





Claire Sehinson

Autism, Mental Health and Mitochondria: Supporting Clients from an Evidence-Informed and Neurodivergent-Affirming Practice

12:00-12:45pm

NMI Summit, 11-12 October 2024



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AUSTISM, MENTAL HEALTH AND MITOCHONDRIA

NMI Summit, 11-12 October

BY CLAIRE-ELIZA SEHINSON





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ABOUT

I am a late diagnosed multiply-neurodivergent educator, researcher, practitioner and disability advocate.

DISCLOSURES

Affiliations:

- The Optimum Health Clinic (Head of Research)
- Psychiatry Redefined (Faculty)
- The Creative Well (Practitioner)

Declarations of interest: None

All opinions expressed are mine and not necessarily representative of anyone I work for

AGENDA

PART 1

What is Autism?

- · History of Autism & the DSM What else is Autism?
 - Neurobiology and Neurodivergence
 - Health disparities

PART 2 Autism, mental health and mitochondria

- Mental health issues
- Autistic burnout
- · Mitochondria, stress and mental health

PART 3 Neurodivergent-affirming care **Case study**

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NMI Summit, 11-12 October

GLOSSARY

Ableism: the prejudice, bias or discrimination in favour of 'able-bodied and minded' people. Or research/therapies where the 'typical ability' is the goal. I.e. "eye contact is a sign of sincerity"

Internalised ableism: where the disabled person absorbs the opinions, viewpoints and expectations of the ableist society. I.e. "you should eat 10 veg & fruit a day"

Alexithymia: difficulty in identifying, expressing or verbalising one's feelings or emotions, exists on a spectrum

Aphantasia: the inability to create mental pictures on

demand, exists on a spectrum Allistic: non-autistic people

AuDHD: the combination of an autism and ADHD diagnosis NMU Summit, 11-12 October (masking): conscious/unconsciously hiding, suppressing or disguising parts of oneself in order to fit in or

survive.

Double empathy theory by Dr Damian Milton states "when people with very different experiences of the world interact with one another, they will struggle to empathise with each other. This is likely to be exacerbated through differences in language use and comprehension".

Diagnostic overshadowing when a healthcare provider mistakenly attributes a patient's symptoms to an existing condition, often overlooking or misdiagnosing other potential health issues ie. mistaking autistic traits for OCD or anxiety. Hyperfocus / monotropism intense fixation and funnelling of attention into a topic or activity of interest Interoception the 8th sensory system allowing us to sense and understand the internal signals of your body Inertia the difficulty initiating or stopping a task

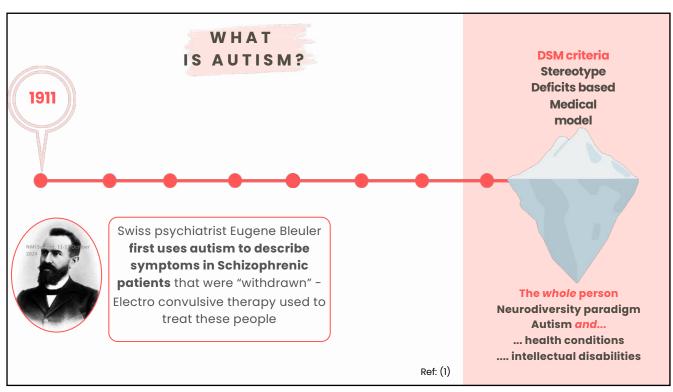
Neurodivergent (ND) "someone who deviates from the neuronormative world to the extent that daily life is impacted by it, Jason Schwartz

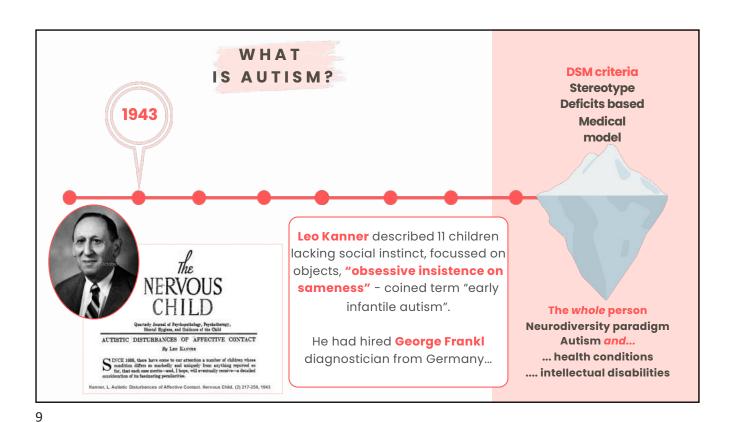
Neurodiversity the concept that people have different types of brain (how we think, learn and process the world) and "different neurotypes" are necessary for a diverse, flourishing and sustainable environment.

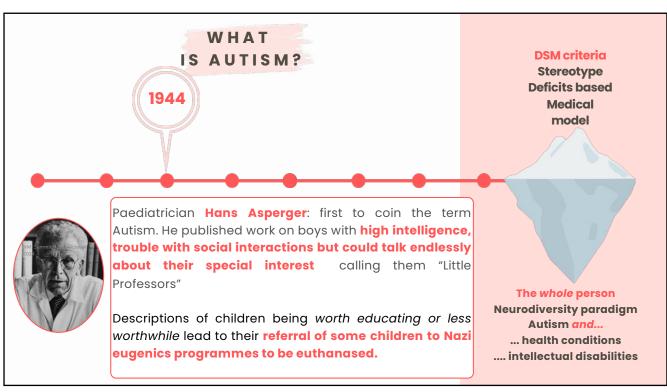
Neurominority the group of people whose brains work different from the majority

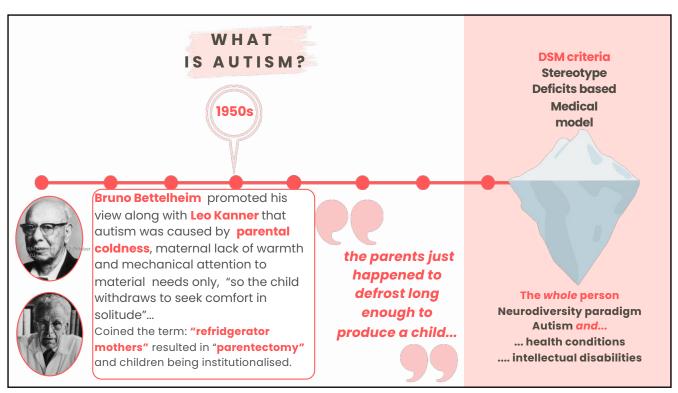
Neurotypical (ND) describes people whose brains work in ways that are considered typical or expected by society Stimming repetitive and often rhythmic behaviours, thoughts or movements that help to regulate the nervous system.

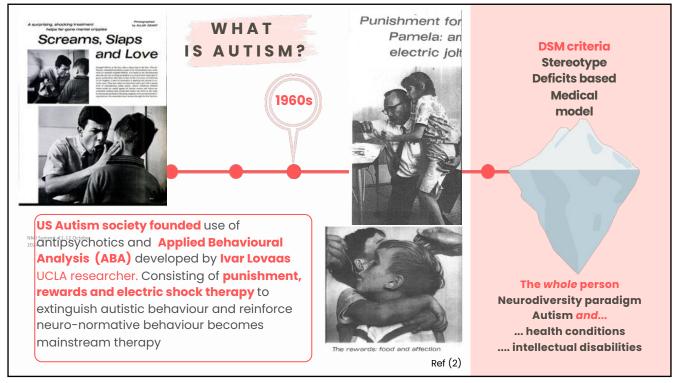


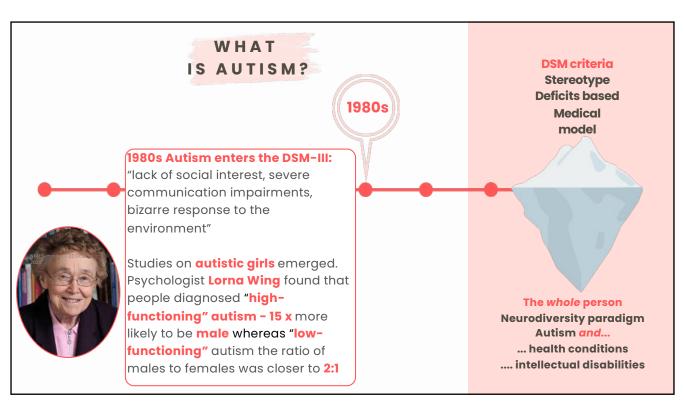


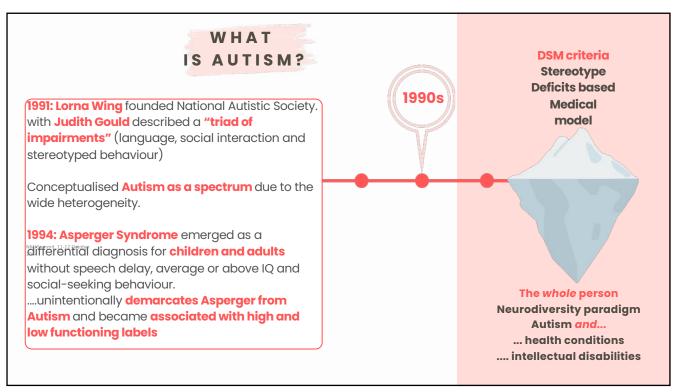


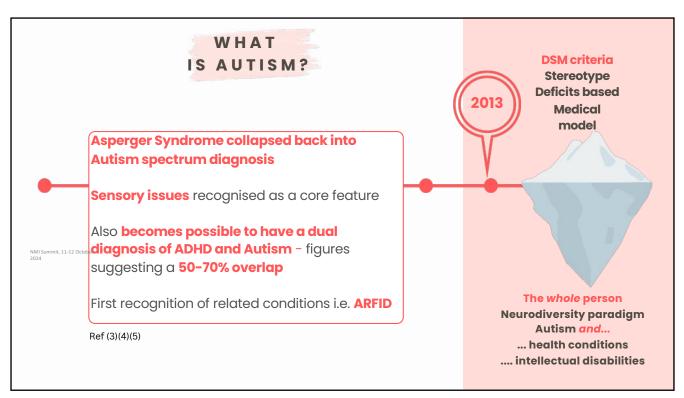


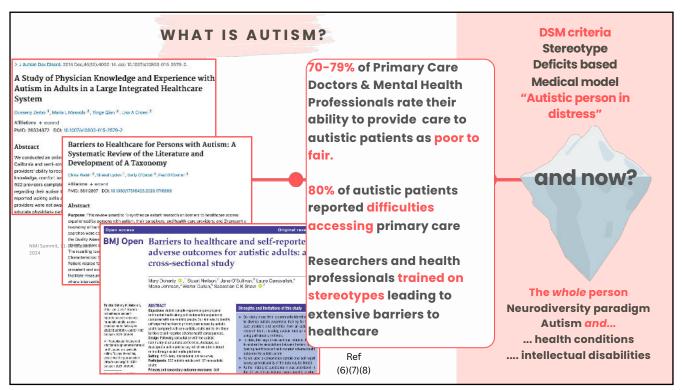


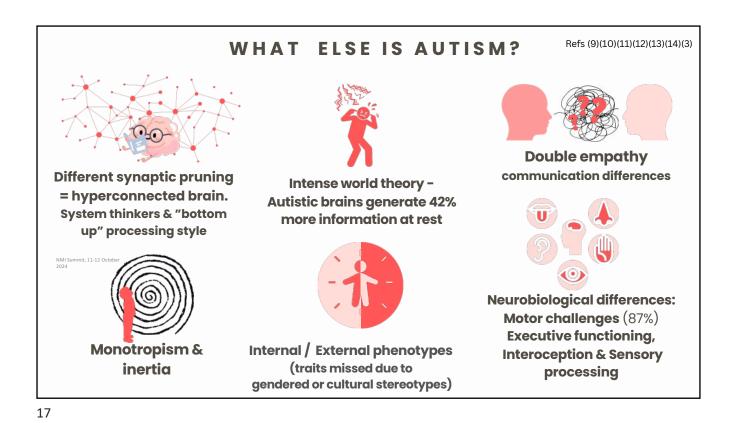


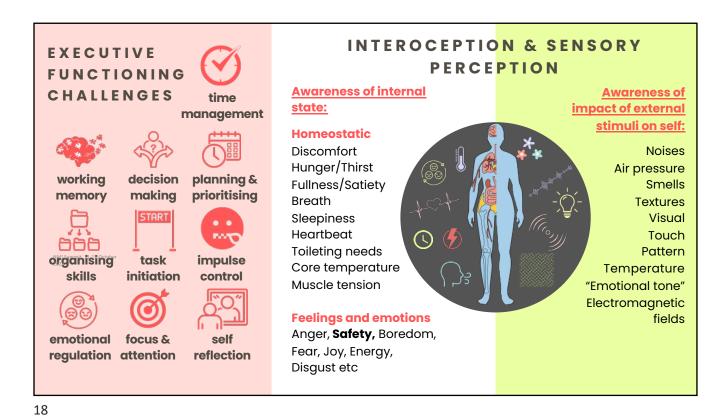














Biological Psychiatry: Cognitive Neuroscience and Neuroimaging

Volume 3, Issue 6, June 2018, Pages 501-513



Interoception and Mental Health: A Roadmap

Sahib S. Khalsa a b 🙎 🖂 , Ralph Adolphs d, Oliver G. Cameron h, Hugo D. Critchley P, Paul W. Davenport , Justin S. Feinstein a b, Jamie D. Feusner e, Sarah N. Garfinkel P, Richard D. Lane k, Wolf E. Mehling f, Alicia E. Meuret J, Charles B. Nemeroff Stephen Oppenheimer m, Frederike H. Petzschner q, Olga Pollatos r, Jamie L. Rhudy c, Lawrence P. Schramm ^{n o}, W. Kyle Simmons ^{a b}, Murray B. Stein ^g, Klaas E. Stephan ^q...

Sensory Subtypes and Anxiety in Older Children and Adolescents with Autism Spectrum Disorder

Mirko Uljarević,* Alison Lane,* Amanda Kelly, and Susan Leekam

This study aimed to identify sensory subtypes in older children and adolescents with Autism Spectrum Disorders (ASD) and examine the relationship of sensory subtypes with anxiety levels in this group. Mothers of 57 children and adolescents with ASD aged 11–17 years (Mean age – 14 years, 2.4 months, SD – 1.81) completed the short sensory purifies and Spence anxiety scales. Model-based cluster analysis was applied to sensory profile some sto identify sensory subtypes. Three sensory subtypes, sensory adaptive (N = 19), sensory moderate (N = 29) and sensory severe (N = 9) were identified. The results indicated that the differences between the subtypes were well characterised by the severity of sensory symptoms and were not attributable to sensory modality or varying types of sensory-selated behaviors. Children and adolescents from the adaptive subtype had adaptionably lover another yours when compared with other two subtypes. There were no differences between subtypes based on chronological age, expressive language, or severtly of autism diagnostic teatures as measured by the social communication questionnaire SCQ (colat score). This is the tiss study to identify the existence of sensory subtypes among older children and adolescents with ASD and explore their association with anxiety levels. Auritsm Res 2016, 9: 1072–1078. © 2016 International Society for Autism Research, Wiley Periodicals, Inc.

Statistically higher rates of:

- Anxiety & depression
- Eating disorders
- · OCD, Tourettes & Tic-disorders
- · Self harm
- Substance addictions
- PTSD
- Chronic pain & Fibromyalgia

People with low interoception can find it hard to self-regulate and attend to the one's physical and emotional

People with heightened sensory reactivity can respond negatively to innocuous stimuli and this this is a specific source of anxiety

Ref

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Autistic adult life expectancy 54 yrs (general pop 70) (with co-occurring intellectual disabilities: 36 yrs)(17)

<u>Leading causes of death:</u>

Epilepsy, Heart disease & Suicide (4-9 x higher rates)

- risk in those with lower support needs... aka "high functioning autism"
- AUtistic children 28 x more likely to consider or complete suicide

Premature mortality & Disease prevalence

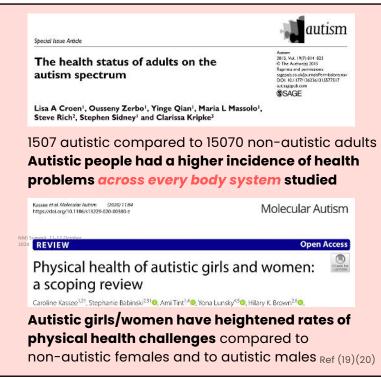
Suicide 9-fold (male 6x, female 13x)

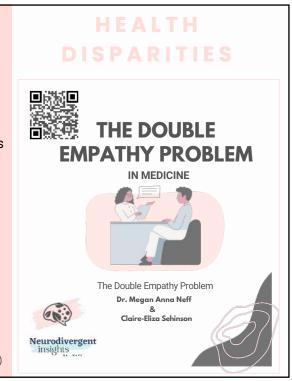
Cancer 2x, Digestive 3.3x, Endocrine 3.5x, Nervous system 7.5x higher in autistic people(8)

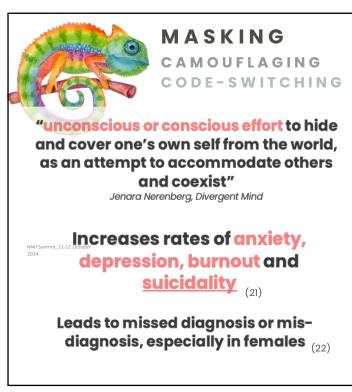
Autistic Doctors International survey: those who considered Autism as a disorder associated w/ higher suicide attempts(18)











- People pleasing "fawning"
- Memorising scripts, rehearsed answers
- Mimicking allistic body language whilst suppressing autistic ones incl. symptoms and pain
- Pretending to have the same preferences or interests as allistic/NT
- Internalised ableism (esp late diagnosed)
- Fixating on social cues and appropriateness > mental exhaustion & shame
- Suppressing stimming
- Hiding sensory discomfort or pain linked to disassociation or use of substances to cope

THE MASKING ICEBERG

well behaved compliant people pleaser helper "high functioning"
"productive"

fun independent easygoing "good girl/boy" model minority

eye contact body language able to speak



feeling too much or too little feeling misunderstood internalised ableism

anxiety related disorders
depression
imposter syndrome
mental health crisis
suicidal ideation

restless or fidgety, symptoms are internalised meltdowns
shutdowns
catatonia
self harm
use of substances & alcohol
to cope

sensory and emotional overload or dysregulation
TRAUMA & PTSD

restricted or binge eating. aversions or sensitivities to food (incl ARFID) chronic illness exacerbated by stress (HPA axis activation)

chronic pain & discomfort

exhaustion, fatigue, burnout

mimicking, rehearsing, memorising scripts, code switching, studying behaviour, supressing traits

lack of belonging / alienation loss of true identity severed relationship with self

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CO-OCCURING MENTAL HEALTH ISSUES

Multiple neurodivergence

50-70% of Autistic people also diagnosed ADHD (5)MI Summit, 11-12 October

OCD: 27.8% meet criteria for Autism + 47% score above clinical threshold up to 35%

girls with *Anorexia nervosa* fit the criteria for autism diagnosis (24)

up to 54.8%

of children diagnosed with ARFID are autistic

50-65%

of autistic adults self-harm (26)

15%

autistic youths self harm ₍₂₇₎

Large population based study found Autistic people have an increased risk of substance-use related problems (28)

Autistic adults suffer from a mental health issue

Report anxiety of which 50% fall into severe category (GAD-7)

Report Depression.
3 out of 10 fall into
severe category
(PHQ-9)

Autistic children
have a mental health
issue (29)

DIAGNOSTIC OVERSHADOWING

Most common misdiagnoses:

- Borderline personality disorder
- Oppositional defiance disorder -in **BIPOC** autistic folx
- · CFS overlaps clinically and can diagnostically overshadow Autism, especially in females.
- Pracs admit feeling unequipped to tease apart ND health consequences and symptoms of complex illness

Refs (20)(48)

Article by Claire Sehinson and Dr Megan-Anna Neff https://neurodivergentinsights.com/blog/autism-and-health-issues

Context is everything for an accurate diagnosis. Accurate diagnosis is everything to get the appropriate support.

Gut issues

Hypermobility/EDS

ARFID & sensory safety

High histamine

Gut microbiome

Obsessive over numbers / exercise

Autonomy

Pyroluria

Trauma

EATING DISORDERS

Centred around dissatisfaction with weight or physical appéarance

Associated with nutritional deficiencies

Unrealistic body ideals or metrics set by trends & rooted in racism (I.e.BMI)

AUTISTIC TRAITS

Attachment to routine or rituals

Food as sensory stimulation (for self regulation)

Sensory or enviroméntal avoidance

Interoception difficulties

Oral-motor challenges

Monotropic interest in food

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AUTISTIC BURNOUT

Characterised by

- 1. Chronic pervasive exhaustion
- 2.Reduced tolerance to stimulus or stress
- 3.Loss of skills

Original Research

"Having All of Your Internal Resources Exhausted Beyond NMI summit, 11-1 Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout

Dora M. Raymaker, PhD,^{1,2} Alan R. Teo, MD, MS,^{3,5} Nicole A. Steckler, PhD,⁶ Brandy Lentz,¹ Mirah Scharer, BS, Austin Dolos Santos, Stoven K. Kapp, PhD,^{2,1} Montigan Hunter, MA,² Andea Joyce, BA,² and Christina Nicolaidis, MD, MPH^{1,2,5,6}

Background: Although autistic adults often discuss experiencing "autistic humout" and attribute serious neg-ative outcomes to it, the concept is almost completely absent from the academic and clinical literature. Methods: We used a community-based participatory research approach to conduct a thematic analysis of 19 interviews and 19 public luternet sources to understand and characterize nutritive humout, interview participants were autistic adults who identified as having been professionally liganced with an autism spectrum condition.

Ref (31)

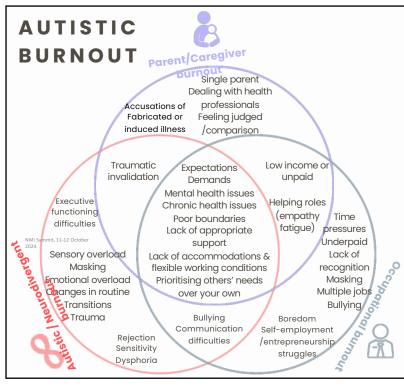
Often mistaken for:

- Depression
- · Bipolar disorder
- · Chronic Fatigue Syndrome



Common characteristics:

- · Chronic fatigue / emotional exhaustion
- No joy in interests
- · Depersonalisation or derealisation
- · Loss of tolerance
- · Loss of abilities (esp EF)
- ↑shutdowns and meltdowns
- · Worsening of mental health issues
- · Changes to eating patterns or food
- · Situational loss of speech "mutism"
- Self harm
- ↑ suicidality
- · Loss of ability to mask



CAUSES of AUTISTIC BURNOUT

- Navigating an allistic world
- Executive functioning demands
- Sensory overstimulation
- Masking
- Life transitions / changes
- People pleasing
- Internalised Ableism & expectations
- Interoception difficulties
- Perfectionism
- AuDHD "paradoxical traits"
- Pervasive unresolved stress cvcles

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TRAUMA AND PTSD

RESEARCH ARTICLE

Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic

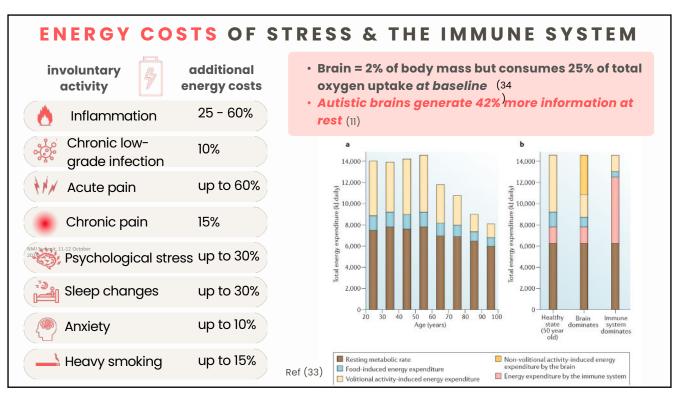
Freya Rumball ¹⁰, Francesca Happé, and Nick Grey

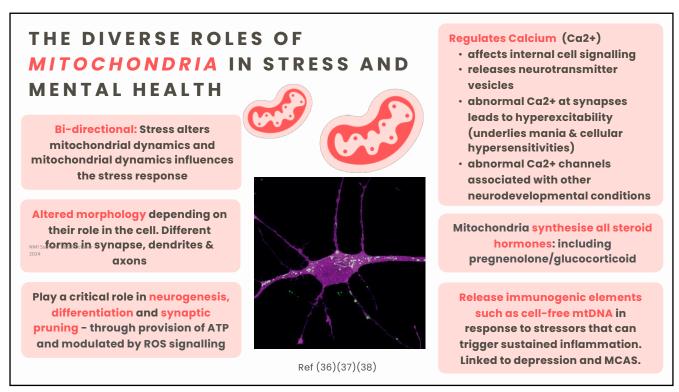
Research to date suggests that individuals with authors exposure to taumatic fife events. It has been posted that characteristics of ASD may affect perceptions of trauma, with a wider range of life events acting a possible catalysts for YSD development. This individuals proceeding the authors of traumatic fife events acting a possible catalysts for YSD development. This individuals of the proceeding of the second process of the proceeding of the proceeding of the process of the pro

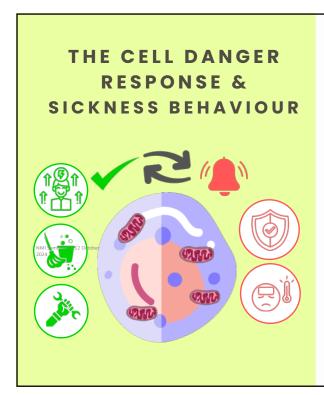
SENSORY TRAUMA Autism, sensory difference and the daily experience of fear . Ref (30)

Ref (35)

Autistic adults experienced a wide range of life events as traumatic. with over showing probable PTSD within the last month and over 60% reporting probable PTSD at some point in their lifetime. life events of the experienced as traumas would not be recognized in some current diagnostic raising concerns that autistic people may not receive the help they need for likely PTSD







- Mitochondria are sensors of 'threat'
- Threats are diverse
- Metabolic changes, immune activation and "Sickness behaviour" occurs:
 - o social withdrawal
 - depression
 - fragmented sleep
 - o increased sensory aversions
 - feeding/eating changes
 - o myalgia, headaches & migraines,
 - fatigue
 - o gastrointestinal issues etc.....
- CDR cannot be switched off until the cell perceives safety
- Continual perception of danger leads to hypersensitisation

Ref (39)(40)

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THE NEED FOR AUTISTIC-**NEUROTYPICAL AUTISTIC** VS AFFIRMING CLINICAL Screen use associated TOOLS Screen use not related to with higher rates of stress, anxiety and depression. anxiety and depression Associated with stressand "internalising reduction and happiness. symptoms" **Atypical responses: Electronic interactions less Electronic interactions** • Medication 78% of autistic viewed as less meaningful that in-person i.e. eye than in-person people had unpleasant contact burden removed response to SSRIs Social media a source of Social media a source of connection to like-minded stress due to comparison individuals, who share · Behavioural interventions: mand pressure to conform niche interests. may be experienced as Screen time mostly spent on Screen use spent on traumatic (45) may increase solitary activities i.e. special interests' and is watching TV and increases loneliness and isolation not related to loneliness in rates of PTSD (46) or isolation • Tendency to increase Removes person from Screen media can provide masking mood-enhancing activities predictability, autonomy i.e. social gatherings, time and comfort. ref (44) outdoors, sleep & exercise

SHORTCOMINGS OF EVIDENCE-BASED PRACTICE IN AUTISM



Focussed on "fixing" and preventing, rather than Autistic wellbeing (47)

"normal" lab ranges not inclusive of all neurotypes

"Autistic" animal models based on the social behaviours of chemically or surgically brain-damaged rodents.

Autistic traits & intentions pathologised - "broken neurotypicals"

Autistic phenotypes stereotyped to ciswhite boys. Lacks diversity (all groups) or cultural understanding of different ethnic groups.



Verbal, facial or physical expression of symptoms may not match the expectations of the provider.

Symptoms invalidated (unintentional gaslighting).

Diagnostic overshadowing common.

Assessment questionnaires & laboratory tests not validated in autistic people.

(Allistic/NT becomes the goal - "normal")

Sensory/interoceptive differences can be pathologized

Communication and executive functioning difficulties not considered or accommodated during intake and when delivering protocols.

Paradoxical reactions to food, supplements, relaxation techniques, mindful eating, tech devices etc

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CASE STUDY

NMI Summit, 11-12 October 2024

Female: 41, Autistic & ADHD, late Dx.

Single parent to 2 ND children, 16 & 18

Occ: Clinical psychologist, NHS. High masking and code-switching at work.

Previous practitioner count: 11!

Seeking help for: chronic fatigue, autistic burnout, ARFID: v.limited food choices due to

digestive pain & sensory issues, sleep difficulties

Co-occurring: Ehlers Danlos, trauma, IBS, Raynauds, POTS, chronic pain

Previous testing/Fx diagnostics - done by prior practitioners:

"mitochondrial dysfunction", mycotoxins present, gut dysbiosis and SIBO, low SIgA, low cortisol awakening, subclinical hypothyroid, multiple food intolerances (to foods *not* in her cultural diet...), low minerals (Mg, Zn, Fe, Cu), low omega-6, suboptimal Vit D, EBV +ve

Mental health and sleep:

Hypervigilant, mental exhaustion, sensitive to external environment

"revenge bedtime procrastination", brain "pinging", hyperfocuses on interests, TV shows 3-4 hrs to get to sleep, wakes easily in night (detects changes in noise levels)

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Gut, Nutrition & Feeding:

Digestive issues: difficulties describing/locating Sx, intense discomfort, feels "poisoned" Exhaustion after eating. Chewing & swallowing tiring, uncoordinated, regurgitates. "Bolts food" as feels full quickly (even w/ water- so doesn't drink enough)

Struggles with morning eating, no appetite, nausea, high EF load Eats lunch at her computer, or on the sofa watching TV - needs screens to regulate No appetite in work canteen or around strangers.

Forgets to eat or drink water

Evenings: uses food to stim - crunchy, salty, sweet. Uses alcohol to regulate.

V. restricted repetitive diet

²⁰Sensory preferences:

Preferences: vegetarian/pescatarian (dislikes meat texture), crunchy, spicy

Aversions: cold food/drinks, lumpy (i.e. oatmeal), fat/oily/slimy (i.e. avocado, mushrooms)

Poor EF: likes cooking, struggles with planning, prep, shopping, chopping & clean-up

Lost joy for cooking and eating

Previous Practitioners & Doctors had put her on: (client's comment)

- · Low histamine diet overwhelming, not compatible w/ Carribean meals, caused more stress
- Low FODMAP diet no guidance, apps are not culturally inclusive, caused isolation
- Gluten, dairy free and blood sugar balancing disliked textures/tastes of alternatives
- Intermittent fasting refused
- Carnivore / Paleo almost stopped eating all together as couldn't handle texture of meat
- Juicing and elemental diets realised she struggles with cold
- "Eat 10 veg a day/30 plants a week" struggles with too many new textures on 1 plate
- Mindful eating get off screens, focus on chewing etc made her more dysregulated
- 'sprinkle green powder on your Jamaican meals' 'drizzle some flax oil' felt culturally insensitive
- Used CGM, Vagus nerve stimulators, Saunas, HRV (oura) etc

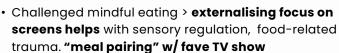
NMIS Supplement protocols: Mitochondrial, Microimmunotherapy, gut healing, MCAS, mould detox, adrenal, viral etc. Nothing has worked, felt "overloaded", becoming hypersensitive to everything.

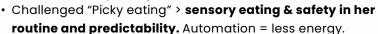
Her experiences: feels more complexly ill than ever, "there is no hope", fantasises about suicide, recovery is exhausting, feels misunderstood, unsure if she has an eating disorder, feels like she's failing, blamed for being non-compliant, trying so hard and struggles with change/forming habits. Has spent tens of thousands £££, diet & chronic illnesses have isolated her from her community/friends/family.

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OUR CONVERSATIONS: FOOD, EATING & SENSORY SAFETY







- No pressure to introduce new foods outside her pace
- Sensory food questionnaire.



- **Reduced overwhelm:** no mixed textures, deconstruct foods. 3 ingredients max
- De-stigmatised food stims
- Optimal eating environment for safety > TV shows / Noislii* app/ Purrble / Loops etc
- **Depathologize/normalise** the use of convenience foods, cooking methods and relying on nutritional supplements
- Oral-motor: foods requiring less chewing w/EDS





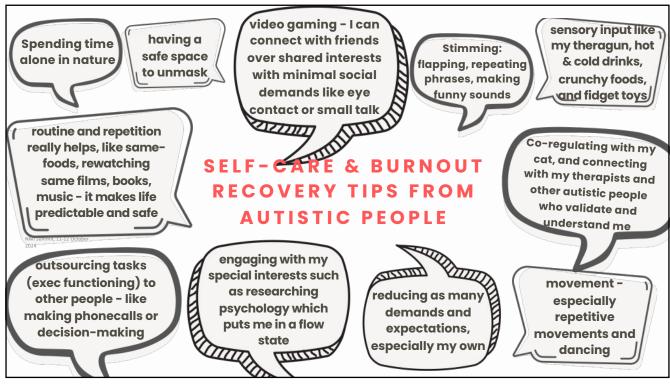




OUR CONVERSATION: EXECUTIVE FUNCTION & COMMUNICATION

- Clarity of instructions no ambiguity, allow additional processing time.
- Alternative communications and descriptors for symptoms, energy levels etc
 (Autism Level Up)
- Outsourcing EF where possible. Asking for help with some tasks and using AI:
 - Reducing overwhelm (no. of steps in self-care tasks & food prep)
 - o Creating shopping lists, meal plans, routines, scripts
 - Interpretation of ambiguous communication
- NMI Sum Using visual and external cueing
 - Looked at her demands and expectations (stemming from societal expectations that become internalised pressures to conform) and what she felt she could release: <u>Shoulds, Wants, Needs exercise</u>
 - Co-created **advocacy scripts** around food, boundaries, disability and identity
 - Connecting to people through her special interests: parallel play

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RESOURCES & FURTHER INFO

Advocacy

The Double Empathy Problem in Medicine - Claire-Eliza Sehinson and Dr Megan-Anna Neff.

All Brains Belong - Advocacy documents, layman explanations of complex health issues in ND

AASPIRE - Autistic lead, community based research, resources & publications (lived experiences)

Further training for practitioners

RDs for Neurodiversity ND-affirming training for nutrition & helping professions

More Than Words - Communication guidelines in healthcare for working with autistic people

Information about neurodivergent health

My blog for articles and advocacy on chronic illness, mental health and resources for ND-folk

Autism and Health Issues Unpacked: Exploring the Intersection of Autism and Chronic Fatique

Syndrome Claire-Eliza Sehinson and Dr Mega-Anna Neff - literature review.

Identification, Assessment, Diagnosis:

Donna Henderson "Is This Autism" accessible

Embrace Autism assessment questionnaires

ND-adapted mental health/self-care resources

Neurodivergent Insights (website) & Self-Care for Autistic People (book) by Dr Meghan Anna Neff The Neurodivergent-Friendly Workbook of DBT **Skills** by Sonny Jane Wise

Interoception Curriculum by Kelly Mahler (includes sensory profiling)

Understanding Autistic Burnout Workbook & support sheets by Dora Raymaker Autistic Masking by Kieran Rose, Dr Amy Pearson **PEACE Pathway Healthcare Communication** passport & other editable resources (i.e. sensory profiling)

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