Unmasking the Lived Experience

of Autistic Individuals

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Introduction

The content is presented from a neuro-affirming perspective that poises autism as a neurotype (i.e., the different ways a brain developed prior to and following birth based on genetics and environmental influences) versus a medical condition that needs to be treated.

Neurodivergence is "a biological truism that refers to the limitless variability of human nervous systems on the planet, in which no two can ever be exactly alike due to the influence of environmental factors." – Sociologist Judy Singer

While neurodiversity was originally coined by Singer to refer specifically to people who are autistic (as is she), the term has broadened in years since.

Neurodivergence now refers to consistent ways in which **brains work differently** for a group of people than they do for the majority of others. For example, autism, attention deficit hyperactivity disorder (ADHD), and others are considered to fall under the neurodiversity umbrella.

SHIFTING PARADIGMS OF AUTISM

The medical model and social disability model of autism are two different perspectives on understanding and framing autism. Each model has distinct approaches to how autism is perceived, treated, and supported. These models can also be extended to other neurotypes, including ADHD.

Medical Model of Disability

The Medical Model of Autism primarily views autism as a disorder or medical condition that needs to be treated, managed, or cured. It focuses on the individual, considering autism a pathology or illness that can be diagnosed, categorized, and potentially treated through medical or therapeutic interventions.

- **Focus**: The medical model emphasizes the neurodevelopmental differences seen in people with autism, viewing these as deficits or impairments in areas such as communication, social interaction, and behaviour. These differences are often seen as symptoms of a disorder that should be addressed.

- **Treatment**: The goal is often to identify the areas of difficulty and implement therapies or interventions to reduce these issues. This might include behavioral therapies, medication, and other forms of intervention aimed at *promoting functioning within a neurotypical societal framework*.

- **Perspective**: The medical model sees autism as a condition that needs to be "fixed" or treated, often focusing on normalizing behavior to fit societal expectations.

- **Criticism**: One major criticism is that the medical model pathologizes autism, treating it as something inherently wrong with the individual. It does not always consider the positive aspects or strengths that may come with neurodiversity, such as attention to detail or deep focus in certain areas. Critics also argue that it overlooks the importance of societal accommodations and support systems (Pisciotta, 2024).

This information was developed with creative and intellectual contributions from Laurel York, Registered Psychologist located in Edmonton, AB [www.yorkpsychology.org]

SHIFTING PARADIGMS OF AUTISM

Social Model of Disability

The social model of disability presents a very different perspective; it sees autism as a natural variation in human development. According to this model, the “disability“ associated with autism is not intrinsic to the individual but is a result of society’s inability to accommodate neurodiversity.

- **Focus**: This model emphasizes the barriers that society places in the path of those with autism. It suggests that disability arises when societal structures fail to accommodate diverse ways of thinking, behaving, and communicating.

- **Perspective**: The social disability model does not view autism as a disorder or deficit but as part of the spectrum of human neurodiversity. The challenge for individuals with autism is not their neurodevelopmental differences but the way society fails to support and include them.

- **Social Inclusion**: The goal of this model is to promote understanding, acceptance, and inclusion. It calls for societal changes such as improved accessibility, better education, inclusive work environments, and greater awareness of neurodiversity.

- **Criticism**: Some argue that the social model may downplay the very real challenges faced by individuals with autism, such as sensory overload, difficulties with communication, or co-occurring conditions like anxiety. While it focuses on societal barriers, it may not always address the need for individual support in some cases (Inclusion London, 2025).

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SHIFTING PARADIGMS OF AUTISM

The Rise of Neurodiversity

In recent years, the neurodiversity movement has gained momentum, aligning closely with the social disability model. The movement views neurological differences, including autism, as natural variations rather than pathologies, advocating for acceptance, accommodations, and celebrating diverse ways of thinking and being.

Neurodiversity emphasizes the idea that society should be more inclusive and adaptable, rather than requiring individuals to change.

Examining the medical model and the social model of disability can help us better understand how autism has been framed historically (medical model) and the new pathway forward to understanding autism as a neurological difference, in which autistic folks experience both a lack of societal accommodations and very real challenges (e.g., sensory differences). The shifting paradigm to the social model of disability highlights how people with autism can be supported in a way that maximizes their potential and quality of life.

A recent Canadian report, from the **Canadian Academy of Health Sciences** (CAHS) – aimed to inform a National Autism Strategy from a social model of disability (CAHS, 2022).

"*Recognition of the neurodiversity paradigm and the social model of disability is fundamental to ensuring a positive transformation of society towards acceptance and true inclusion for all. It is also necessary so that we can modulate the types of supports and services available to focus on the expressed needs of Autistic people.*" (CAHS, 2022, p. 9).

The committee included Autistic researchers, clinician-researchers, Indigenous advisors, and advisors with lived experience of Autism. This is an important step towards the social model; a national report funded by the Public Health Agency of Canada.

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CURRENT DIAGNOSTIC CRITERIA

Autism Spectrum Disorder (299.00) has two categories of features that one must experience: social communication and repetitive/restricted behaviours

Autism Spectrum Disorder

Category A. Person must <u>experience all 3</u> challenges with social communication and social interaction as indicated by differences in all of the following:

1. Social-emotional reciprocity (initiate and respond to social interactions),
2. Nonverbal communicative behaviours used for social interaction (integrating verbal and nonverbal communication), and
3. Developing, maintaining, and understand relationships

Category B. Person must experience <u>at least 2</u> of the following 4 'restricted, repetitive patterns of behaviour, interests, or activities', as indicated by at least two of the following:

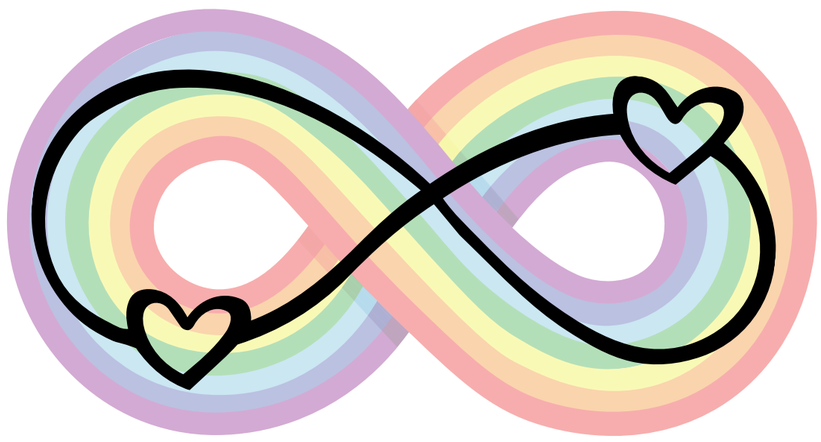
1. 'Repetitive' motor movements, use of objects, or speech (lining up toys; echolalia),
2. Insistence on sameness, routines, or patterns of verbal or nonverbal behavior (distress at small changes, need to take same route),
3. Interests that are different in intensity or focus, or
4. Hyper- or hypo-reactivity to sensory input or interest in sensory aspects of the environment

Also noted as required is:

Category C. Features must be present (but not necessarily fully manifested) in the early developmental period

Category D. Symptoms cause clinically significant challenges in social, occupational, or other important areas of current functioning

Category E. These challenges are not better explained by an intellectual developmental disorder or global developmental delay



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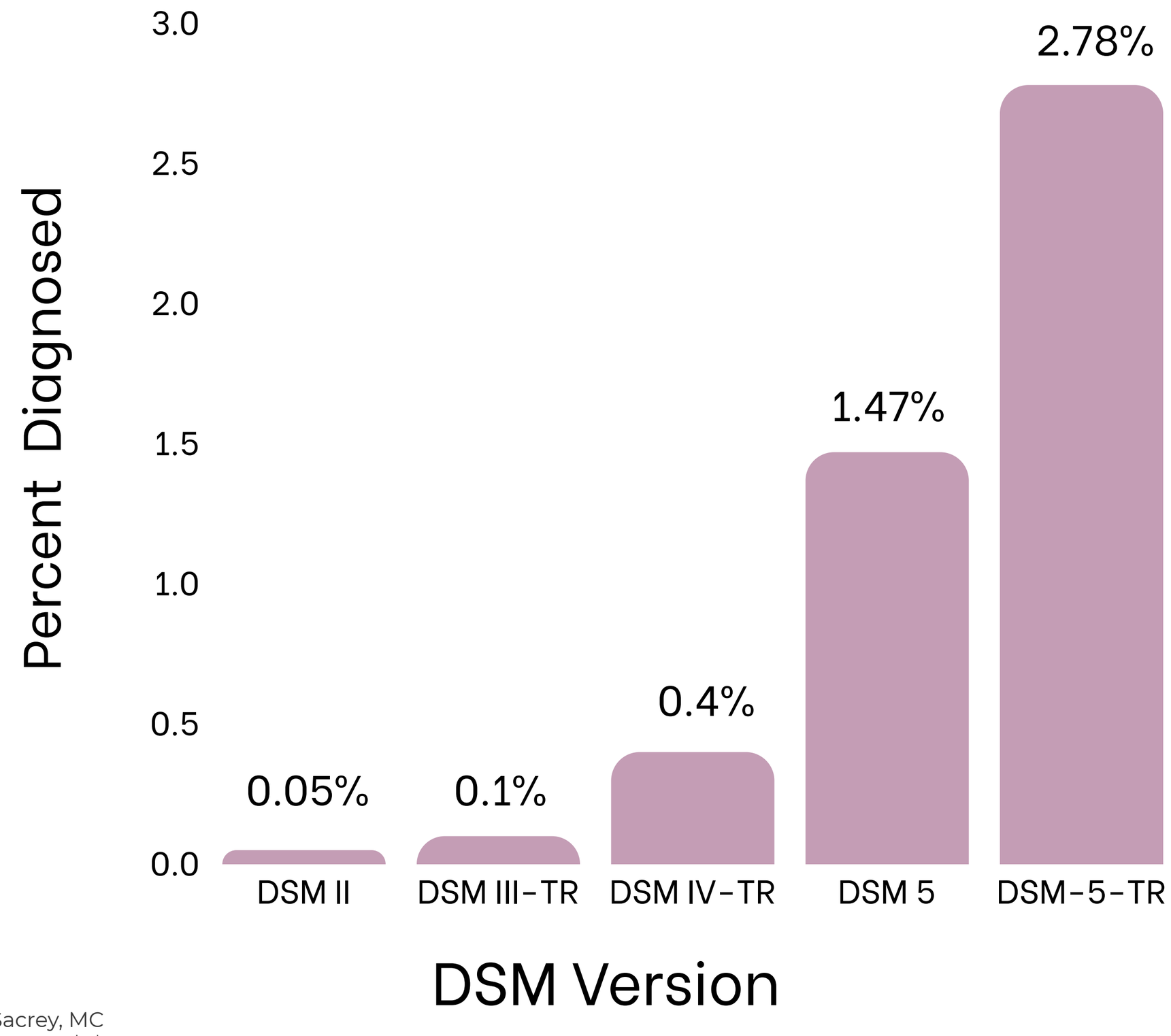
DIAGNOSTIC HISTORY

Table 1. Changes to diagnostic characteristics in Autism since 1960's

DSM EDITION	TERMINOLOGY	SYMPTOM CRITERIA	PREVALENCE
DSM-II (1968)	Infantile Autism (under Schizophrenia)	Narrative description; no specific criteria	~1 in 2,500 to 1 in 1,500 children
DSM-III (1980)	Infantile Autism	Structured criteria; onset before 30 months	~1 in 2,000
DSM-III-R (1987)	Autistic Disorder	Refined criteria; differences in social, communication, and behavior	~1 in 1,000
DSM-IV (1994)	Autistic Disorder (part of PDD)	Detailed criteria; onset before age 3	~1 in 500
DSM-IV-TR (2000)	Autistic Disorder (part of PDD)	Detailed criteria; onset before age 3	~1 in 250
DSM-5 (2013)	Autism Spectrum Disorder (ASD)	Two domains: social communication + restricted behaviors	~1 in 68
DSM-5-TR (2022)	Autism Spectrum Disorder (ASD)	Clarified language and examples	~1 in 36

Compiled from ADDM (2025); CDC (2025)

Figure 1. Change in diagnostic rates for autism from 1968 (DSM II) to present



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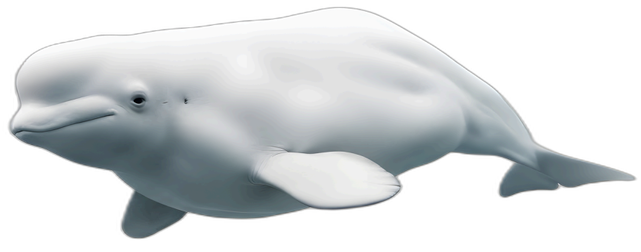
Three Layers of Autism

I like to conceptualize autism as comprised of three separate layers

What was my inspiration? This idea came to me as I was recalling paging through my grandmother's encyclopedias when I was younger.
I really liked the one about whales (because whales are awesome) and the one on human anatomy that contained the transparencies where you could overlay different parts from the skeleton to muscles to circulatory system to skin/clothes.



When I conceptualize autism, and neurodiversity more broadly, I think of it like those transparencies.

The **skeleton** is a metaphor for the diagnostic criteria as outlined in the Diagnostic and Statistical Manual (DSM).

You then overlay this with the **musculature system**, which includes the things that the person experiences that may or may not be a part of the DSM criteria.

Finally, the overlay with the **skin and clothes** represents the mask or the concept of self that one presents to the world.

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