

The Autism Matrix

[Narrative to accompany the diagram]

Background:

In recent years, the trend in Autism Spectrum Disorder diagnostics has been toward a relatively binary approach. Under the DSM-5, for example, all individuals with ASD impairments (persistent difficulties in the social use of verbal and nonverbal communication, and restricted, repetitive patterns of behavior, interests, or activities) are described by a single label, with little attempt to disaggregate the diverse population, even though the differences among individuals often greatly outweigh any initial similarities.

For the purposes of initial diagnosis, such a simplified approach may have value: trajectories can be difficult to predict and access to services can be important. But a single-bucket approach loses conceptual and pragmatic relevance over time. As individuals with ASDs grow past early childhood, they develop an extreme variety of manifestations—from mild social and sensory impairments to compulsive self-injury with profound intellectual impairment. These differences have important implications for policy, public understanding, interventions, epidemiology, research, service eligibility and design, and long-term care. Greater appreciation for functional difference is therefore needed to better characterize older children, adolescents and adults with ASDs.

The Autism Matrix disaggregates those with a professional diagnosis of ASD into subgroups with like features in the most notable elements of functioning—social and adaptive impairment, and intellectual deficits, emphasizing shortcomings in language use. It is not intended as a diagnostic instrument or standardized tool, but instead as a common-sense adjunct tool to present a realistic view of autism. A real-world conceptualization such as the Matrix can enrich public and scientific dialogue about autism while also diffusing some of the unnecessary but enduring confusion over what is best for “autism” or what people with “autism” are like. The design is based on reports and input from parents, caregivers, and clinicians, as well as people with ASDs who have sufficient cognitive and functional capacity to provide comment.

Major features of the Autism Matrix: Zones and Tiers

The Matrix offers two ways to think about functional distinctions within the autism spectrum: zones and tiers. It contains 10 zones (A1, B1, B2, C2, C3, C4, D3, D4, D5, E5) as well as 3 tiers (Tier 1, Tier 2, Tier 3) relevant to ASD.

The Normal Zone— The Normal Zone includes the great majority of the population—those without social, adaptive, and intellectual impairment. It encompasses people with exceptional ability and eccentricity, as well as those with learning challenges, ADHD and mild personality disorders, but who lack the significant impairments of ASDs.

Those not diagnosed with ASD but with significant intellectual or adaptive impairment fit into the Matrix but outside of the ASD-associated zones. For example, a person with Down Syndrome with mild to moderate intellectual impairment but strong social and adaptive functioning may correspond to zone B3, and a person with adult onset mental illness may correspond to zone D1. Both of these zones are outside of the Autism Zone as neither have the core characteristics of professionally diagnosed ASD.

The Zone of Confusion—The Zone of Confusion is where the A1 type of autism, sometimes called Aspergers, bleeds over into normal functioning with quirky traits or substantial learning differences. It can be difficult from a clinical or practical perspective to distinguish between those with ASD and those without in this zone. This grey area tends to generate the most controversy and confusion in terms of autism diagnostics, epidemiology and prevalence, and service entitlement. Once outside of this zone this existence of the ASD tends to be unmistakable and clearly disabling in nature.

The Autism Zone— The zones represent individuals at a point in time, and are somewhat fluid and simplified. For example, someone in the E5 zone can move to the E4 or D4 zone with appropriate interventions or development over time. Also, many people will have functions that span more than one zone, and there are also wide variations in traits among individuals within any given zone. The Matrix does not capture subtleties in functioning or exceptional skills, which may be present in people with or without autism. Therefore, the Matrix, though more detailed than other representations, is still by practical necessity a simplification.

The Zone's axes:

X-axis: Deficits in social-adaptive functioning.

[Normal social-adaptive functioning column is omitted because people with good functionality by definition cannot have autism.] The five categories are:

A: Borderline

Social/sensory challenges, with few functional disabilities. Independent but with need for therapeutics to achieve functioning.

B: Mild deficits

More social/sensory challenges, compromised executive functioning. Greater adaptive struggles.

C: Moderate deficits

Dependent on continuous support, poor daily living and adaptive skills, but behaviorally fairly adaptable.

D: Severe deficits

Intensive support needed owing to low adaptive skills and/or high dysregulation, disruptive behaviors.

E: Profound deficits

Max support, very high dysregulation and dangerous behaviors.

Y-axis: Intellectual disability

The five categories are:

1: Normal

Normal language, cognitive skills and academic capacity; usually capable of college level work.

2: Borderline intellectual disability

Verbal, odd pragmatics, tendency to loop (perseverate), many social and sensory struggles. Conversational, and can usually graduate high school with supports.

3: Mild to Moderate intellectual disability

Slow or unusual language, impaired cognition and learning, frequently or usually stuck in loops. Some academic abilities such as some reading and writing.

4: Moderate to Severe intellectual disability

Minimal or no language, poor learning, consistent looping behaviors. Some, but minimal academic achievement.

5. Severe Intellectual disability

Minimal or no language, poor learning, consistent looping and often disruptive and challenging behaviors. Minimal academic achievement.

Intellectual function as described in the Matrix represents approximate measurable intelligence; untapped, unmeasurable or latent intelligence in individual cases is possible.

The Tiers— The Matrix describes three Tiers of autism:

Tier 1 is characterized by solid language with mild to moderate functional impairments and social and/or sensory challenges. They are mostly independent with ongoing supervision/coaching to address social, sensory, pragmatic, executive functioning and behavioral deficits. Those with intact intellect are mainly capable of college-level work; those with borderline cognition are typically capable of high school academics, with special education assistance. Many are capable of competitive employment, with training, supports and accommodations.

Tier 2 individuals tend to be mildly to moderately verbal with moderate to substantial functional impairments. They usually can function in small supervised groups without 1:1 care. They have striking mental disability, slow or obviously unusual language, and global learning challenges. They are frequently or usually stuck in loops, or perseverative behaviors. They are dependent on continuous support owing to poor daily living and adaptive skills. Some in the B3 and C4 zones can behaviorally be fairly adaptable, but those closer to the D column are often highly dysregulated, with intermittent aggression or disruptive behaviors as a consequence. Though individuals in this tier require fairly continuous supervision, they often can function in small supervised groups without 1:1 care.

Tier 3 individuals are minimally verbal with often incapacitating functional impairments, often or usually requiring 1:1 care and often requiring intensive lifelong supports. They have minimal or no language, poor learning, and almost constant, consistent looping, or perseverative, behaviors. They have minimal academic achievement. Those in the C column tend to have mild behaviors while those in the D and E columns frequently exhibit destructive behavior, including at times aggressive and self-injury, requiring intensive support.

Other comments on the Autism Matrix:

Co-morbidities— Co-morbid traits can have profound impacts on functioning and therefore zone placement. Apart from intellectual disability, which is the most prominent co-morbid feature in individuals with ASDs, however, co-morbidities are not listed on the Matrix, but should nevertheless be considered as contributors to functioning. Co-morbidities include but are not limited to: seizures and epilepsy, sleep disturbance, gastrointestinal illness, depression, poor gross or fine motor skills, tics and catatonia, obesity, headaches, aggression, self-injurious behaviors, pica, mental illness, depression, immune dysfunction, apraxia, visual perception challenges, mutism, anxiety, and dental pathology.

Settings/context— Another contributor to functioning level is that of settings and context. Environments with sensory overload, lack of open or calming spaces or desired activities, stressful family or situational dynamics, lack of proper caregiving, bullying and abuse, or poor nutrition, for example, can influence level of functioning at any given time.

Etiology— The Matrix is agnostic as to etiology of the variety of mental pathologies with autism features. Similar inducements (eg, a certain mutation) may result in varied phenotypic traits, and conversely, different triggers (eg, prematurity or genetic variant) can yield similar phenotypic traits. The Matrix is only intended to promote more precise and realistic understanding of the characteristic outcomes, and not causes, of ASDs. That said, mounting evidence suggests that ASDs are physiological in nature. The looping thoughts and behaviors described in the Matrix likely stem from enduring dysregulation and maldevelopment of neural circuitry and synaptic functioning.

Note on examples— Examples in the Matrix are either taken from popular books, online videos or websites, or used with permission.

The Autism Matrix is a work in progress based on input gathered from both professional and lay sources. Further commentary is appreciated. Email: jill.escher@gmail.com.

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