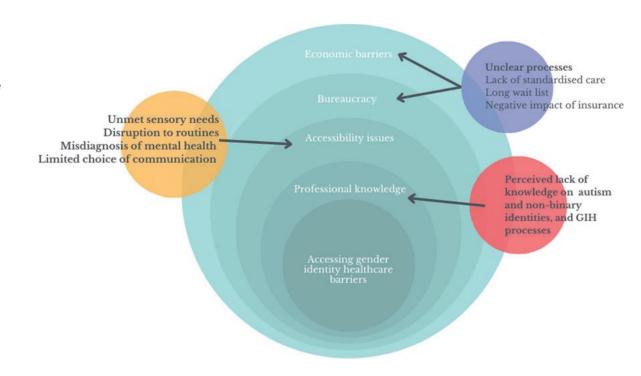
One study found that 20% of people being treated for gender dysphoria displayed autism-like signs. (Van Der Miesen, Hurley & De Veries, 2016)

Studies show that Queer Autistic people have worse mental health outcomes than those are either Queer people or Autistic people. (George & Stokes, 2018)



Autism and LGBTQIA+ (cont.)

Another Study (Bruce,
Munday & Kapp, 2023)
found that "poor knowledge
of professionals,
accessibility issues, and
bureaucratic and economic
barriers impacted
participants' experiences
when accessing Gender
Identity Health Care."



Autistic Women

In a survey I conducted of 144 autistic adults in Washington state, I found that autistic women were diagnosed 12 years later on average compared to autistic men.

Most trainings will tell you that there are 4 autistic men to every 1 autistic woman. This is not correct. The ratio becomes much less when looking at autistic people with high support needs.

Autistic women tend to be diagnosed with ADHD, depression, bi-polar disorder type ii, or borderline personality disorder - and may receive inappropriate medications.



BIPOC Intersection

"The patterns of racial disproportionality in autism seem to be influenced by numerous factors. These include varying state definitions of autism, disparities in resource distribution, differences in symptom recognition across cultures, service preferences, cultural mismatches between professionals and families, and prevailing biases and stigmas, as revealed by the reviewed studies" - (Kim et al, 2024)

"(...)gaps remain in the equitable detection of Black and Latine children with AS without significant developmental impairment." (Martin et al, 2024)

Autistic people of color have "very limited representation" in evidence based practice research, yet the research often reports findings as generalizable for all Autistic people. (West et al, 2016)

"Race, symptom complexity, and co-occuring conditions predicted age of final diagnosis and wait time between first concern and final diagnosis, both of which were staggeringly high." (Miller et al, 2022)

How Can Autism Impact a Person and How Can They be Accomodated?

Table 2. Barriers to Healthcare Checklist Short-Form item-level responses between autistic and non-autistic participants, number of people who answered yes (*N*=333).

| Item | Autistic (n = 263) | Non-autistic (n=70) |
|--|--------------------|---------------------|
| | n (%) | n (%) |
| Fear, anxiety, embarrassment or frustration keeps me from getting primary car | 103 (39.16) | 10 (14.29) |
| I have trouble following up on care | 104 (39.54) | 4 (5.71) |
| I have difficulty understanding how to translate medical information into concrete steps that I can take to improve my health | 50 (19.02) | 0 (0) |
| I don't understand the healthcare system | 44 (16.73) | 0 (0) |
| It is too difficult to make appointments | 76 (28.90) | 9 (12.86) |
| I have problems filling out paperwork | 36 (13.69) | 0(0) |
| My behaviours are misinterpreted by my provider or staff | 79 (30.04) | I (I.43) |
| My providers or the staff do not take my communications seriously | 72 (27.38) | 2 (2.86) |
| I cannot find a healthcare provider who will accommodate my needs | 65 (24.71) | 4 (5.71) |
| My providers or the staff do not include me in discussions about my health | 24 (9.13) | 0 (0) |
| Communication with my healthcare provider or the staff is too difficult | 66 (25.10) | 3 (4.29) |
| When I experience pain and/or other physical symptoms, I have difficulties identifying them and reporting them to my healthcare provider | 107 (40.68) | 4 (5.71) |
| Sensory discomforts get in the way of my healthcare | 86 (32.70) | I (1.43) |
| Concerns about cost or insurance coverage keep me from getting primary care | 118 (44.87) | 10 (14.29) |
| I do not have a way to get to my doctor's office | 8 (3.04) | I (I.43) |
| I have inadequate social, family or caregiver support | 57 (21.67) | 4 (5.71) |
| I find it hard to handle the waiting room | 111 (42.21) | I (I.43) |

Question

Please select all physical health diagnoses you feel apply to you:

| | Total responses (N): 98 Did not respond: 24 | | |
|------------------|---|-----------|------------|
| Numeric value | Annua | F | D |
| | Answer | Frequency | Percentage |
| 1 | Seizure disorder or epilepsy | 11 | 11.22% |
| 2 | Gastrointestinal problems (please specify in the write-in box) | 36 | 36.73% |
| 3 | Sleep or circadian rhythm disorder | 49 | 50.00% |
| 4 | Cerebral Palsy | 1 | 1.02% |
| 5 | Ehlers-Danlos Syndrome or joint hypermobility syndrome | 16 | 16.33% |
| 6 | Developmental Coordination Disorder or dyspraxia | 18 | 18.37% |
| 7 | Autoimmune disorder (please specify in the write-in box) | 19 | 19.39% |
| 8 | Other neurological condition (please specify in the write-in box) | 27 | 27.55% |
| 9 | Trouble with my bowels (Irritable Bowel Syndrome, etc) | 36 | 36.73% |
| 10 | Migraines | 34 | 34.69% |
| 11 | Asthma | 25 | 25.51% |
| 12 | Hormone imbalances | 19 | 19.39% |
| | | | |

Please select any co-occurring diagnoses you have received, or you feel like apply to you:

| | Total responses (N): 137 Did not respond: 3 | | |
|-----------------------|--|-----------------|----------------------|
| Numeric Value 1 | Answer Intellectual disability | Frequency 23 | Percentage 16.79% |
| 2 | ADHD/ADD | 63 | 45.99% |
| 3 | OCD | 32 | 23.36% |
| 4 | Learning disability | 31 | 22.63% |
| 5 | Anxiety | 113 | 82.48% |
| 6 | Depression | 91 | 66.42% |
| 7 | Eating Disorder | 24 | 17.52% |
| 8 | Oppositional Defiant Disorder | 3 | 2.19% |
| 9 | Substance Use Disorder | 9 | 6.57% |
| 10 | PTSD | 53 | 38.69% |
| 11 | Difficulty expressing or regulating emotions | 70 | 51.09% |
| 12 | Social Anxiety or difficulty with crowds | 94 | 68.61% |
| 13 | Difficulty knowing what emotions I am feeling | 54 | 39.42% |
| 14 | Difficulty with eye contact | 84 | 61.31% |
| 15 | Difficulty communicating with words | 59 | 43.07% |
| 16 | Sensory processing disorder | 78 | 56.93% |
| 17 | Auditory processing disorder | 49 | 35.77% |
| 18 | Speech disorder | 14 | 10.22% |
| 19 | Dyslexia | 16 | 11.68% |
| 20 | Dyscalculia | 8 | 5.84% |
| 21 | Body dysmorphia | 21 | 15.33% |
| 22 | Please list any other disorders you feel apply to you in this box: | 17 | 12.41% |

AUTISTIC











S

P

A

Physical

Processing

Emotional

Sensory

Predictability

Acceptance

Communication

Empathy

History of Autistic Space

- Autistic space as a term was first used in 1992 in the autistic advocacy community to describe spaces that are accessible for autistic people.
- Marty Doherty, Sue McCowan and Sebastian CK Shaw from Autistic Doctors International used the term in 2023 as a framework to describe how to make medical settings accessible for autistic people.
- https://www.magonlinelibrary.com/doi/pdf/10.12968/hmed.2023.0006

Autistic SPACE: Overview

- Sensory needs: Inaccessible spaces are distressing and prevent us from being present.
- Predictability: A lack of predictability causes anxiety and removes our ability to think on our feet. Not knowing the process or how long something may take is stressful.
- Acceptance: We carry a lot of shame around us based on how our differences have been treated, and many of us have had negative experiences with medical

- providers or other professionals based on stereotypes of our differences.
- Communication: Autistic people have different communication styles and needs compared to non-Autistic people and we need those differences accommodated.
- Empathy: Providers struggle to empathize with us because of our different ways of being. Implicit Bias has a huge impact against Autistic People.

Sensory Differences

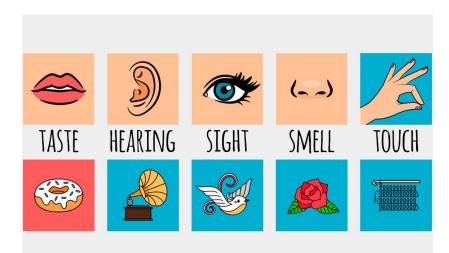
Every sense can be impacted

Sight. Sound. Smell. Taste. Touch. Tempraturem. Proprioception. Interoception. Pain

Hyper-arousal vs Hypo-arousal. Sensory Seekers vs Sensory Avoiders

Ever-changing based on mood and other events

Probably the most underrated difference in autism



Sensory Accomodations from SPACE

- Sight: Turn off or turn down artificial lights. Remove flickering or oscillating environmental features. Avoid highly stimulating décor. Promote the use of sunglasses
- **Sound:** Consider environmental sounds. Reduce auditory clutter. Avoid conversation in noisy environment. Promote the use of noise-cancelling headphones and/or ear plugs
- **Smell:** Avoid wearing perfume or highly scented cosmetics or toiletries. Avoid aerosols or chemical 'air fresheners.' Avoid highly scented cleaning products. Consider ventilation; open windows where possible

Sensory Accomodations from SPACE

- Taste: Respect sensory preferences when considering nutrition. Consider taste and texture of medications.
 Consider non-standard medication formulations where necessary
- Touch: Ascertain tactile preferences and modify examination technique. Avoid casual touch. Promote sensoryfriendly clothing choices. Sensory aids such as weighted blankets may be helpful
- **Temperature:** Consider environmental temperature. Adjust temperature

- where required
- Proprioception: Understand the need for proprioceptive input. Avoid making inferences from unusual body posture.
- Interoception and pain: Ask directly about internal sensations but understand that answering may be difficult. Pay attention to verbal reports of pain where possible. Be aware that non-verbal expression of pain may be different. Consider the need for adapted pain scales

Sensory Accommodations (From Ask JAN)

Non-Fluorescent Lighting

Earplugs or noise canceling headphones

White Noise Machines

Workspace in a quiet environment or working from home

Soundproof offices

Also important: Sensory Aids



One Example of a Sensory Aid

Column: Are fidget spinners a threat to America? Yes. Yes, they are.





Social Differences



every admirer is a secret admirer if you're unable to pick up on social cues

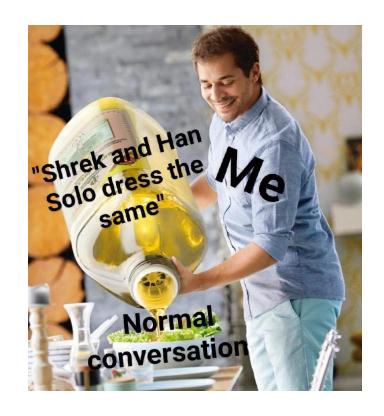
Thinking about your current hyperfixation

Realizing you were in the middle of a conversation



Social Interactions & Communication Differences

"Autism is like being a cultural outsider, where others may not be able to tell you are an outsider."



Social Interactions and Communication Differences

Additional time is needed to process verbal instruction. Auditory Processing Disorder is a common co-occurrence.

The person may experience difficulties in inferring mental states or detecting non-verbal communication from others.

Some of us are concrete thinkers.

Stress, sensory overload and unfamiliar situations can reduce or remove ability to communicate

Routine is important when communicating and being-in-theworld as an autistic

Provider Recommendations from SPACE

- Understand autistic verbal and non-verbal communication differences
- Know that communication ability is reduced by anxiety and sensory stress
- Clear unambiguous communication required
- Avoid phone-based appointment systems

- Promote use of augmentative and alternative communication (AAC)
- Recognize that autistic people feel empathy but may display it differently
- Empathy towards autistic patients or students may be more challenging for non-autistic healthcare providers or educators

Meltdowns and Shutdowns

I don't know what this cat is going through but I can relate.





Meltdowns: An Overview

Meltdowns happen when an autistic person's ability to cope is overwhelmed and they are unable to adapt to the present situation.

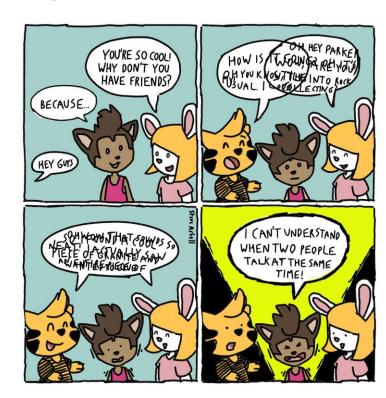
Length and intensity depend on the reason and person.

Sensory overload is often the main reason.

Changed expectations/plans are a close second.

Consider the impacts of masking.

Not a tantrum and not intentional.



What do meltdowns look like?

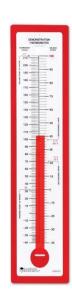
Dependent on person

May gradually escalate - an increase in irritability over time

May see increase of stimming during the build-up

Everyone has a point of no-return - figure out what that looks like for the individual

Yelling, screaming, chair throwing, biting, self injurious behaviors, etc.



What to do during a meltdown:

Best thing to do is avoid them in the first place!

Give space if possible, reduce sensory input such as lights or noise

Know that what could help depends entirely on the person

"Crowd control"

What to do after a meltdown:

If the meltdown was caused by sensory dysregulation, make sure the stimulus is removed to prevent a another meltdown

Is the student willing to talk about it? Many may not remember what happened during a meltdown.

Difference in blame versus responsibility.

It always depends.

What is a shutdown?

Triggered by prolonged periods of extreme stress

Can last from minutes to days

Person's processing ability will nearly shutdown

May appear catatonic or in dream-like state

Person will be non or minimally communicative

Not defiance; a physiological reaction

What to do after a shutdown:

How long do they usually last for the person?

What is the student's sensory profile?

Aftercare plan.

Shutdowns are usually a sign the autistic person is overexerting themselves. This can lead to autistic burnout.

Executive Functioning

Executive Functioning refers to the ability to be able to plan and orient brainpower to specific tasks.

It can be difficult and overwhelming to break down the necessary details and activities required to perform a specific task, like washing the dishes or cleaning a room.

Time demands or production demands can be dysregulating.

Consider the role of sensory dysregulation.



Tips For Supporting Executive Functioning

Break down the tasks' necessary components.

- Do the tasks need to be done in a specific way?
- Is there an easier way in can be done?
- Can a list be made for visual reference?
- Can tasks be color-coded?
- Would images be helpful?
- Can technology be used to help in some way?
- Would a modified break schedule be helpful?

Important: Easy can mean different things to neurodivergent and neurotypical people.

Thanks so Much! Our Names and Emails:

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