Mass General Brigham

Healthcare Equity and Access Concerns in Autism

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Wednesday, May 21, 2025

About Me

EDUCATION & ACADEMIC TRAINING

Massachusetts General Hospital for Children, Boston MA
Pediatric Gastroenterology and Nutrition Fellow, *anticipated June 2026*

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Combined Internal Medicine/Pediatrics Residency

Tufts University School of Medicine, Boston, MA
Doctor of Medicine, *Honos Civicus Society*

Smith College, Northampton, MA
Bachelor of Arts, Biochemistry, *cum laude, highest departmental honors*

About Me

I love someone with autism

This is my brother, Payam

Disclosures

I have no financial disclosures or conflicts of interest with the presented material

The views and opinions expressed in this webinar are my own and do not necessarily reflect those of my organization.

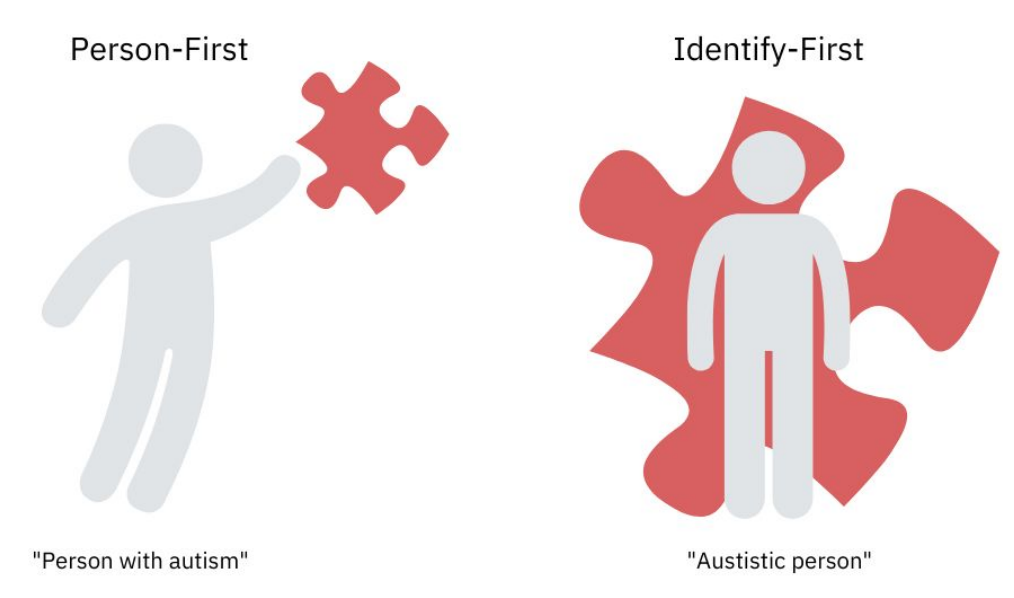
Trigger/Content Warning

This webinar will discuss sensitive and challenging topics, including discrimination, eugenics, and historical injustices.

Please take care of yourself and step away if needed.

Disclosures

Words matter



In this presentation, I will be using person-first language as it reflects the preference and experience of my family.

However, I understand that some individuals may prefer identity-first language.

If you are unsure about which language to use, please feel free to ask. Your understanding and respect for individual preferences are appreciated.

Disclosures

Discussions on autism and healthcare equity are shaped by a rapidly changing political and social climate. Policies and protections vary widely by state and continue to evolve. This presentation may not reflect the most current or local developments. **We encourage continued awareness and advocacy.**

First, some historical context

This is just the tip of the iceberg—disability studies is a vast and evolving field.

Understanding this history helps explain how we've arrived at current approaches to autism and healthcare equity.

First, some historical context

Early years:

- Between 1907-1939, 32 states passed laws allowing forced sterilization of individuals in state institutions deemed "unfit" to parent
- In 1927, the Supreme Court ruled in Buck v. Bell that state-enforced sterilization of individuals deemed “feeble-minded” was constitutional, reinforcing eugenics policies

Reilly, P. R. (2015). Eugenics and involuntary sterilization: 1907–2015. Annual review of genomics and human genetics, 16(1), 351-368.

First, some historical context

In 1943, Leo Kanner published the first systematic description of early infantile autism.

In 1950, The Arc (originally the Association for Retarded Citizens) was founded by parents of children with intellectual disabilities.

- *Note*: The term "retarded" was once commonly used but is now considered outdated and offensive. The organization has since changed its name to reflect respectful and current language.

In the 1950s–60s, the “refrigerator mother” theory grows, falsely blaming autism on cold, unloving parenting and advocating for “parent-ectomies”

Harris, J. (2018). Leo Kanner and autism: a 75-year perspective. International review of psychiatry, 30(1), 3-17.
https://thearc.org/about-us/history/
Crowell, J. A., Keluskar, J., & Gorecki, A. (2019). Parenting behavior and the development of children with autism spectrum disorder. Comprehensive psychiatry, 90, 21-29.

First, some historical context

Civil Rights Movement (1964):

- Outlawed discrimination based on race, color, religion, sex, or ethnicity
- Included healthcare facilities that receive federal funding
- Notably, did NOT include disability status

In 1969, Judy Heumann was denied a teaching license in NY due to her use of a wheelchair, prompting her to file a lawsuit and later help found Disabled in Action (DIA), a leading disability rights organization.

https://www.archives.gov/milestone-documents/civil-rights-act#:~:text=Despite%20Kennedy's%20assassination%20in%20November,theaters%2C%20restaurants%2C%20and%20hotels.
https://www.schools.nyc.gov/learning/subjects/social-studies/hidden-voices/contentdetails/hidden-voices/2024/05/20/how-judith-heumann-became-the-mother-of-the-disability-rights-movement

First, some historical context

Section 504 of the Rehabilitation Act (1973)

- The first federal law protecting people with disabilities, banning discrimination in programs receiving federal funding
- After delays in enforcing Section 504, Judy Heumann helped lead the 504 Sit-In at a San Francisco federal building in 1977—the longest nonviolent occupation of a federal building in U.S. history

In 1980, diagnostic criteria for “infantile autism” was included for the first time in DSM-III.

https://www.dol.gov/agencies/oasam/centers-offices/civil-rights-center/statutes/section-504-rehabilitation-act-of-1973
Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: From Kanner to DSM-III to DSM-5 and beyond. Journal of autism and developmental disorders, 51, 4253-4270.

First, some historical context

The Americans with Disabilities Act (ADA) of 1990 prohibits disability discrimination in most public and private spaces, including jobs, schools, transportation, and businesses.

In 1994, diagnostic criteria for autism as a spectrum disorder was updated in the DSM-V.

In 1998, a since-retracted *Lancet* study falsely links the MMR vaccine to autism, fueling widespread vaccine mistrust and straining relationships between parents and providers.

https://www.ada.gov/topics/intro-to-ada/
Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: From Kanner to DSM-III to DSM-5 and beyond. Journal of autism and developmental disorders, 51, 4253-4270.
https://www.chop.edu/vaccine-education-center/vaccine-safety/vaccines-and-other-conditions/autism

First, some historical context

In 1997, Judy Singer (an Australian sociologist) was credited with coining the term “neurodiversity” while completing her honors thesis.

In 2000, the CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to track and report prevalence data.

The Autism CARES Act (2014) replaced the earlier Combating Autism Act (2006), shifting from a focus on curing autism to a more inclusive approach emphasizing lifespan services, support, and equity. It has been regularly reauthorized, most recently in 2024, and continues to fund federal efforts through the NIH, CDC, and HRSA.

https://www.theguardian.com/world/2023/jul/05/the-mother-of-neurodiversity-how-judy-singer-changed-the-world
https://www.cdc.gov/autism/addm-network/sites.html
https://iacc.hhs.gov/about-iacc/legislation/autism/cares-act-2019/

Current state of things

In 2024, Title II of the ADA added clear protections requiring state and local governments to provide equal access to their services and programs for people with disabilities, preventing discrimination and ensuring accessibility.

Despite overwhelming scientific evidence disproving any link between vaccines and autism, some public figures and organizations continue to promote this false narrative, fueling vaccine hesitancy, public mistrust, and harmful stigma around autism.

https://www.mass.gov/info-details/americans-with-disabilities-act-ada-title-ii-digital-accessibility-information-and-requirements#:~:text=Americans%20with%20Disabilities%20Act%20Title%20II,-What%20is%20the&text=The%20ADA%20guarantees%20equal%20opportunity,local%20government%20services%2C%20and%20transportation.

Onwards…

Models of disability

Medical Model

- Views autism as a disorder to be diagnosed and treated
- Focuses on symptoms, deficits, and “fixing” behaviors

Social Model

- Sees autism as a natural variation of brain development
- Attributes challenges to societal barriers
- Emphasizes changing environments and attitudes for inclusion

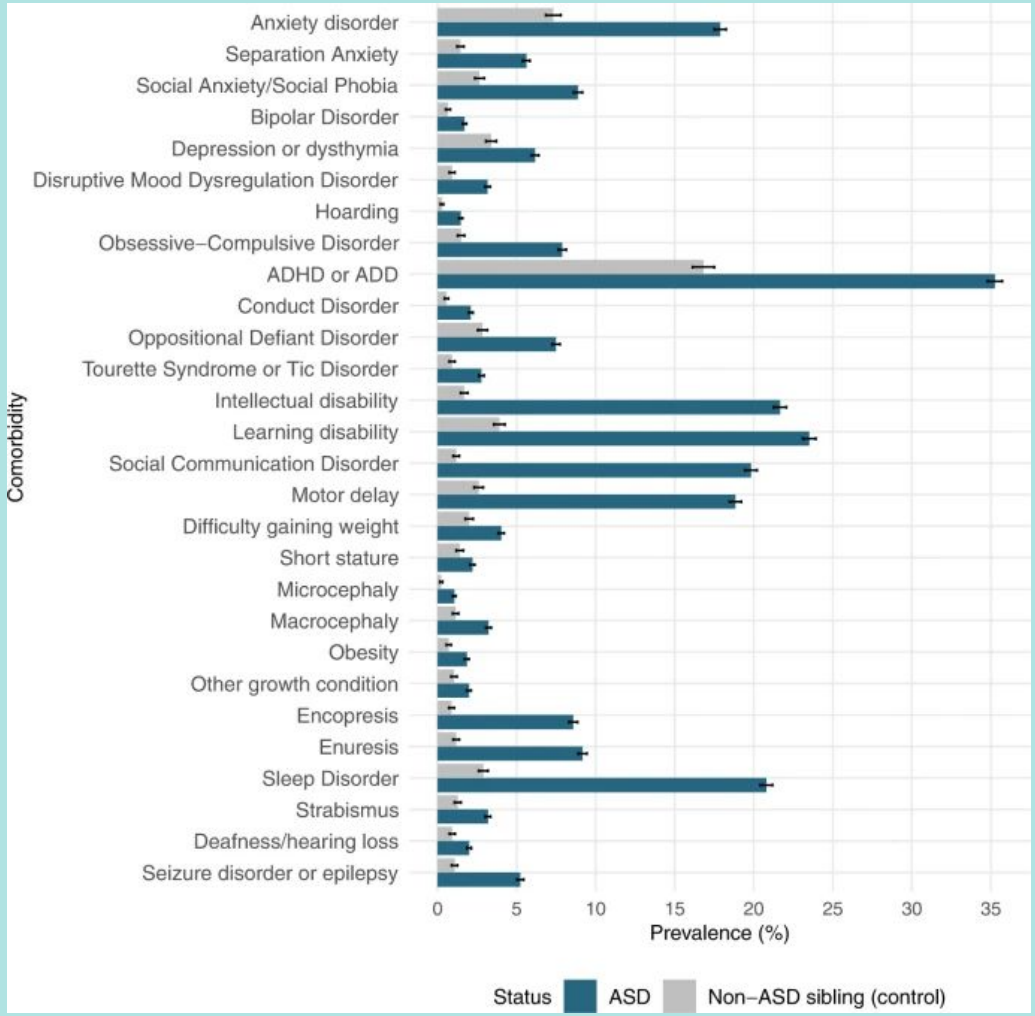
Models of disability

Biopsychosocial Model

- Recognizes that autism is influenced by brain development (biology), individual behaviors and emotions (psychology), and societal context (social)
- Encourages a personalized approach to support that considers medical needs, mental health, and environmental adaptations
- Supports collaboration among healthcare providers, educators, families, and communities to address the full range of needs

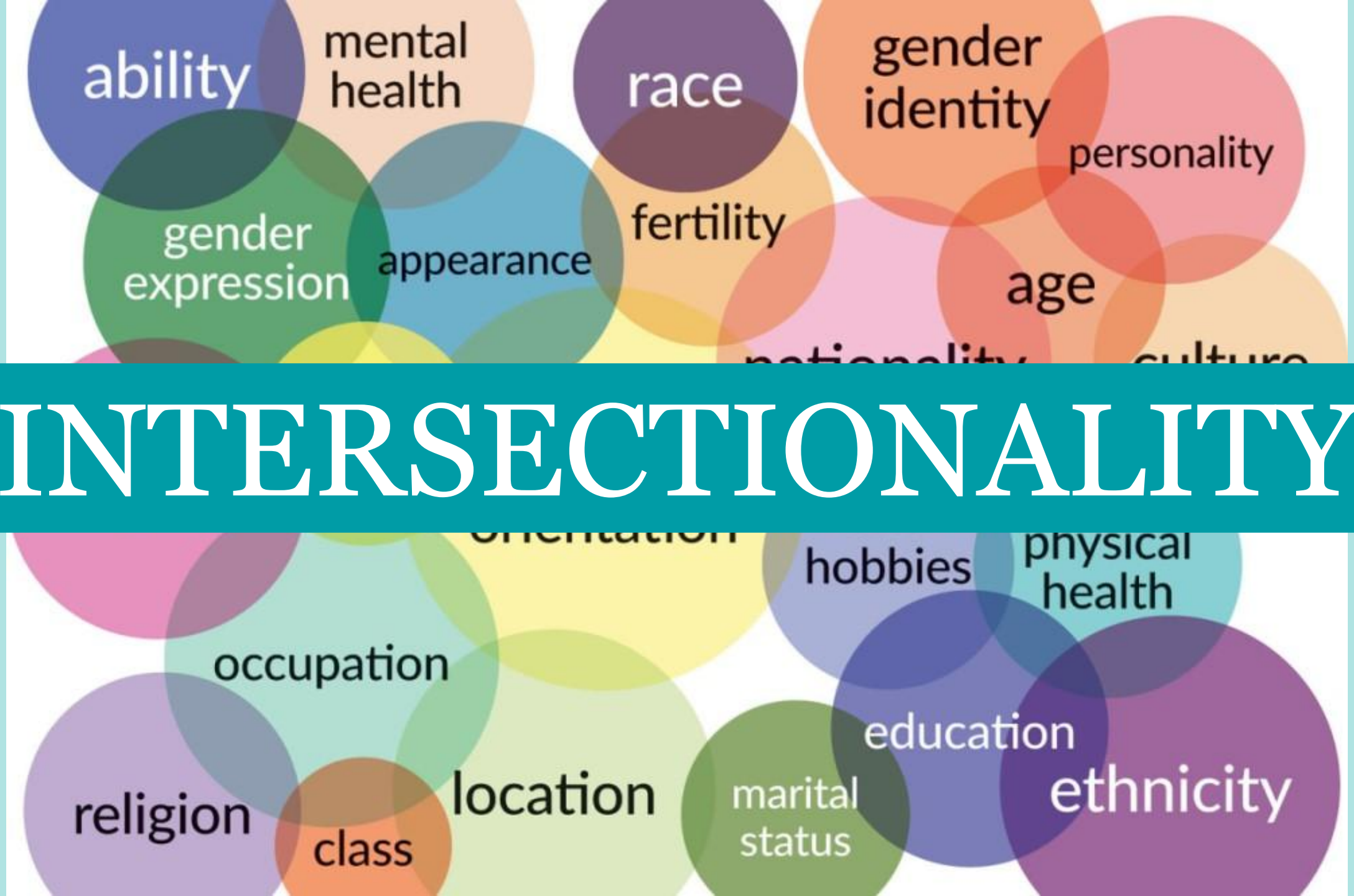
ASD comorbidities

- Genetic conditions (ex: Fragile X, tuberous sclerosis)
- Intellectual disability -> very difficult to assess, estimated ~30%
- Seizure disorders
- Other neurologic conditions
- Psychiatric disorders (e.g. ADHD, anxiety, depression, OCD)
- Gastrointestinal disorders
- Autoimmune conditions
- Sleep disturbances



Doshi-Velez, F., Ge, Y., & Kohane, I. (2014). Comorbidity clusters in autism spectrum disorders: an electronic health record time-series analysis. Pediatrics, 133(1), e54-e63.

Khachadourian, V., Mahjani, B., Sandin, S., Kolevzon, A., Buxbaum, J. D., Reichenberg, A., & Janecka, M. (2023). Comorbidities in autism spectrum disorder and their etiologies. Translational Psychiatry, 13(1), 71.



INTERSECTIONALITY

Who is effected?

Sex:

Male predominance (4:1) -> although concern for female masking/camouflaging

Gender:

High prevalence of gender fluidity & dysphoria

Race:

Historically, overall ASD prevalence among White children was 50% higher than among Black or Hispanic children

While ASD prevalence in white children rose 14.6% from 2018 to 2020, it increased by more than 30% in Asian, Black and Hispanic 8-year-olds -> Believed to reflect improved screening, awareness, and access to services among historically underserved groups

Maenner, M. J. (2023). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020. MMWR. Surveillance Summaries, 72.
Alaghband-Rad, J., Hajikarim-Hamedani, A., & Motamed, M. (2023). Camouflage and masking behavior in adult autism. Frontiers in psychiatry, 14, 1108110.
Kallitsounaki, A., & Williams, D. M. (2023). Autism spectrum disorder and gender dysphoria/incongruence. A systematic literature review and meta-analysis. Journal of Autism and Developmental Disorders, 53(8), 3103-3117.

Accessing primary care services

80% of autistic adults report difficulty accessing a GP (vs. 37% of non-autistic adults)

Top barriers:

- Uncertainty about when to seek care
- Phone-based booking systems
- Communication challenges, & feeling misunderstood by providers
- Sensory overload in waiting rooms

Doherty, M., Neilson, S., O'Sullivan, J., Carravallah, L., Johnson, M., Cullen, W., & Shaw, S. C. (2022). Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study. BMJ open, 12(2), e056904.

Accessing primary care services

Consequences:

- Missed screenings and referrals
- Untreated conditions, often resulting in need for more intensive treatment

Autism-specific accommodations (e.g., text-based booking, quiet spaces) are essential—as vital as ramps for wheelchair users

Doherty, M., Neilson, S., O'Sullivan, J., Carravallah, L., Johnson, M., Cullen, W., & Shaw, S. C. (2022). Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study. BMJ open, 12(2), e056904.

Three major barrier categories identified:

Individual

- Increased health needs
- Communication challenges
- Poor transition support

System

- Limited provider knowledge
- Poor care coordination
- Stigma and lack of transparency

Environment

- Sensory overload
- Uncertainty around care
- Difficulty using phone systems

Calleja, S., Islam, F. M. A., Kingsley, J., & McDonald, R. (2020). Healthcare access for autistic adults: A systematic review. Medicine, 99(29), e20899.

Systematic Review and Meta-Analysis

Medicine®

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Healthcare access for autistic adults

A systematic review

Shenae Calleja, BHSc (Hons)*, Fakir M. Amirul Islam, BSc (Hons), MSc (JU), MApp Science (CQU), PhD (UQ), GradCertTeachLearn(HEd), Jonathan Kingsley, BScApp, BAppHSc (Hons), MHort, PhD, Rachael McDonald, BAppSc(OT), GCHE, PGDip(Biomech), PhD

Abstract

Background: People with autism spectrum disorder (ASD) have an increased susceptibility for many chronic health conditions compared with their peers. An increasing number of adolescents are transitioning from pediatric to adult healthcare services. Thus, being able to access appropriate healthcare services that can not only address specific needs of the person but enable them to better manage healthcare conditions and decrease the development of preventable disease is necessary. A systematic review was conducted to identify barriers and enablers of healthcare access for autistic adults.

Methods: The studies included in the review were quantitative and qualitative and were published between 2003 and 2019. The participants for the review are considered to be adults (over 18 years of age) with a primary diagnosis of ASD.

Results: In total, 1290 studies were initially identified and 13 studies were included based on the inclusion and exclusion criteria outlined in a previous protocol paper. The analysis of these studies identified areas of concern to access appropriate healthcare, such as clinician knowledge, the environment, and life events.

Conclusion: Identifying the barriers to healthcare, highlights ways healthcare services can regulate scope of practice, the physical environment, and the process of managing health conditions, thus, autistic adults can strive for optimal health. This review contributes to peer-reviewed evidence for future research and up-to-date information when developing and piloting health interventions for autistic adults.

Ethics and dissemination: There are no human participants, data, or tissue being directly studied for the purposes of the review; therefore, ethics approval and consent to participate is not applicable.

Registration and Status: PROSPERO 2018 CRD42018116093

Abbreviations: ASD = autism spectrum disorder, MMAT = mixed methods appraisal tool.

Keywords: adults, autism spectrum disorder, barriers, enablers, healthcare access

Research in Autism Spectrum Disorders 105 (2023) 102165

Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd

All-cause and cause-specific mortality in people with autism spectrum disorder: A systematic review

Laurence Forsyth [a], Marc McSorley [a], Ewelina Rydzewska [a,b,*]

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ARTICLE INFO

Keywords:
Autism spectrum disorders
All-cause mortality
Cause-specific mortality
Systematic review

ABSTRACT

Background: The aim of this systematic review was to synthesise the current literature on all-cause and cause-specific mortality in individuals with autism spectrum disorders (ASD) to identify whether they experience an increased risk of mortality compared to the general population and to establish which specific causes of death are most prevalent in people with ASD.
Method: Medline, Embase, CINAHL and PsycINFO databases were searched. The review was registered with PROSPERO (CRD42021219582).
Results: 26 of the 8505 retrieved papers were included. 25 studies reported an increased risk of mortality for people with ASD. Out of 21 studies reporting the relevant statistics, 15 found autistic individuals to have at least a two times higher risk of dying when compared to the general population. 11 studies suggested that females with ASD were at an even greater risk of death when compared to their male counterparts. The most common causes of deaths were from external causes (particularly suicide) and neurological disorders.
Conclusions: Recognising the increased mortality experienced by people with ASD is an important factor in how clinicians, support workers and healthcare systems in general should plan and approach care for this population. Although a significant portion of deaths in this group occurs due to intentional or unintentional external causes, the reviewed literature also indicates that many people with ASD die from underlying health conditions. As the increased mortality risk seems to be partially mediated by the co-occurrence of other conditions, it is of great importance to provide an increased level of support and care for this population.

Individuals with ASD have 2–10x higher mortality than the general population

Leading contributors:

- Epilepsy and seizures
- Suicide and accidental deaths
- Chronic medical conditions (e.g., cardiovascular, gastrointestinal, and respiratory issues)

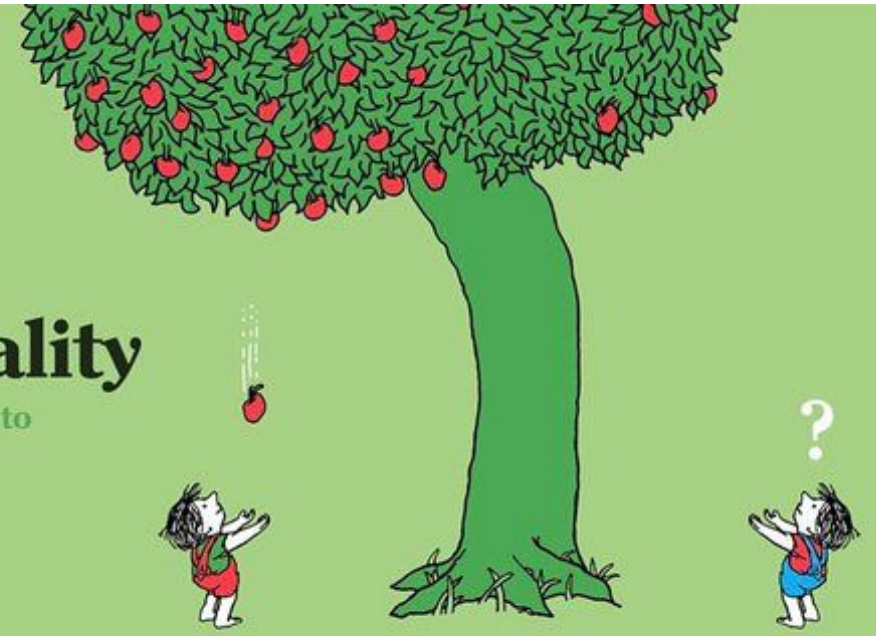
Forsyth, L., McSorley, M., & Rydzewska, E. (2023). All-cause and cause-specific mortality in people with autism spectrum disorder: A systematic review. Research in autism spectrum disorders, 105, 102165.

Increase mortality in ASD

Individuals with co-occurring intellectual disability face the highest risk

Delayed diagnosis, barriers to preventive care, and systemic healthcare inequities likely contribute significantly to increased mortality risk.

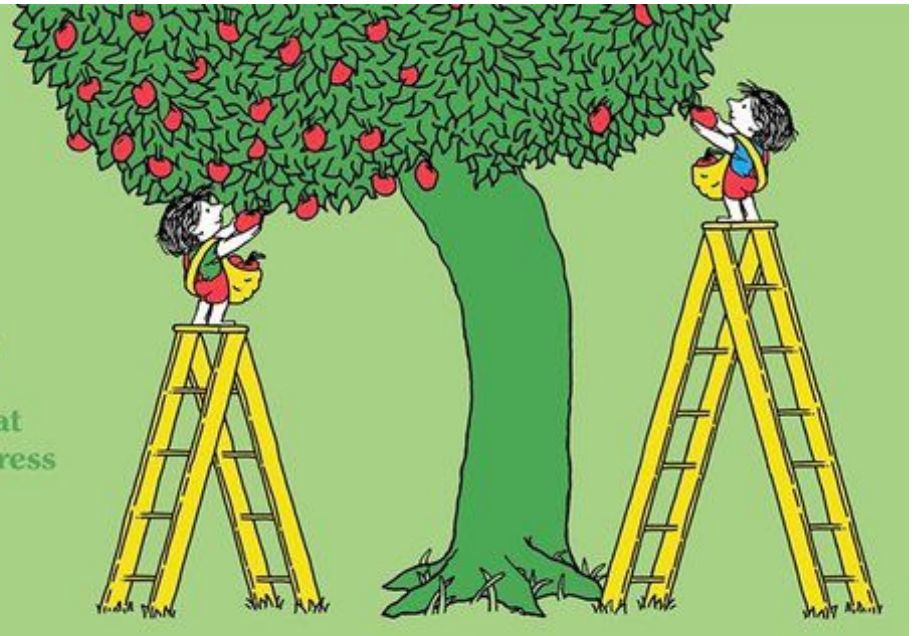
Forsyth, L., McSorley, M., & Rydzewska, E. (2023). All-cause and cause-specific mortality in people with autism spectrum disorder: A systematic review. Research in autism spectrum disorders, 105, 102165.



Inequality

Unequal access to opportunities

With apologies to Shel Silverstein from @lunchbreath

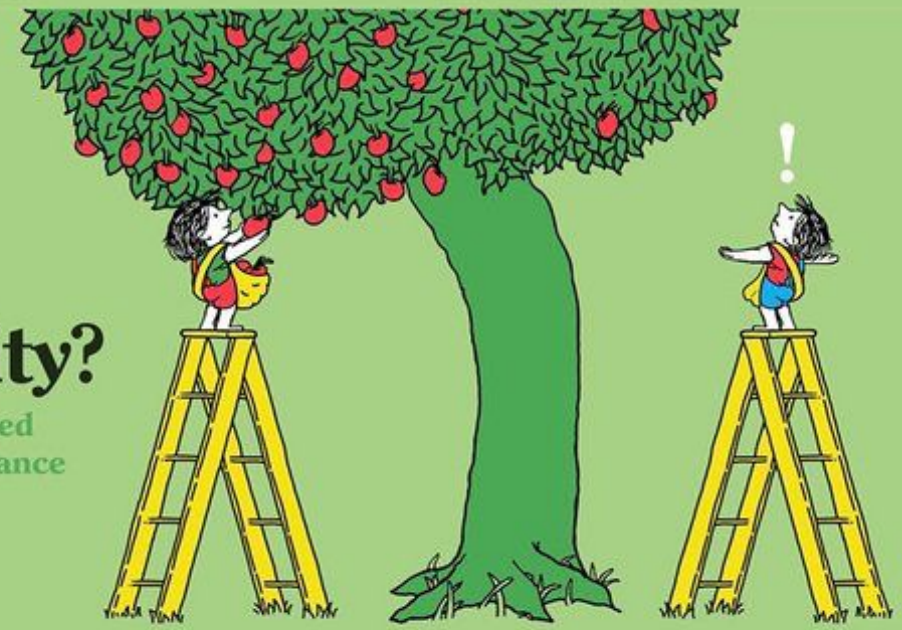


Equity

Custom tools that identify and address inequality

With apologies to Shel Silverstein from @lunchbreath

2019 Design In Tech Report | Addressing Imbalance



Equality?

Evenly distributed tools and assistance

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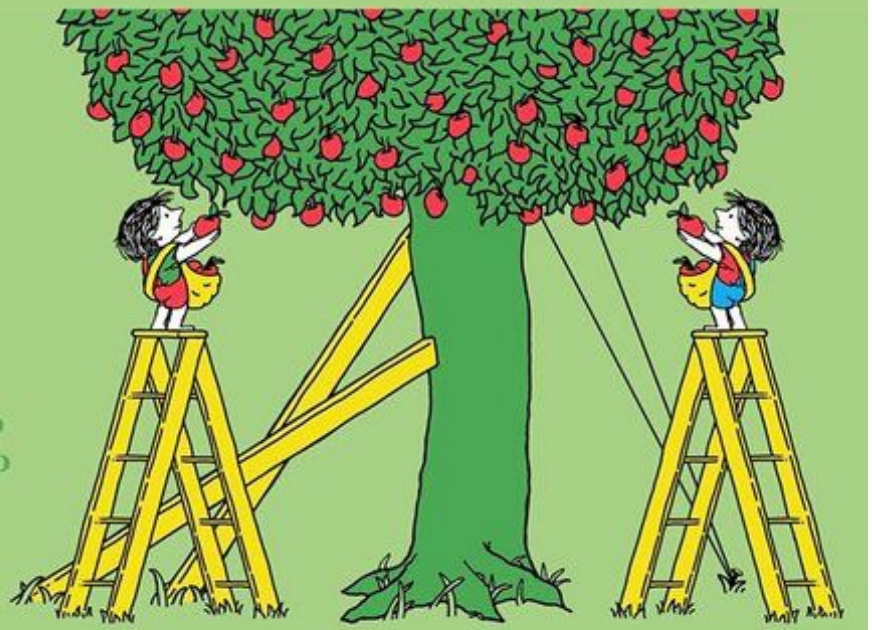

Justice

Fixing the system to offer equal access to both tools and opportunities

With apologies to Shel Silverstein from @lunchbreath

2019 Design In Tech Report | Addressing Imbalance

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BRITISH JOURNAL OF HOSPITAL MEDICINE

Review

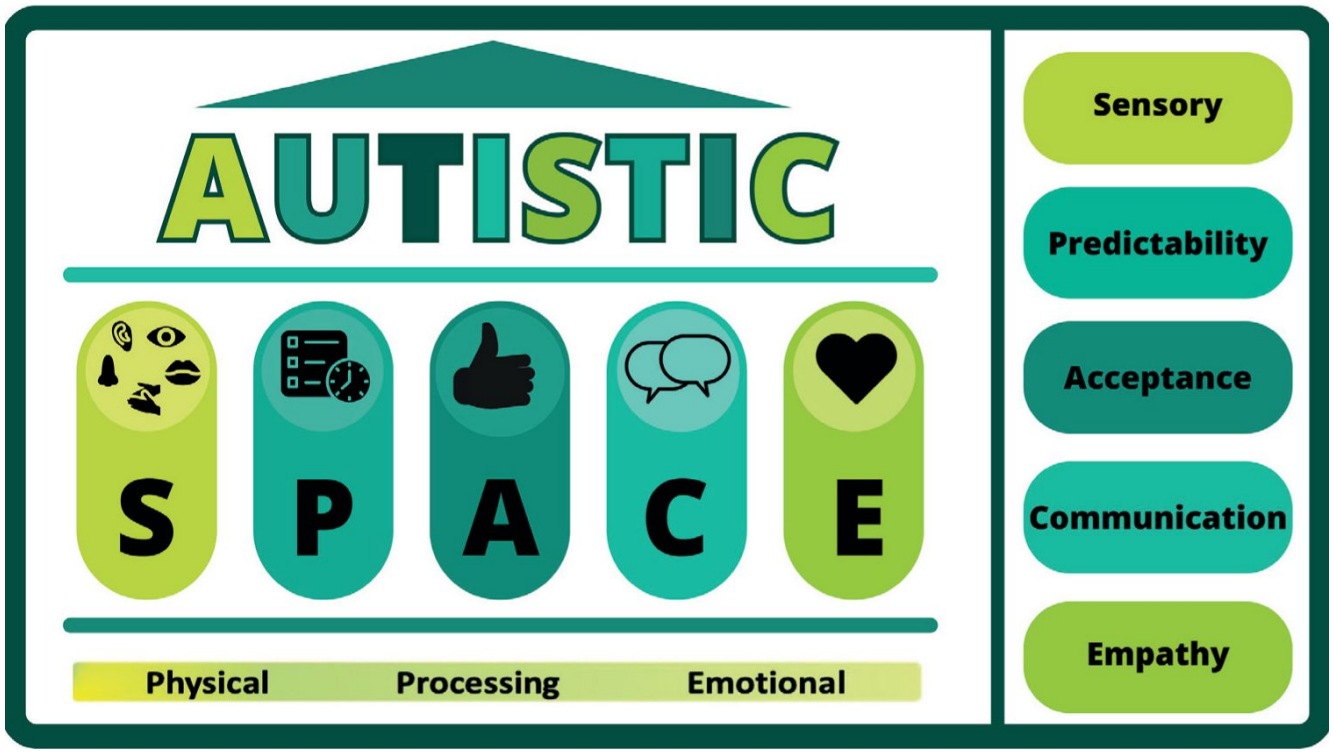
Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings

Mary Doherty, Sue McCowan, Sebastian CK Shaw

Autistic people experience significant health disparities and reduced life expectancy. Barriers to accessing healthcare are associated with adverse health outcomes. Autism training and healthcare professionals' knowledge about autism is variable, and heterogeneity among autistic people leads to additional educational and clinical complexities. Autism remains nebulous for many practitioners, who are unclear about communication differences, access needs or life experiences common to autistic people. Healthcare environments can be challenging for all patients but autistic people may require specific accommodations to allow equitable access. The authors have developed a simple framework which may facilitate equitable clinical services at all points of access and care, using the acronym 'SPACE'. This encompasses five core autistic needs: Sensory needs, Predictability, Acceptance, Communication and Empathy. Three additional domains are represented by physical space, processing space and emotional space. This simple yet memorable framework encompasses commonalities shared by autistic people.

Key Words: Autism • Autistic adults • Healthcare • Healthcare access • Healthcare inequities • Reasonable accommodations

Submitted: 3 January 2023; accepted for publication: 27 February 2023



Doherty, M., McCowan, S., & Shaw, S. C. (2023). Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings. British Journal of Hospital Medicine, 84(4), 1-9.

Table 2. Recommendations for supporting Autistic SPACE in practice

SPACE framework aspect		Recommendations for implementation
Sensory	Sight	Turn off or turn down artificial lights
		Remove flickering or oscillating environmental features
		Avoid highly stimulating decor
		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
	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 sensory-friendly 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
Predictability		Give realistic information in advance
		Ensure clear and accurate directional signage in physical spaces
		Provide photographs or videos of the physical environment and staff
		Allow waiting in a familiar environment (eg a patient's own car or outside)
		Ensure care is provided by staff familiar to the patient where possible
Acceptance		Neurodiversity-affirmative approach beneficial
		Understand autistic stimming and monotropic thinking patterns
		Facilitate need for detailed factual information
		Understand distress behaviour
Communication		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)
Empathy		Recognise that autistic people feel empathy but may display it differently
		Empathy towards autistic patients may be more challenging for non-autistic healthcare providers
Physical space		Expect a need for increased personal space
		Avoid proximity to other people where possible
Temporal space		Allow increased time to respond to questions
		Allow increased time for decision making
Emotional space		Expect differences in emotional expression
		Allow restorative solitude to recover (without additional input) if distressed

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Sage Journals

Special articles

Autism in ICU

Rosaleen Baruah

Abstract

Autism is a lifelong neurodevelopmental condition. Autistic people face challenges as patients in the intensive care unit (ICU) and as providers of healthcare in the ICU. This article describes the experience of autistic people using a neurodiversity-affirming approach. Using the 'Autistic SPACE' framework, the needs of autistic people are described in terms of sensory needs, need for predictability, need for autistic acceptance, communication differences and how to approach them, and the benefits of a person-centred empathy-based approach to autistic people. The approach to autistic patients is described in terms of reasonable adjustments within a framework of positive risk taking. For supervisors and managers of autistic healthcare professionals, autism-friendly adjustments to training and working practice, with rationales, are suggested.

Keywords

Autism, intensive care, reasonable accomodations

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Guest Editorial

Autism in Critical Care

Dawn M. Turnage, PhD, DNP, APRN, FNP-BC
Brian C. Peach, PhD, RN, CCRN

Autism spectrum disorder (ASD) is a developmental disorder characterized by impaired communication and socialization and the preference for rigid routines.[1] This disorder occurs along a spectrum, meaning there are differences in the severity of the symptoms. The current *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition (DSM-5) classifies severity levels as level 1,"requiring support"; level 2, "requiring substantial support"; and level 3, "requiring very substantial support."[1] Individuals with all levels of severity require support; however, those with level 3 ASD require higher levels of support because of the severe impairments in communication and socialization.[1] The *Lancet* Commission on the future of care and clinical research in autism recently highlighted the greater need for support for people with ASD, particularly those with profound autism.[2] In this editorial, the terms *severity* and *profound* are used interchangeably to denote individuals with level 3 ASD.

Autism spectrum disorder is present in all races, ethnicities, and socioeconomic backgrounds, with males having a 4 times greater risk than females.[3] In 2018, 1 in 44 people were diagnosed with ASD, compared with 1 in 200 in 2013.[3] This ongoing increase in prevalence is attributed to better assessment and diagnosis, as well as inclusion of ASD in the *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition.[1] Because more people are living with ASD, more adult patients will present with this condition to hospitals, including in critical care units.

Presentation of ASD

Because ASD is a spectrum disorder, patients with this condition may exhibit 1 or more of the following symptoms[1]:

- Impaired social and emotional function
- Limited or no verbal communication
- An intense desire for repetitive behaviors or routines
- Repetitive movements and/or speech
- Hyposensitivity or hypersensitivity to sensory stimuli
- Intense focus on objects or hobbies

On the autism spectrum, patients can have challenges that are mild to profound, dependent on the severity of their diagnosis. Patients with severe ASD may be nonverbal, be unable to function independently, and require constant care and supervision.

Autism spectrum disorder often presents with other comorbidities, which can further complicate care. Common comorbidities include seizures, sleep disorders, speech and language delays, intellectual disabilities, motor problems, bowel and bladder incontinence, constipation and/or diarrhea, obesity, attention-deficit/hyperactivity disorder, anxiety,

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COMMENTARY

Ableism at the Bedside: People with Intellectual Disabilities and COVID-19

Caitlin Chicoine, MD, Erin E. Hickey, MD, Kristi L. Kirschner, MD, and Brian A. Chicoine, MD

People with intellectual and developmental disabilities have a higher risk of mortality from COVID-19 than the general population. Providers may assume that this is due to the burden of comorbidities for this population; however, the disparity in mortality persists even when controlling for comorbidities. We review the current policies and practices that may be contributing to this higher level of mortality. We contend that pervasive ableism among medical providers leads to a variation in the medical care options that are provided to people with intellectual disabilities and their families. Due to this bias, poor outcomes for people with intellectual disabilities may become a self-fulfilling prophecy. We make recommendations to address the modifiable factors that are contributing to the higher level of mortality for people with intellectual disabilities who are infected with COVID-19, provide strategies to combat ableism within the medical field, and discuss the unique role of the primary care physician as an advocate. (J Am Board Fam Med 2022;35:390–393.)

Keywords: **Ableism, COVID-19, Down Syndrome, Intellectual Disability**

Viewpoint

Structural ableism in public health and healthcare: a definition and conceptual framework

Dielle J. Lundberg[a,b,*] *and Jessica A. Chen*[c,d]

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[b]Department of Global Health, Boston University School of Public Health, Boston, MA, USA
[c]Health Services Research & Development (HSR&D) Center of Innovation for Veteran-Centered and Value-Driven Care, Veterans Affairs (VA) Puget Sound Health Care System, Seattle, WA, USA
[d]Department of Psychiatry and Behavioral Sciences, University of Washington, Seattle, WA, USA

Keywords: **Structural ableism; Ableism; Disablism; Disability; Neurodivergence; Chronic illness; Mental illness; Madness; Structural determinants of health; Health equity**

The Lancet Regional Health - Americas 2024;30: 100650

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Structural ableism has received limited attention in the public health and health services literature as a determinant of health outcomes and disparities.[1,2] This is notable for several reasons. First, disabled people represent an estimated 16% of the world's population,[3] that these fields have been complicit in perpetuating and legitimizing ableism. This exploration is particularly timely given the National Institutes of Health (NIH)'s designation in September 2023 that people with disabilities are a population with health disparities and

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"I'm completely off base here on what this child is capable of": A qualitative analysis of how medical ableism manifests in PICU clinicians' care of children with severe neurological impairment

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ABSTRACT

Background: Children with severe neurological impairment (SNI) are at heightened risk of experiencing medical ableism from clinicians in the pediatric intensive care unit (PICU), where barriers such as time scarcity and heavy workloads limit clinicians' ability to provide personalized care.
Objective: To examine medical ableism and strategies to support PICU clinicians in understanding the lives of children with SNI and their families.
Methods: This US-based, single-center, qualitative study included PICU clinicians identified by the parents/caregivers of a child with SNI. Semi-structured 1:1 60-min interviews about the challenges of caring for children with SNI were conducted virtually. Coded data were extracted, thematically analyzed, and further conceptualized using the Dual Process Theory (DPT) bias reduction framework.
Results: Nineteen PICU clinicians participated. Three major themes emerged: 1) *assumptions and misconceptions about children with SNI and their families*, 2) *barriers to providing personalized care,* and 3) *clinician-suggested strategies to honor the lives of children with SNI*. These themes aligned with the DPT framework. As outlined in the DPT, system 1 "fast thinking" errors occur when quick observations inform decisions (e.g., snap judgments about a child's capabilities). Second, barriers (e.g., insufficient time for meaningful interactions) may prevent clinicians from providing unbiased care. Third, system 2 "slow thinking," where complex decision-making occurs, and can be enhanced through personalization strategies (e.g., viewing visuals of the child at baseline health).
Conclusions: Increasing clinician awareness of their potential implicit biases and utilizing bias reduction strategies to mitigate medical ableism in care are critical areas for future research.

Example:
Pediatric Endoscopy

ASD PRE-SCREENING PHONE CALLS

MASSACHUSETTS GENERAL HOSPITAL

ENDOSCOPY - AUTISM PRE-PROCEDURE SCREENING

Patient: [redacted]
MRN: [redacted]
Age: 13 y.o.
Primary Pedi GI: [redacted]

Date: [redacted]

Upcoming procedure: EGD, Colonoscopy [redacted]

The following information was obtained from the past medical records and mother. No interpreter services needed.

Guardianship Information (only for patients >18yo)

Is there guardianship paperwork on file (if applicable)? Not applicable

Communication and Behavioral Information

Autism Care Questionnaire completed? No, will need to be obtained

Verbal Communication Status: Non-verbal, limited to a few spontaneous words, "Go home." Gestalt language - uses scripted language from StoryBots, the Muppets, Finding Nemo and Charlie Brown. [redacted] **does not like when other individuals repeat his scripted language. He is often very fixated on going home and will state "Go home." This request should be acknowledge by using first/then language or stating he will "go home later."**

Known Triggers (e.g., loud noises, bright lights, specific smells, etc.): [redacted] very sensitive to loud noises, **especially other children crying, which will often trigger attempts to elope.** [redacted] additionally is sensitive to certain smells such as alcohol wipes as well as adhesives/bandaids, but mother has been able to redirect historically.

Known Reinforcers (things that calm or reward the patient): iPad (esp. StoryBots, the Muppets, Finding Nemo and Charlie Brown), sensory toys especially chews (due to hx of severe PICA), weighted lap belts

History of Behavioral Dysregulation: History of aggression (e.g., biting, hitting, kicking). [redacted] will often show signs of anxiety/agitation with large vocalizations and throwing his arm upwards. **His primary aim when dysregulated is to elope and may have aggressive behavior towards people in his way** (especially in doorways) which may involve hitting, kicking, pushing. He will rarely have self-injurious behavior when upset due to a behavioral antecedent (e.g. iPad removed) and will present primarily as throwing his body into the wall.

Medical History and Procedure-Related Questions

Previous Experiences with Endoscopy Procedures: Yes (please describe): Last EGD in June 2022.

Prior Experiences with Anesthesia: Yes (please describe): Has required anesthesia for procedures and imaging.

Has the patient experienced any challenges with previous medical or procedural visits? Yes (please describe):

Has the patient required premedication in the past for procedures? Yes (please describe): [redacted] **had significant anxiety around entering the procedure room itself and attempted to elope. Required IM ketamine + physical restraint.**

Will the patient wear a hospital gown? Unsure, mother states this is still very challenging for [redacted] **She will be bringing him in button up pajamas in case they need to be removed after anesthesia induction**

Will the patient wear a hospital ID band on their wrist? No

Blood Draw/IV Placement: Can tolerate with support. **Family has been working diligently with** [redacted] **to improve tolerance for blood work. Mother feels he will be able to tolerate an IV if he receives calming medication immediately afterwards (e.g. PRN benzodiazepine), and time in minimized between IV placement and start of anesthesia induction. Mother does NOT feel** [redacted] **will tolerate IV placement inside the procedure room itself, and feels this should be done in the pre-procedure unit.**

Vital Signs (blood pressure cuff, EKG stickers, etc.): Can tolerate blood pressure cuff (called "arm hug"), pulse oximeter (called "alligator bite"). Unsure if he will leave on EKG stickers or nasal canula.

Additional Notes/Considerations:
[redacted] and his family have made incredible progress over the past year! He previously was unable to tolerate most health care interventions, but is now able to sit on the exam table, measure his weight, measure blood pressure + pulse oxygen, and even obtaining blood work. He has been primarily able to accomplish this through an ABA approach with the use of positive reinforcement and social stories.

RECOMMENDATIONS:
- Consider home premedication. No history of paradoxical reaction to benzodiazepines. Clarified this with mother due to prior documentation of negative effect. She is willing to trial again. Consider lorazepam 1mg trial on a day PRIOR to procedure day. If tolerated, then could use on day of procedure. **Will defer to primary GI provider to prescribe.**
- Endoscopy social story provided via Patient Gateway
- Discussed pre-procedure on-site tour, feel this would be confusing for patient based on prior experiences.
- Recommend IV placement in pre-procedure unit followed by immediate IV benzodiazepine premedication. This should be done just prior to transition into endoscopy room
- Avoid physical restraint as this adds to patient's anxiety and escalates him behaviorally
- Low threshold for IM ketamine premedication if signs of increased anxiety or agitation

Endoscopy Social Story
To help children feel more comfortable and prepared for medical procedures, we've created a social story for endoscopy. While social stories are commonly used with individuals who have neurodevelopmental disabilities, such as autism spectrum disorder, they are also a helpful tool for any child who may feel anxious or nervous about medical care. These stories provide clear, simple explanations of what to expect, helping reduce anxiety and make the procedure feel less intimidating. We recommend that you read this first and choose what information you think will be helpful for your child. Additionally, please note that not all of the material may be relevant to your specific case. If you have any questions about what is pertinent, we recommend discussing them with the medical team for further clarification.

If you have any questions or need guidance on using the social story, please reach out to Dr. Mojdeh Mostafavi, who is leading this effort, at mmostafavi1@mgb.org.

https://bit.ly/endoscopysocialstory

ENDOSCOPY SOCIAL STORY

PEDIATRIC GASTROENTEROLOGY AND NUTRITION

MassGeneral Hospital *for* Children

SOCIAL STORY:

I am going to have an endoscopy

A note to caregivers:

This social story outlines a general visit to our pediatric endoscopy unit at Mass General Hospital *for* Children where we perform upper endoscopy (EGD) and colonoscopy procedures. However, the steps may vary depending on your child's medical history and needs. As such, not all sections may apply to your child. For any specific concerns, please reach out to your medical provider to discuss prior to your child's procedure.

You know your child best. This social story was created as a tool to aid in preparing your child for their upcoming procedures. We recommend that you read this first and choose what information you think will be helpful for your child. Please feel free to use and modify this in conjunction with language and other tools your child is familiar with. For instance, the phrase "I am safe" may not be the most successful language in reassuring your child. An abridged daily schedule is provided at the end of this social story. For some, it can additionally be helpful to practice modifications of these steps at home or come for a pre-visit tour. For additional information, please contact your medical provider.

Many children benefit from the use of positive reinforcers, or rewards, after completing a task such as this. We have small prizes for patients to select from to take home. Please feel free to bring additional rewards from home that you feel will be reinforcing for your child. One way to present the idea of a reward to your child is through a token-based system. Please see the customizable tool on the last page of this story that can assist with this.

We understand that coming to the doctor and undergoing a procedure can be stressful. Please bring any comfort items you feel your child would benefit from.

We are committed to ensuring both you and your child have the best experience possible. Please do not hesitate to let us know how we can best support you and your child.

Sincerely,

Your Pediatric Gastroenterology Team at Mass General Hospital *for* Children

ENDOSCOPY SOCIAL STORY

PEDIATRIC GASTROENTEROLOGY AND NUTRITION

MassGeneral Hospital for Children

SOCIAL STORY:

I am going to have an endoscopy

Haitian Creole

Arabic

ENDOSCOPY SOCIAL STORY

My name is _____ .

I am _____ years old.

I like _____ .

I am going to have an endoscopy at Mass General Hospital. I am going with my

_____ _____

An endoscopy is a special test to make sure I am healthy.

IF HAVING A COLONOSCOPY PREP

To get ready for my test, I will need to have a special drink.

The drink will help me poop. My belly might feel different. It will not hurt.

I can do it!

1	2	3	4	5	6	7
8	9	10	11	12	13	14

The number of servings may vary based on your child's age and size. Please discuss with your medical provider and modify the tracker as needed.

In the morning I am going to wake up.

I am not going to eat or drink. I can still have medicine.

Here are some things I can do while I wait

_____ _____

ENDOSCOPY SOCIAL STORY

We are going to drive the car to Mass General Hospital.

We will park the car. We will walk inside the building.

The nurse will check my weight.

I will take off all my clothes. I will put on a hospital gown. I may feel cold. I can use a warm blanket.

IF HAVING ANESTHESIA VIA INTRAVENOUS (IV) LINE

The nurse will push on my hand or arm. The nurse will wrap a blue rubber band around my arm. This will feel tight.

The nurse will clean my arm with a swab. This will feel cold and wet.

ENDOSCOPY SOCIAL STORY

IF HAVING ANESTHESIA VIA INTRAVENOUS (IV) LINE

Endoscopy Schedule

- ☐ 1) Wake up
- ☐ 2) Go to hospital
- ☐ 3) Waiting room
- ☐ 4) Check weight
- ☐ 5) Change clothes
- ☐ 6) Check temperature
- ☐ 7) Check blood pressure
- ☐ 8) Check oxygen
- ☐ 9) Wait in special room

I am working for :

_____

☐ ☐ ☐ ☐ ☐

☐ ☐ ☐ ☐ ☐

ENDOSCOPY SOCIAL STORY

https://bit.ly/endoscopysocialstory

Advocating for yourself or a loved one

1. Prepare Ahead

- Bring a written list of concerns/symptoms, medical history & medications
- Note any specific sensory or communication needs
- Request accommodations (e.g. quiet room, written instructions)

2. Communicate Clearly

- It’s okay to say, “We need more time to process this”
- Use preferred communication style (e.g. written, visual)
- Ask providers to explain things in simple, clear terms

Advocating for yourself or a loved one

3. Speak Up About Needs

- Share what works well (or doesn’t) in medical settings
- Remind staff of any previous experiences that were helpful
- Ask for clarification or second opinions if needed

4. Know Your Rights

- You have the right to respectful, accessible, and equitable care
- Reasonable accommodations must be provided under the ADA
- You can bring a support person or advocate to appointments

Advocating for yourself or a loved one

5. Follow Up

- Request after-visit summaries or written plans
- Reach out if things aren’t going as expected
- Keep a record of visits and care plans

Everyone deserves compassionate, accessible, and equitable healthcare— individuals with autism and their families are no exception

Next steps

The autism community plays a vital role in shaping healthcare and policy by raising awareness and fighting stigma. In today's challenging political climate, ongoing advocacy is essential to protect rights, secure access, and advance equity.

Together, we must fight to ensure a more inclusive future.


Mass General Brigham