

# THE PHYSICAL THERAPIST'S ROLE IN SUPPORTING AUTISTIC PATIENTS ACROSS THE LIFESPAN

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[bit.ly/CPTA\\_Autism\\_2023](https://bit.ly/CPTA_Autism_2023)

Autistic Physical Therapist  
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# About me:

Iris Warchall, PT, DPT (she/they)

- Autistic self-advocate
- Parent to Autistic child
- PT with 10 years experience supporting adults with many of the conditions more prevalent among autistic patients:
  - *Hypermobility Spectrum Conditions*
  - *Chronic Pain*
  - *Pelvic Health*
  - *Movement Disorders*
- Continuing education for PT's and others on supporting autistic patients

**Slides, Bibliography,  
Handouts:  
[bit.ly/CPTA\\_Autism\\_2023](https://bit.ly/CPTA_Autism_2023)**

# Objectives

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- Describe autism through the lens of the neurodiversity paradigm
- Discuss ways to mitigate, in physical therapy settings, the common access barriers to health care that autistic individuals encounter
- List common support and referral needs for autistic adults and children
- Discuss the role physical therapists can play in supporting autistic patients across the lifespan

# The role of the physical therapist in supporting autistic patients:

- Destigmatize and affirm autistic experiences and needs
- Make PT care accessible to autistic patients
- Screen and refer for common co-occurring conditions and support needs
- PT support for movement challenges and other conditions
- Advocate for a shift towards neurodiversity-affirming practice within the broader health care community

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# Note on Language: IFL vs PFL

- Identity-first language (IFL) = Autistic person
- Person-first language(PFL) = Person with autism
- The vast majority of autistic adults prefer using identity-first language to describe themselves as they see being autistic as a central part of their identity
- Always use the language your individual patient prefers

# Monk et al. 2022:

Table 1. Practical strategies for replacing potentially offensive terms with autistic-preferred terminology to reduce the stigmatisation, misunderstanding, marginalisation, and exclusion of autistic people

Potentially offensive	Autistic preferred	Insight and perspectives from the autistic community	Example of preferred language use in research
Autism spectrum disorder (ASD)	Autism, autistic	Disorder is unnecessarily medicalised and reinforces negative discourses that autism is wrong or needs curing	'Autism is a neurodevelopmental difference...'
Person-first language (person with autism)	Identity-first language [autistic (person)]	Identity-first language emphasises autism as inseparable from the person and an integral part of their identity, whereas person-first language suggests a separation between autism and the individual	'A total of 125 autistic adults participated in the study.'
Autism symptoms and impairments	Specific autistic experiences and characteristics	Medical terminology pathologises the characteristics and experiences of autistic people as deficient and abnormal	'This study recruited autistic participants with a high sensitivity to sensory stimuli.'
At risk of autism	May be autistic; increased likelihood of being autistic	Danger-oriented terms (vs. probabilistic terms) imply that autism is a negative (possibly preventable) outcome	'Children with an increased likelihood of being autistic were also included in the study.'
Co-morbidity	Co-occurring	Autism is not a disease, even though it often co-occurs with other neurodivergences or medical conditions	'Individuals with co-occurring medical conditions were excluded from the study.'
Functioning (e.g., high/low functioning) and severity (e.g., mild/moderate/severe) labels	Specific support needs	All autistic people have a range of strengths, skills, challenges, and support needs that can vary over time and in different situations and environments	'Individuals with sensory and communication support needs.'
Cure, treatment, or intervention	Specific support or service	Autism does not need to be cured, treated, or modified. Supports should not be targeted at autism characteristics, although autistic people may benefit from individualised supports	'The participants were receiving occupational therapy to reduce sensory overload in those with high sensory needs.'
Restricted interests and obsessions	Specialised, focussed, or intense interests	Deficit-based terminology pathologises the interests of autistic people rather than celebrating their knowledge	'The participant had specialised interests in computers and politics.'
Normal person	Allistic or non-autistic	Allistic is an empowering term that reframes autism and autistic traits as a difference instead of an abnormality	'The comparison group included allistic (non-autistic) people.'

# WHAT DOES THE WORD “NEURODIVERSITY” MEAN?

What about neurodivergent? Neurodiverse? Neurodivergence?



# Neurodiversity

- Refers to the wide range of neurocognitive function present within the human population
- “Our school offers multiple learning strategies to accommodate the neurodiversity of our student body.”



# Neurodiversity paradigm

- Neurodiversity is a natural and valuable form of human diversity.
- “Normal” = Social construct
- Social power inequalities exist between people of majority and minority groups of neurocognitive styles

# Neurodivergent

- Term coined by autistic activist Kassiane Asasumasu
- “**Neurodivergent**, sometimes abbreviated as **ND**, means having a mind that functions in ways which diverge significantly from the dominant societal standards of “normal.””
- *“Our school aims to be inclusive of students who are Autistic, dyslexic, or otherwise neurodivergent, though there are some types of neurodivergence that we’re still seeking ways to accommodate.”*
- **Neurodivergence** = *A particular way of being neurodivergent*

# Examples of neurodivergence

- Autism
- ADHD
- Dyslexia
- Dyspraxia (DCD)
- Cerebral palsy
- Post-CVA
- Anxiety
- Depression
- Post-TBI
- MS
- PD
- Epilepsy
- Tourette's
- Down's syndrome
- PTSD

# Neurotypical

- **“Neurotypical... means having a style of neurocognitive functioning that falls within the dominant societal standards of “normal.”**
- Neurotypical can be used as either an adjective (“He’s neurotypical”) or a noun (“He’s a neurotypical”).”

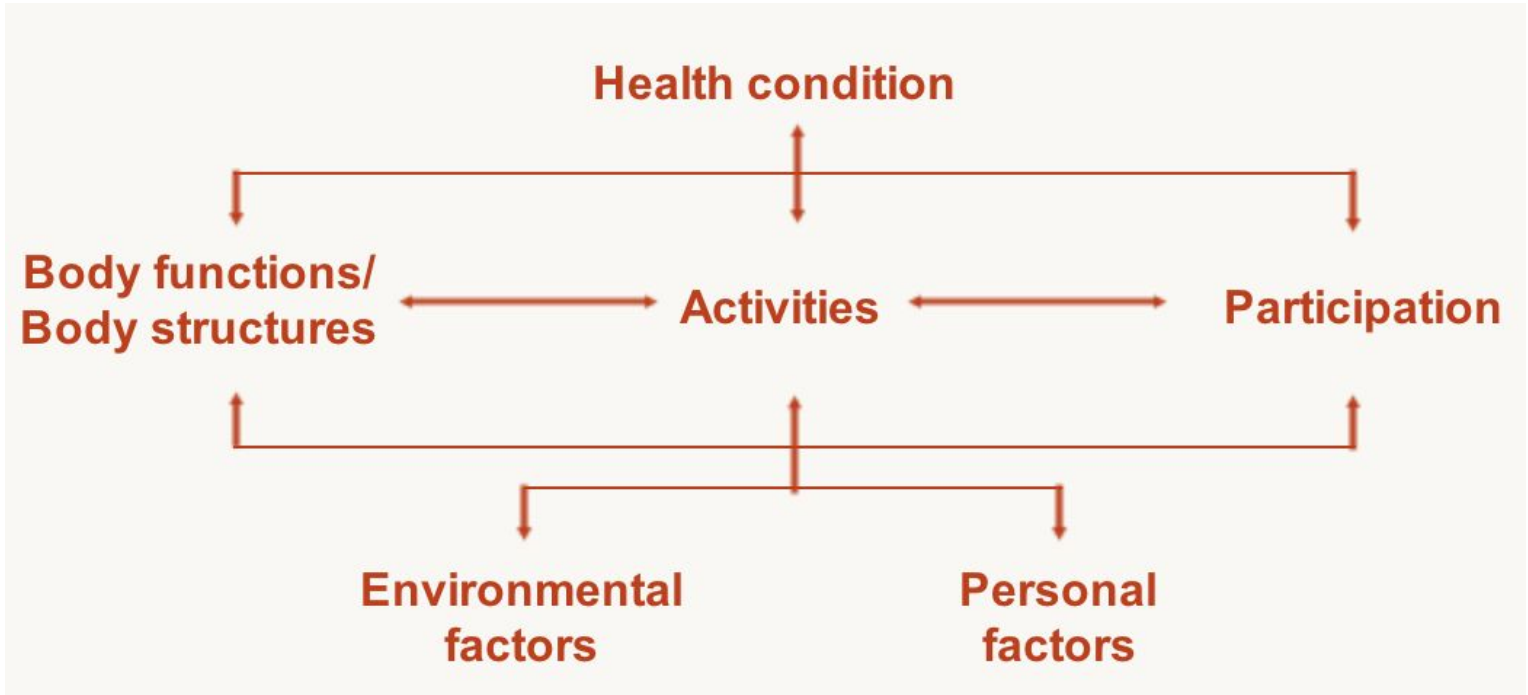
***Food for thought:  
Is “neurotypical” actually the most common  
neurocognitive style?***

# Neurodiversity-affirming practices **align with the principles of the neurodiversity paradigm**

- Neurodiversity is a natural and valuable form of human diversity.
- Normal = Social construct
- Social power inequalities exist between people of majority and minority groups

# ND-affirming care is informed by the **social model of disability**, as opposed to by the **medical model**

- Healthcare professionals are primarily trained through the lens of the medical model of disability:
  - Disability results “from an individual person's physical or mental limitations, and is not connected to the social or geographical environments.
- The neurodiversity paradigm exists within the wider paradigm of the social model of disability:
  - Disability is a consequence of environmental, social and attitudinal barriers that may prevent people from fully participating in society



International Classification of Functioning, Disability and Health

HOW COMMON IS  
AUTISM?

... AND WHAT IS  
AUTISM, ANYWAYS?



# Understanding autism and prevalence: Key themes

- Autism is common, and always has been
- Most autistic patients who have currently reached adulthood are undiagnosed / unidentified
- Autistic people have brain connectivity differences that affect their patterns and rhythms of executive functioning, movement, and sensory processing

# How common is autism?

In US, about 1 in 36 eight year-old children has received an autism diagnosis

<https://www.cdc.gov/ncbddd/autism/data.html>

# How common is autism?

- Common enough that you **ARE** treating autistic patients on a regular basis, regardless of your area of practice!

# DSM-V Criteria

- <https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>

# What is autism?

- Lifelong neurodevelopmental disability
- Brain connectivity differences (notably between basal ganglia, cerebellum, and other brain regions)
- Atypical patterns and rhythms of starting, stopping, and scaling brain functions related to:
  - *Movement*
  - *Executive functioning*
  - *Sensory processing*
- In autistic people, many of these differences in patterns/rhythms tend towards monotropism
  - *At any given time, brain tends towards a smaller number of functions at a higher intensity, leaving fewer resources for other processes, and potentially requiring a longer time to shift to the next set of functions*
- Common co-occurrence: ADHD

Subramanian et al. 2018, Miller et al. 2023, Tripi et al. 2018, Bhat et al. 2020, St. John et al. 2021

# What is autism?

- Generally, clinicians observe functional differences in:
  - *Communication*
  - *Posture and body language*
  - *Interaction with one's sensory environment*
  - *Working/learning styles*

# What is autism?

- For a given person to be considered autistic, that person will experience significant difficulty accessing:
  - *Activities of daily living*
  - *Education*
  - *Employment*
  - *and/or community participation*
- These difficulties arise due to a lack of fit between the individual's neurocognitive style and their social/physical environment

# What is autism?

- Considerable variability of traits from one autistic person to another
- Varying levels of support and/or accommodation needs throughout the lifespan for any given individual



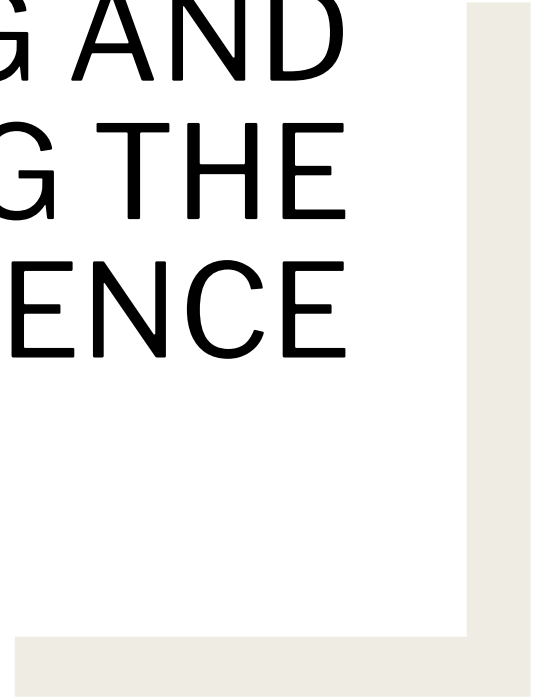
# Nonspeaking autistic people

- Approximately 25% of autistic children are non-speaking
- Non-speaking or non-reliably speaking (i.e. those who have periods of mutism during overwhelm) autistic people benefit from use of Augmented and Assistive Communication (AAC) devices

# Intellectual Disability

- ~20-35% of autistic people diagnosed with ID, as compared to ~2% of general population
- One study found increase of 30-70 IQ points when a more appropriate cognitive assessment was used
- Question: Do traditional IQ assessments accurately capture cognitive function in autistic people with more significant motor control and communication challenges?
- **Presume competence!!!!**

# DESTIGMATIZING AND AFFIRMING THE AUTISTIC EXPERIENCE



# Learn about autism from autistic people

- Seek out perspectives of autistic people with a diverse variety of types and levels of support needs, racial / ethnic / socioeconomic backgrounds
- Handout: **Online Support Resources for Autistic Patients and Families/Caregivers**
- [https://iriswarchall.com/\\_recommendedreading/](https://iriswarchall.com/_recommendedreading/)

# Decreasing stigma: Key themes

- Autism is a difference in brain connectivity that can result in disability
- Autism is not a disease and as such does not need to be treated or cured
- Autistic communication differences are differences (that need understanding and accomodation), not deficits
- Stimming is functional, not pathological
- Many autistic traits have motor components. The PT profession is particularly well equipped to understand and explain to help reduce stigma associated with these traits.
- Masking / camouflaging autistic traits is linked to negative mental health outcomes

# Implicit bias

- First impressions of videos of autistic people compared to controls:
  - *Far less favorable*
  - *Viewers had reduced intentions to pursue social interaction*
- Biases disappear when impressions are based on transcript without video/audio, suggesting that motor differences drive negative impressions

# Q: What is stimming?

## A: Functional!

- “...any **action** that falls outside the boundaries of the social performance of normativity, and that **provides some form of sensory stimulation in order to facilitate**, intentionally or otherwise, **some particular cognitive or sensorimotor process, or access to some particular state or... experience.**”
- Self-regulatory mechanism

# Stimming

- Both noun and verb
- Forms of stimming include:
  - *Proprioceptive*
  - *Tactile*
  - *Vestibular*
  - *Visual*
  - *Auditory*
  - *Olfactory or gustatory*
  - *Verbal*
  - *Any combination of the above*

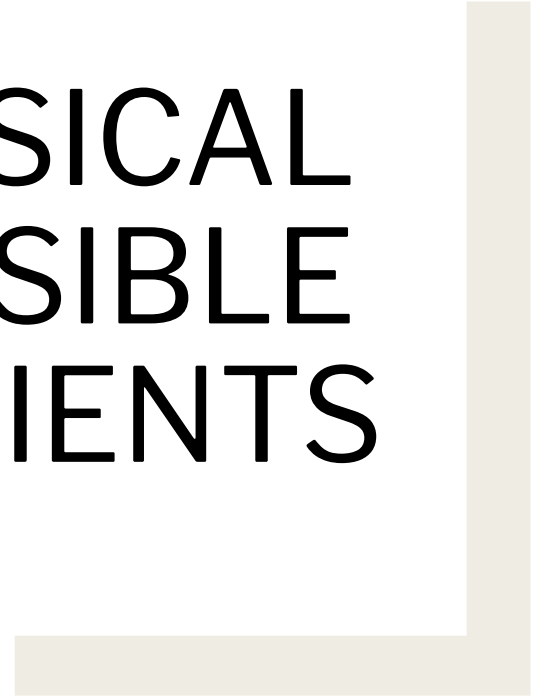


# Masking/camouflaging autistic traits

- Camouflaging may include:
  - *hiding behaviours associated with autism*
  - *using explicit techniques to appear socially competent*
  - *finding ways to prevent others from seeing social difficulties*
- Camouflaging associated with:
  - *Exhaustion*
  - *Threats to self-perception (who AM I, even?)*
  - *Anxiety*
  - *Depression*
  - *Suicidality*

Hull et al. 2017, Hull et al. 2021, Cassidy et al. 2020

# MAKING PHYSICAL THERAPY ACCESSIBLE TO AUTISTIC PATIENTS



# Accessibility: Key Themes

- Autistic people commonly encounter barriers to accessing healthcare, and we can mitigate these barriers in PT settings
- Domains of barriers:
  - *Provider knowledge and practices*
  - *Sensory*
  - *Communication*
  - *Executive functioning*

# Barriers to Primary Care

- Provider knowledge and practices
  - *Knowledge about autism*
  - *Ability to have individualized care and patient/professional partnerships*
- Communication
  - *Difficulty communicating with HCP*
  - *Not feeling understood*
  - *Difficulty making appointments by telephone*
- Sensory input
  - *Waiting room and clinic*
- Logistics / Executive Functioning
  - *Deciding if symptoms warrant a visit*
  - *Scheduling logistics*
  - *Cost*
  - *Transportation*
  - *Wait time*

# Resources: Mitigating Access Barriers

- More than Words Guidelines
- Autistic SPACE Guidelines
- AASPIRE Toolkit

# Universal Design: Sensory

- Avoid:
  - *Fluorescent lights*
  - *Loud background noise – ask patient preference regarding music in clinic*
  - *Crowded spaces (esp with multiple voices)*
  - *Scents/fragrances*
  
- Consider the sensory effect of your physical presence:
  - *Posture/seating arrangements and personal space*
  - *Eye contact (don't force, and don't be put off if patient does not reciprocate eye contact)*
  - *Handshakes, etc (best to avoid unless initiated by patient)*
  - *ALWAYS ask permission prior to touching patient*
  - *ALWAYS explain purpose of touching patient*
  
- May be helpful to provide:
  - *Stim/fidget toys*
  - *Space to move while communicating*
  - *Variety of white noise options*
  - *Variety of seating options*

# Interoception

- The ability to register internal bodily sensations (hunger, thirst, bowel and bladder urges, overheating, fatigue, illness, pain, emotion, etc)
- Many autistic people have differences in interoception
  - *Can under-register certain sensations (examples: tendency to become “hangry”)*
  - *Can register many sensations at once and have difficulty prioritizing/filtering*
  - *Can hyper-register certain sensations (example: urinary urgency/frequency, pain)*

# Alexithymia

- Interoceptive challenges of registering and identifying emotions
- May influence:
  - *Subjective reporting of emotional states*
  - *Ability to register and communicate distress*
- Common in neurodivergent people
- Important to consider as part of trauma-informed care
  - *Watch for bodily signals of distress (increased respiratory rate, mm tension, anxious stims) as signs to hold off or discontinue even if patient states they consent to an intervention*



# Universal Design: Executive functioning

- Let patients know the purpose/plan for the appointment ahead of time
- Provide options to schedule and complete intake paperwork online, via phone, or in-person
- Provide option to communicate with PT online or via phone between appointments
- Appointment reminders- options for phone/email/text
- Offer first or last appointment of the day if patient desires

# Universal Design: Executive Functioning

- Discuss plan for session at the beginning of session
- Regularly pause to explicitly communicate opportunities for patients to ask questions
- Provide reminders for time left in session
- Point out upcoming transition between activities in session a few minutes beforehand
- Summarize (verbally, and in writing/pictures) what was learned during the session at the end of the session

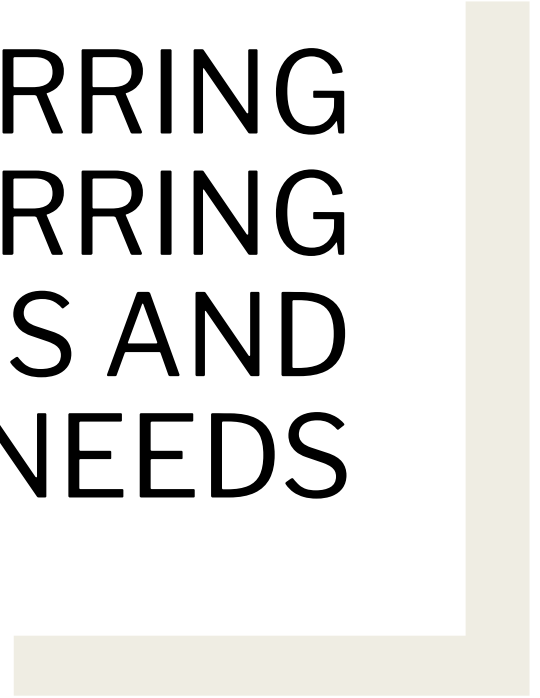
# Universal Design: Executive Functioning

- HEP and Education Materials
  - *Pictures/Videos*
  - *Clear, concise language*
  - *Apps are great to provide reminders and track progress, less easy to lose*
  - *Consider that some patients do prefer paper, may have sensory or EF challenges with screens/devices*
  - *Some patients may benefit from “body doubling” support from a loved one, caregiver, or friend*

# Universal Design: Communication

- Consider any patient could be autistic
- Adapt sensory environment
- Consider interoceptive challenges
- Create reliable, predictable environment
  - *Support single-focused attention*
- Be alert to situational mutism
- Support AAC use
- Double empathy problem
- Pay attention to content, not facial expression/body language
- Trauma-informed approach
- Variety options for making appointments

SCREENING / REFERRING  
FOR CO-OCCURRING  
CONDITIONS AND  
SUPPORT NEEDS



# Screening and Referring: Key Themes

Screen and refer for:

- Unmet sensory, communication, ADL support needs
- Health needs of hypermobile patients
- Mental health conditions
- Other systemic conditions more prevalent among autistic people

# Developmental Disability Support

- CA resources for coordination and implementation of developmental disability supports/services
- Information:
  - [Regional Centers](#)
  - [IHSS](#)
    - For those with Medi-CAL eligibility determination, support to live at home instead of at out-of-home placement like nursing home, board and care facility

# Sensory and Communication Needs

- Occupational Therapy
  - *Understand sensory needs*
  - *Fine (and gross) motor development, accommodations / adaptive devices*
  - *Feeding*
- Speech Therapy
  - *Communication (oral, AAC)*
  - *Feeding*
  - *Executive functioning*



# hEDS/HSD and Neurodivergence

- Significant relationship between autism and hypermobility
  - *Autism and hEDS-co-occur more often than expected by chance*
  - *hEDS/HSD associated with ADHD, tic disorders such as Tourette syndrome, and autism*
- Much overlap in traits and co-occurring conditions between autism and hEDS/HSD

# Ehlers-danlos syndromes: EDS

- The Ehlers-Danlos syndromes (EDS) are a group of hereditary disorders of connective tissue that are varied in the ways they affect the body and in their genetic causes.
- EDS patients may present with:
  - *Joint hypermobility/instability/subluxations/dislocations*
  - *Scoliosis and other joint deformities*
  - *Skin hyperextensibility (skin that can be stretched further than normal) and abnormal scarring*
  - *Hernias and organ prolapse through the pelvic floor*
  - *In the rarer types of EDS, there is also weakness of specific tissues that can lead, for example, to major gum and dental disease, eye disease, cardiac valve and aortic root disorders, and life-threatening abdominal organ, uterine, or blood vessel rupture. ”*

<https://www.ehlers-danlos.com/what-is-eds/>

# hEDS/HSD: co-occurring conditions

- Aortic and other aneurysms
- Hernias
- Pelvic organ prolapse
- Postural orthostatic tachycardia syndrome (POTS)
- Mast cell activation syndrome (MCAS)
- Chronic fatigue
- Upper cervical spine instability
- Chiari malformation
- CSF leaks
- Tethered cord

# hEDS/HSD/EDS diagnosis

- EDS subtypes usually diagnosed by medical geneticist, sometimes by cardiologist, rheumatologist, or other specialist
  - *Some PCP's knowledgeable in supporting hEDS/HSD*
- Screening for hEDS/HSD/EDS as a physical therapist:
  - *Become familiar with the types of EDS and diagnostic criteria for hEDS/HSD*
  - *Hypermobility screening tools (Beighton, other)*

# Potential referral needs for hypermobile patients

- Geneticist
- Rheumatologist
- Cardiologist
- Allergist
- Neurosurgeons: Chiari, upper cervical instability, CSF leaks, tethered cord
- Gastroenterologist
- Urologist/Urogynecologist

# Other conditions more prevalent among autistic people

- Autoimmune conditions
- Epilepsy/seizures
- Parkinson's disease\*
- Osteoporosis\*
- Cognitive disorders\*
- Heart disease\*
- Cancer\*
- Cerebrovascular disease\*
- Osteoarthritis\*

\* in older adults

# Resource for neurodivergent patients and their PCP's

- <https://allbrainsbelong.org/all-the-things/>

# Mental health conditions

- Autistic Burnout
- Depression
- Anxiety
- Suicidality
- Substance abuse
- Eating disorders
- Hx of sexual, physical, or emotional abuse
- PTSD

*Raymaker et al. 2020, Hudson et al. 2018, Nimmo-Smith et al. 2020, Kolves et al. 2021, Nickel et al. 2019, Lobregt-van Buuren et al. 2021*





# Autistic Burnout

- Primary characteristics of autistic burnout:
  - *chronic exhaustion,*
  - *loss of skills,*
  - *and reduced tolerance to stimulus.*
- Participants described the following as helping them recover:
  - *acceptance and social support,*
  - *time off/reduced expectations,*
  - *and doing things in an autistic way/unmasking*
- **Autistic burnout appears to be a phenomenon distinct from occupational burnout or clinical depression.**

PHYSICAL THERAPY  
SUPPORT FOR MOVEMENT  
AND OTHER RELATED  
CONDITIONS



# Direct PT Support: Key Themes

- Developmental movement challenges
- Musculoskeletal and chronic pain
- Pelvic health
- Movement disorders
- Integumentary
- Functional limitations associated with neurologic, cardiovascular, autoimmune, autonomic, other systemic conditions

# ALL autistic people experience motor developmental differences to one degree or another

- Developmental Coordination Disorder / Dyspraxia
- Developmental differences in tone
- Balance, gait challenges
- Tics/Tourette's
- Differences in posture, body language, facial expressiveness, tone/rhythm of voice

# Pediatrics

- Sensory, EF, and communication accessibility
  - *Children*
  - *Parents/caregivers*
- Collaboration with OT and SLP
  - *Matching AAC with motor skills*
- Support educational access
- Educate families, guide towards ND-affirming supports

# Neurodivergence and chronic pain

- 76% report chronic pain, 32.5% report chronic widespread pain
- Significantly more likely to have musculoskeletal pain as compared to a control group

Aztely et al. 2019, Csecs et al. 2022

# Bowel and bladder

- Prevalence range for constipation was 4.3-45.5% (median 22%), for diarrhea was 2.3-75.6% (median 13.0%)
- Over 2/3 reported urinary incontinence, 1/3 reported fecal incontinence

# EDS/HSD

- Musculoskeletal
- Pelvic Health
- Dysautonomia
- Integumentary



# Other acquired conditions supported by PT

- Cancers
- Sequelae of cardiovascular/cerebrovascular disease
- Osteoporosis
- Autoimmune conditions
- Parkinson's disease

# ADVOCATING FOR A SHIFT TOWARDS NEURODIVERSITY-AFFIRMING PRACTICES



Autistic Physical Therapist  
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# Advocating within the PT profession, and beyond

- Guide others towards learning from autistic individuals:
  - *Autistic-led research*
  - *Books, media published by autistic authors*
- Educate others on how motor disability contributes to many observed autistic traits
- Collaborate with other allied health professionals trained in ND-affirming supports (OT's, SLP's, mental health clinicians)
- Advocate for autistic people of all ages to receive individualized supports to address needs
  - *Question practices that teach autistic individuals to prioritize compliance or masking/camouflaging above meeting their access needs*
  - *Question practices that aim to “treat autism”*

# Develop the following network of ND-affirming providers and supports

- OT
- SLP
- Psychotherapy
- PCP
- RD/Nutrition
- Neurology
- Psychiatry
- Physicians with knowledge/specialty in hypermobility spectrum conditions
- Online autistic-led resources/groups
- In-person autistic-led support groups

Thank you!  
Let's keep the  
conversation  
going.

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