

## Controversial Themes and Issues Surrounding Autism: A Chronological Timeline Analysis

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### ABSTRACT

The phenomenon of autism, as in known today, has a history with several vicissitudes. Contemporary students and practitioners unconnected with its history are unlikely to see the larger picture. This article seeks to outline the timeline of autism before narrowing it into various controversial themes, unresolved issues, and unanswered questions on autism. The themes revolve around the disputed construct of autism, its meaning, definition, characteristics, theories, and official classifications. Equally debated are matters related to epidemiology, causes, and treatments for autism. There is disagreement whether autism is a disorder or a difference. The claims of freaks, exceptional prodigies, and savants in autism, the role of genetics, notions of posthumous diagnosis, commercialization, and commodification of autism in the media are raised. Raising controversies can lead to constructive discussion or further reflection than attempting to answer them.

**Key Words:** Epidemiology, Commodification, Genetics, Prodigies, Savants

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### Abbreviations

APA: American Psychiatric Association; DAN: Defeat Autism Now; DSM: Diagnostic and Statistical Manual; ICD: International Classification of Diseases; ICF-CY: International Classification of Functioning, Disability, and Health-Children and Youth Version; MMR: Measles, Mumps, and Rubella; NDD: Neurodevelopmental Disorders; PDD: Pervasive Developmental Disorders; WHO: World Health Organization.

### INTRODUCTION

Chronological timelines involve serialized visualization of the temporal patterns of actions and events for a given phenomenon. Each timeline segment has a title, period (first and last dates of occurrence), the interval between them, and pivot point anchoring the events within that time frame. This technique helps undertake root cause analysis, significant incident identification, establish cause-effect inter-relationships, detection of frauds and crimes. Research data for these studies is typically collected from available archives, secondary sources, records, and recollections. Although there is no manipulation of variables in this research design, they help us know what happened in the past to understand the ongoing present. In short, a timeline is a story worth telling. This method is used to examine changing trends in disability management [1], trajectories in language learning [2], cyber-crime during the ongoing pandemic [3], history and systems of psychology [4].

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; [5]) categorizes autism as an "Autism Spectrum Disorder". It is a cluster of symptoms. It is mainly characterized by a deficit in social communication and interaction and some repetitive and odd behaviors. It has its onset in the early years of a child's development. It is one of the complex disorders under the umbrella of neurodevelopmental disorders. Therefore, undertaking timeline analysis for autism aims to narrate the course before extracting controversial themes and issues surrounding this disorder.

### **The Autism Timeline**

A perusal of the chronological timeline shows that Eugen Bleuler, a German psychiatrist, coined the term autism in 1911. The etymological origin means "self or inner-directed," which was a symptom of schizophrenia [6]. This concept continued till the 1950s. The starting point of autism was 1943 when Kanner's landmark paper *Autistic Disturbances of Affective Contact* described eleven children who were highly intelligent but displayed "a powerful desire for aloneness" and "an obsessive insistence on persistent sameness." The condition was then named "infantile autism."

In the 1960s, autism described unconscious fantasy life and hallucinations in infants/children by child psychologists like Jean Piaget, Lauretta Bender, and Leo Kanner. The condition was then understood as a childhood variant of adult schizophrenia involving detachment from reality. This notion is seen in the then Diagnostic and Statistical Manual (1st ed.; DSM; [7]).

Between 1950 and the 60s, by extending but overdoing Kanner's notions, Bruno Bettelheim dubbed autism as a severe form of an emotional disorder owing to "refrigerator mothers" who are cold, aloof, and detached. In the 1960s, the concept of infantile autism was challenged and reformulated to describe the exact opposite of what it had meant till that time. Despite the lack of clarity on the definition of autism, epidemiological studies beginning from the first by Victor Lotter posited a rate of 4.5 per 10,000 children in a general population as being autism. In 1964, Bernard Rimland, American psychologist and founder of Autism Research Institute, California, created the controversial program called "Defeat Autism Now" (DAN). Since his son was diagnosed with autism, he took personal offense to the then-prevailing notion of "refrigerator mother." He argued why his other children born to the same mother were unaffected. He propagated the belief that vaccines cause autism. The affected children needed chelation therapy to remove heavy metals from their bodies.

By the 1970s, the ingredient of hallucinations was permanently eliminated by moving autism outside the realm of "psychiatric disorder" and calling it "communication disorder." In the 1960-the 70s, there was a spurt in the growth of speech therapy services, closure of institutions for the "mental defectives," and the understanding that autism is associated with profound mental retardation. In the 1980s, Hollywood found it is de jour supporting the cause of autism with movies beginning from "Rain Man," of which Rimland was the technical adviser. Further, T.V. shows, soap operas, biographies, documentaries, family dramas, science fiction, comedies, and romance flooded the market. Fiction reached out to achieve many things that facts could not. Around the time, DSM-3 [8] morphed the concept of autism by introducing the category of "pervasive developmental disorder" as distinct from schizophrenia, with four subcategories. The diagnostic criteria were now laid; lack of interest in people, severe impairment in communication, bizarre responses to environment appearing in the first 30 months of life. For cases that did not fit into the criteria, sub-types like "atypical" and "residual" were kept open for a filling.

Another phrase, "spectrum," was added in DSM-4 [9], which was revised as DSM-4-R [10], new terms like "Asperger's Disorder," "Childhood Disintegrative Disorder," and "Rett's Syndrome" was included. The 1990s was a period of great upheaval in the history of autism. There were ongoing vaccine wars. Autism was made an integral part of the Human Genome Project spread over 50 research centres in 11 countries. The project used genetic testing as a tool for the individualized diagnosis and treatment of autism. By 2019, the world's largest autism whole-genome database reached 10000 milestones. Despite more than 700 genome-scanning publications and nearly \$100 billion spent by geneticists, no unequivocal evidence of a faulty gene or biomarker is evidenced. High tech gadgets to map brain electrophysiology like fMRI and new words like "endophenotypes" were invoked to understand autism. There was a shift from research on population genetics to molecular genetics. The ground was fertile for the proliferation of guestimates, bogus

claims on causes and cures, quick fixes and magical solutions, pseudo-professionalism in the field. Everything is akin to the proverbial search for a needle in the genetic haystack.

In 2013, DSM-5 [5] removed the subcategories of "Childhood Disintegrative Disorder" and "Rett's Syndrome." Another new diagnosis of "Social Communication Disorder" got introduced. These revised terms meant the loss of insurance coverage for children with the earlier labels. However, another 18<sup>th</sup>-century term, "Neuro Developmental Disorders" (NDD), appeared officially in DSM-5. More than 35 conditions were recognized under this category. There was further loosening of the concept, criteria, and definition of autism. For different reasons, the term "mental retardation" was changed to "intellectual disability." The neurodevelopmental approach was far too elastic. It accommodated anything as the cause, correlate, or consequence, most suitable for explaining an enigmatic clinical condition like autism.

In June 2018, the WHO released the ICD-11 replacing its earlier version published 28 years ago (ICD-11; [11]). This document was more in line with the DSM-5, at least concerning autism. Both used the official term "autism spectrum disorder" with two symptom domains, including sensory sensitivity, removed the age of onset, and allowed for co-occurring diagnosis. While DSM-5 recognized atypical autism as a "social (pragmatic) communication disorder," ICD-11 names it as "Developmental Language Disorder."

Away from, outside, and against the medical models of ICD and DSM that are symptom-oriented, the rights-based activists in autism lobbied for the "person-in-environment" approach of ICF-CY [12]. An attempt was made to capture aspects of functioning and contextual factors in persons with autism than listing deficits, stereotypes, or labels. This classification is based on an interactive-bio-psycho-social model of functioning than dysfunctions, disorders, deviance, or disease. It was not about what a person cannot do. It is about what one can do. It is about activities and participation. It is about body functions and environmental factors that can ameliorate them.

### Themes

From the preceding chronological timeline, one can draw either deductive (general to specific) or inductive (specific to general) instances to derive themes for consideration on the chosen phenomenon of autism.

### Theories of Autism

There is no single theory on autism. The **mind** or mind blindness theory explains autism as the inability to form a mental representation of other people's minds. The **strategic social behaviour model** recognizes caregivers as a source of sustenance and nurturance-the absence of which is explained as the basis for autism. **Biological theories** involve the frontal lobe and limbic system to describe their emotional and motivational behaviour's. The role of the oxytocin hormone is implicated to explain their deficits in affiliation and social attachment. Neurotransmitters like dopamine, serotonin, acetylcholine, norepinephrine, and catecholamines are also invoked to describe autism. Amygdala is linked to their deficits in empathy. The orbitofrontal cortex is connected to emotional regulation. The **theory of executive dysfunction** is used to explain their cognitive, language, and communication difficulties. Insults related to obstetric events related to prenatal, natal, and postnatal periods are connected to autism. Genetic links to autism are postulated. **The central coherence theory** explains how persons with autism cannot derive the overall meaning since they focus excessively on minute details. They are good with the parts, but not with the wholes. The **unified theory of autism** mentions monotropic as the characteristic tendency of narrowed interests and singular preoccupations of persons with autism. The **social-motivational theory** uses a bio-psycho-social model to explain constricted interests and behavioural deficits in autism. The **sensory-perceptual theories** highlight how individual preferences in using one sense organs, with hyper or hypo seeking sensory inputs and their integration, are at the root of autism. The **anthropological theory** views autism as a 20<sup>th</sup>-century socio-political construct (non-existent earlier) created by medical and mental health professionals. Is this condition deemed to exist in pre-literate and tribal societies is a debatable issue? The **existential theory** supports autism experience as one's personal choice.

### Epidemiology

There is no single agreed-upon statistic on the epidemiology of autism. Leo Kanner's definition of autism in the 1960s estimated that 1 in 2500 children had autism. Studies in 2000 reported 4.5-9.9 per 1000, which changed in 2020 to almost fourfold as 18.0-19.1 per 1000 children with autism in the United States. This

included 1 in 34 for boys, four times diagnosed by gender than 1 in 141 girls. About 31% of children with autism are shown to have intellectual disabilities. The minimum age for diagnosis of autism has always been controversial. Whether autism is to be diagnosed by age four or as early age two.

The prevailing DSM-5 and ICD-12 disregards age as criteria for diagnosis [13]. The estimated figures vary considerably by the year, source, or place of study, whether school and medical records are taken, home-schooled children and those who live in remote areas are included, surveys or single questionnaire formats are used. There are differences in the methodology of case detection. Therefore, no real-time increase in the prevalence of autism can be guaranteed. Are they an artifact of changing definitions and diagnostic practices? There is no consensus among epidemiologists, researchers, and clinicians. Different yardsticks are being used to screen autism by different investigators at different places and times. Some include cases with intellectual disabilities in their gamut of autism, while others exclude them [14]. Studies on the **incidence rates of autism** have not been investigated as much. The methodological challenges in undertaking incidence studies are more significant. The follow-up of birth cohorts until the onset of autism or demarcating the exact onset time is not defined. Is it 18 months or around four years? Which type of incidence (cumulative or incidence proportion and rates) is unclear and leaves them incomparable [15, 16].

### Is There a Real-Time Increase in Autism?

Skeptics argue that the **loosening of the earlier rigid diagnostic criteria** and age of diagnosis is the root cause of numbers' apparent swelling. Children earlier identified to be having "mental retardation" (or intellectual disability) were increasingly labelled autism. A California-based study noted how the prevalence of autism increased from 6 to 15 cases per 10000, while the prevalence of intellectual disability during the same period decreased from 29 to 19 per 10000 [17]. Diagnostic substitution accounted for at least one-third of the increase in autism prevalence during comparable study periods [18, 19, 20].

Apart from **diagnostic substitution**, another proposition called "virtual autism" or "digital autism" is also used to explain the explosive rise in the diagnosis of autism. It is contended that children who spend too much screen time on television, iPad, video games, and tablets are labelled autistic. Once their screen time is taken away, the autism symptoms diminish. Such children tend to enact or repeat words from television shows without knowing their meaning [21, 22, 23, 24, 25].

There is a **growing trend in favor of diagnosing more cases of autism**. In a studied sample, only around 20 percent of the children eventually qualified for the final diagnosis of autism against the set official criteria [26]. Due to the lesser apparent stigmata associated with the label autism (as compared to intellectual disability or it is still more stigmatized term mental retardation), stakeholders prefer this diagnosis for various compelling reasons. While overdiagnosis and misdiagnosis may be one side of the issue, in clinical practice, there is also a compulsion in some practitioners to label or diagnose every child that is brought for consultation [27-28].

**Funding for autism has increased exponentially**, especially in the United States. Reimbursements are made for their pre-approved treatments, air-travel for families in need of medical care, payment of consulting charges for speech, occupational therapy, and Applied Behaviour Analysis sessions, limited, targeted educational investments, and for purchase of iPads, augmentative communication devices, bathing, and feeding chairs, sensory equipment, and gift cards for holidays. There are funds disbursed as Disability Living Allowance, Carer's Allowance, financial help for single moms having a child with autism, and others. The diagnosis of autism is preferred over intellectual disability even though the distinctions between the two are a matter of never-settled debate and controversy at all times. The diagnostic validity of autism against various subtypes and other non-autism conditions is probably the biggest problem with most screening instruments [29-31].

### Genetics

While the preceding covers autism epidemiology based on phenotypes or outward symptomatology, there is much less discussed **genetic epidemiology of autism**. They are population projections based on gene-environment interactions, epigenetics, endophenotypes, genomics, and neurobiology. The search aims to identify candidate risk genes, the role of genetic modifiers such as copy number variation, single nucleotide polymorphisms, and epigenetic alterations in altering the phenotypic spectrum of autism. The hunt for a

genetic basis for autism often touted as investigations between molar (phenotype) and molecular (genotype) levels, is akin to the proverbial search for a needle in the haystack [32].

The cause of autism is still unknown. The role of genetics in autism has been invoked. Its heritability was enquired using sibling, twin, and family study techniques. This was followed by the evolution of the DNA era and, later, the genomic era. The search for a candidate gene was pursued quite along with limited success in the end. The studies on the abnormalities of the chromosomal structure are called cytogenetics. Genes with epigenetic modulating function are being projected as being involved in susceptibility to autism. No autism risk gene has been discovered. The autism gene puzzle has proved to be a tough nut to unravel. Since autism affects males many more times than in females, is there a sex-linked gene is another unanswered question. What might be the clinical implications of **resolving these genetic tangles of autism** is anybody's speculation. In short, there are still no definite answers to several questions: how is autism inherited? Which parent carries the autism gene? What is the most commonly known genetic cause of autism? Is there a synoptic problem in autism? Will an abnormal gene tell the whole story of autism? [33, 34].

### Meaning and Definitions

There has **never been an agreed-upon meaning or definition of autism**. By and large, autism is defined as a developmental disorder almost always presenting in infancy or the preschool years. The symptoms of autism are deemed to persist throughout life, although partial compensation for completing "cures" is claimed in some quarters. Deficits in sociability, verbal and non-verbal communication, an atypical range of interests, restricted or repetitive activities, and cognitive skills are often listed as its identifying characteristics. Sometimes, sensory difficulties and unusual abilities are added to this list. The once extensive list of sub-types of autism is no more accepted. The heterogeneity in the presentation of symptoms is disguised as "spectrum." To add to this confusion, links were added to other clinical conditions like Attention Deficit (and Hyperactivity) Disorders, epilepsy, gastrointestinal disorders, anxiety, bipolar disorder, Downs Syndrome, intellectual disabilities, eating and sleep disorders, as "co-morbid" or "co-occurring" conditions. The latest phrase "neurodevelopmental disorders" is gaining use with an amalgamation of research from neuroscience, molecular and developmental genetics, neuroimaging, cognitive psychology, child and adolescent development, and related fields concerned about brain functions [32].

What was narrowly defined in the 1980s, mainly in academic and medical centres, gave way in the 1990s to include the "mentally retarded" as part of the "autism spectrum" around 2000? Popular media depictions added even "less attentive, delayed speech-language, overactive, avoidant, anxious, passive, and poorly socialized children" into that category. During the ongoing pandemic, all stimulation quarantined infants and preschool children are dubbed "autistic." So much so, diagnosing a child as "normal" has almost become non-existent [35].

What is recognized as corona-induced developmental problems in toddlers and preschool-aged children facing repeated lockdowns, migration, loss of peer relations, changed parenting practices, decreased face-to-face interactions and proximal supports from neighbours and extended family members cannot be mistaken as autism. The increase in virtual world contacts, sedentary lifestyle, and screen time for young children without optimum play, language stimulation, and involvement by elders have impacted their development. This is not to be mistaken as autism [36-37].

### Freaks, Exceptional & Prodigies

Coupled with media sensationalism, autism has gained the dubious distinction of being stereotyped as freaks, exceptional, and prodigies. Persons with intellectual disabilities to highly gifted are all subsumed under the heading of autism. Their "gifted," "genius," or "exceptional" activities are named "splinter skills." Conveniently, such persons were once even identified as "Idiot Savants," "Savant Syndrome," or "High Functioning Autism," or "Asperger's Syndrome." There is the question of the stability and longevity of such skills. How long-lasting are these "special skills" in supposedly these "mind readers" or "calendar calculators?" Prodigiousness in childhood has rarely predicted adult eminence. Systematic, case-controlled longitudinal follow-up studies of such anecdotal reports seldom happen. There is a massive list of failed prodigies in their later life. After discounting the controversies surrounding such claims, one must be wary

of differentiating fictional prodigies from factual ones. Many media followers believe that persons with autism have high intelligence, unique talents, or abilities. These claims are anecdotal narratives, unpublished thesis, biographies, or testimonials authored by close relatives. Such records are based on personal episodic memories that are subjective, biased, lack authenticity or standardization. They equate coincidence as "cause-and-effect," The incidents may be taken out of context [38-41].

### **Screening & Identification**

The screening and diagnostic criteria for the identification of autism have never been stable continuously over five to ten years. There has never been any single, standard, agreed-upon screening tool for autism. The label or nomenclature for this condition has also not been the same over the years. In 1943, what Leo Kanner recognized as "infantile autism" to describe socially isolated and withdrawn children became invalid in the 1980s with the advent of DSM. A positive screening needs to be further assessed and followed up for a longer time (how much is not specified) before the autism label is affixed to the suspected case [42].

There is a growing penchant for google-enabled, Alexa-voice guided virtual services or Artificial Intelligence-assisted self-diagnosis, especially teenagers and young adults with access to the net [43-45]. The net is full of medical applications that enable online self-diagnosis. The user must enter the symptoms and answer simple questions. Within the snap of a finger, "Dr. Google" (as it is named), one can get all the answers from diagnosis to treatment. Self-diagnosis carries safety risks. It gives the impression that the study of mental health specialty is easy. The net is based on a mixed bag of resources which can be baseless or misleading. They undermine the role of the doctor. The practice of googling for symptoms and a diagnosis-especially for autism, has not been a welcome experience [46].

It requires an evaluation of 20-100 behaviour for a given person before arriving at a diagnosis of autism. To overcome cost and inordinate waiting time in securing appointments with specialists, new trends of machine-based diagnosis of autism have got into place. Many undiagnosed adults' resort to a belated self-diagnosis [47-51].

### **Intelligence**

IQ has never always and consistently been a defining character of autism. Although autism and intellectual disability are different conditions with different levels of general intelligence, gross versus specific delays in the history of their developmental milestones, capacities, and level of independence in daily life, the two conditions have often been in clinical practice confused, and even co-diagnosed. Similar confusions prevail in the diagnosis of mental illness with autism. There are "autistics" with I.Q.'s of 47 and those above 150 too. When I.Q. is high, they were conveniently labeled Asperger's or High Functioning with splinter skills or savant abilities. Most researchers have stayed away from studying intelligence in autism. This is another way of saying that no one knows the nature of intellectual disability in autism. It is not clear whether intellectual disability is a fact in autism. Measuring intelligence in children who do not talk is an inexact science [52].

### **Disorder or Difference**

The argument of "neurodiversity" is invoked. Neurodiversity refers to variations in the human brain regarding sociability. It is the concept that one size does not fit all. The differences seen in people with autism are variations in the human genome. Some people see autism as a tragic disability exclusive to the affected people. Others see the autistic community covers their family, friends, friends, and caregivers. Many believe that autism is a genetic neurological difference, and as such, not subject to cure. Neurodiversity believes the condition is a normal variation of the human experience. Rather than bend the person into a so-called "normal" mode, their differences must be allowed, accepted, or acknowledged [53]. Neurodiversity extends from the concept of biodiversity. Autism, like dyslexia, hyperlexia, Tourette's Syndrome, bipolar disorders, intellectual disabilities, or many other neuropsychiatric conditions, represents different sub-populations within a large group. They do not represent a defect to be rectified or a disorder that is to be cured. Neurodiversity helps persons "lose" their diagnosis. It eliminates the stigma attached to the labels. Some claim "recovery" from the condition. Others claim, "best outcome" or "optimum outcome." Still, others are identified as "outgrowing" their diagnosis. In sum, the argument is whether to call it a disability or

"disability/differ ability"? This entire notion was a rebuttal or in retaliation to the over-medicalization or medical model of autism. These ideas lead to the evolution of notions like "disability pride" "autistic art." It is like how homosexuality was classified as a disorder earlier and has now been discredited into a preferred way of life. So, is it with autism [54]?

### **Causes, cures & treatments**

There is no biomarker or medical test to diagnose autism. A huge list of "causes" for autism is available. Based on the analysis of transcripts derived by data mining of netizens, about 350 causes were raised by respondents. The list covered bio-medical, diet-based, sensory, metabolic, neuroanatomical/neurophysiological, prenatal, natal, obstetric, chromosomal, and environmental-cultural causes of autism. In the same study, nearly 250 types of cures or treatments were listed for autism. They ranged from nutrition-diet therapies, bio-medical, education-based, medicines, sensory, instrument-based to complementary alternative medicine (CAM; 55).

### **Vaccine Wars**

The false association claimed between vaccines-autism is the most negative occurrence in history. Initially published in a prestigious British journal, the Measles, Mumps, and Rubella (MMR) vaccine as the presumed cause of autism was later retracted in 2010. The investigators were found guilty of unethical practices, intentionally leaving correct information, and making false statements [56]. Much damage was already done. The between 1980-2000, endorsed by Bernard Rimland, the founder of Autism Research Institute, many parents were already convinced that vaccines cause autism. His expensive and risky method of "curing" autism, named "Defeat Autism Now" (DAN), through "chelation," was doing roaring business. Anecdotal records were claiming a complete "cure" for autism. There was no research evidence to support this. The DAN protocol was discontinued in 2011. Its belated spillover effects can be seen in many of its takers even now. The peak was in 2001 when a Prime Minister of the United Kingdom succumbed to the anti-vaccine lobby by not vaccinating his child for fear of autism. This jeopardized the universal immunization programs across several nations. The media-created MMR hoax was diligently maintained for ten years [57-59].

### **Gluten Free Casein Free (GFCCF) Diet**

Similarly, Krigsman, the American gastroenterologist who, like Wakefield, believed in another disproved notion that autism was caused by laxatives, enemas, restrictive diets, and antifungals. Diet-based therapies have gained popularity following the debunking of vaccine causes of autism. There is another hypothesis that children with autism have an allergic reaction to gluten. There is no evidence either against or in favour of gluten avoidance for managing symptoms of ASD in children. Nonetheless, there are GFCCF celebrities to endorse such a cause [60].

### **Animal-Assisted Therapies (AAT)**

Venkatesan [61] found that about 40 percent of the publications on AAT in autism were anecdotal, followed by single-subject designs, multiple baseline designs, review papers, meta-analytic studies with least on RCTs. The research design was not mentioned for most of the studies. There is no uniformity in using these methods about the intensity or duration of their use. The outcome variables, wherever studied, were not homogeneous or standardized. In conclusion, there is no convincingly empirical solid evidence in favor or against the efficacy of AAT. It was, at best, still gathering evidence to justify its use as an independent intervention. A few areas like cost-benefit analysis, validation of theoretical models to explain its rationale, research on guidelines for its practice, social-cultural dimensions, or questions about its future remain still unavailable literature [61].

### **Complementary & Alternative Medicine (CAM)**

A lengthy list of treatments falls under this category, including Ayurveda, Acupuncture, Tibetan/Chinese Medicine, Homeopathy and Naturopathy, Unani, and Siddha. Another list may include body or touch-based treatments like Chiropractic Medicine, Massage, Yoga, Body Movement, Drinking Green Tea, and

Tai Chi. Diet and herbs-based therapies are other categories of therapy covering the use of nutrients and dietary supplements. External energy therapies for autism use Reiki, Quigong, or Magnets. Mind-based practices propagate meditation, mindfulness, biofeedback, and hypnosis. Sensory-based treatments involve dance, drama, music, aerobics, aromatherapy, art, visualization, and guided imagery. Wikipedia lists more than 200 forms of alternative medicine. Half of the children with autism are reported to be using CAM [62, 63, 64, 65].

Going by the available literature, one may assume that there are treatments for autism. Against its unknown aetiology, online and offline cures or treatments are claimed and hyped. Unsupported by empirical research, the scenario continues to proliferate. Available evidence includes personal testimonials, authorities' opinions, anecdotal reports from expert committees, biographical narratives, success stories, and single descriptive qualitative case studies without data. The next level of evidence comes from systematic reviews. At the next level, headcount surveys, correlational research, and cohort studies are given. Evidence from well-designed controlled trials with or without randomization is minimal. To establish cause-effect relationships, multi-site meta-analytic RCTs are needed. Unfortunately, evidence at this highest level wants treatment efficacy across all disciplines in autism [66, 67, 68].

Common red flags against accepting treatment are checking whether there are enough peer-reviewed studies in respected medical and science journals. Grandiose claims of cures and miraculous breakthroughs, oversimplified scientific theories, claims of dramatic and "miraculous" results benefic to more than one condition is to be suspected. Wherein specific treatment goals or target behaviors are not identified, chances of fraud, the practice of quackery in the guise of questionable diagnosis and dubious, controversial, pseudoscientific, and fad therapies or treatments is likely [69].

Nonetheless, the "cure de jure" phenomenon is still alive and expanding exponentially by packaging or repackaging them in different names. The list of quackery-based therapies is enormous: pet me, squeeze me, sniff me forms of therapies, aromatherapy, relationship-based treatments, and many more. Busy parents nowadays use virtual voice services like Amazon's Alexa to engage their children in social, functional, and verbal communication skills. The device uses applause as a reward as they complete each step and music to supplement or ease stress upon completion of a task. It gives a virtual companion continually for the child and connects as a family.

Non-specific effects often confound results in intervention studies. Many studies fail to explain the placebo effect and the role of novelty in bringing positive results. **Resentful demoralization** occurs when participants aware of not receiving the active treatment turn resentful and respond more negatively than the treatment group to confound results. **Internal validity** is threatened when potentially therapeutic events other than the intended treatment influence the outcomes during the study. For example, historical maturation, natural growth, or developmental factors bring in changes not due to the administered therapy. **Experimenter or expectancy effects** unintentionally bias the results. **Multiple intervention interference** occurs when simultaneously or sequentially administering two or more treatments other than the intended one, which makes it difficult to isolate the effects of individual treatments. **Demand characteristics** are some participants' tendency to alter their responses during therapy according to their suspicions about the research hypothesis. **Regression towards the mean** is the tendency of extreme scores to become less extreme on re-testing. **Informant bias** occurs when informants selectively recall improvement due to their hopes and expectations (retrospective bias) or unintentional distortion of improvement. The improvements following interventions may be due to testing itself as attributed to **practice effects**. **Selection bias** occurs in case-controlled studies owing to the choice of retention of participants. Information or misclassification bias can happen due to inaccurate measurement, classification of disorders, misdiagnosis, recall bias, missing data, social desirability responses, inaccurately calibrated instruments, etc. [32, 61]. With so many confounding factors in place, one must be wary of claims or counterclaims on cures for autism.

### **Retrospective/posthumous diagnosis**

A retrospective diagnosis is a practice of identifying an illness condition after the death of a person. It attempts to give a modern name to an ancient or bygone occurrence—often separated even by several centuries. In doing so, historical, or religious records maybe even touted as scientific evidence. The whole exercise is a pointless and fallacious endeavor, given that it is based on incomplete or unverifiable



information. To call Ahalya, a mythological character in the Indian epic Ramayana, as having suffered catatonia, or to claim that the first instance of plastic surgery occurred in ancient India when Lord Ganesha was replaced with an elephant's head is as fallacious as to declare Charles Darwin, the founder of Theory of Evolution, had Asperger's Syndrome, or Albert Einstein had Learning Disability. Equally unscientific, it is to postulate certain living legends like Bill Gates as possibly suffering from autism because he shows rocking motions while thinking, lacks eye contact, or has monotonous speech patterns. The phenomenon of retrospective diagnosis is anachronistic because it tries to diagnose a past condition based on present times. Diagnostic labels are manufactured categories, and they do not exist in the absence of a diagnostician. The diagnostic labels themselves frequently get altered or eliminated as homosexuality is a treatable mental disorder no longer today. It also raises ethical issues related to damaging a dead person's reputation with a modern-day label. Although they help promote, advertise, sell, merchandise, and market the cause of autism through media, they result in commodifying [70-72].

### **Cost, commodification, & media**

Over the decades, the field of autism has grown into the largest and most complex human service delivery system worldwide. Millions of dollars are transacted every day with few regulatory mechanisms to monitor or audit them. A good amount of manual labour goes into delivering these services with or without equally matching results. The seeking for services is more than the supplies. Licensing and certification are minimally present. In the guise of public education, autism is being promoted with a spice of fiction through movies. Their Indian makeovers are not far behind. Television shows are popularized, novels, documentaries, family dramas, science fiction, comedies, romance, autobiographies, and biographies eulogizing these persons are gaining attention. Museum exhibitions and regular newspaper columns have fuelled popular imagination on autism. The prevailing system, often nicknamed Autism Industrial Complex (AIC; 73), covers the various businesses and industries that monopolize by thriving, capitalizing, and profiting in the name of autism. In short, autism is currently a big business. If there is an autism ABA industry on one side, many others are pandering to pseudoscientific treatments in the names of hyperbaric oxygen therapy, hippotherapy, zeolite therapies, and many others [74, 75].

No other clinical condition has attracted media attention as autism. Although intended to spread awareness, media has ended in spreading stereotypes, sensation, and commodifying autism. Since the 1970s, media portrayals beginning from "Rain Man," for which Rimland was the technical adviser. Fiction can reach out and achieve many things that facts may not. Brand Ambassadors and endorsements by political and film personalities have frequently hyped the whole issue of autism. Whether it was Jennifer Ann McCarthy, actress, model, and television host who turned into an American anti-vaccine activist in the 1990s after an impression that her son was autism (which later turned out to be wrong), or another speculation later that Bill Gates, the Microsoft giant, had all the indicative signs and symptoms of Asperger's Syndrome, or the high functioning autism there has never been a formal psychometric diagnosis. It was just an armchair impression. Time magazine said so. The fallout was that the Bill and Melinda Gates Foundation took a firm stance in the infamous vaccination debate. They started the Autism Hiring Program at Microsoft with full reimbursement for ABA interventions. This resulted in another publicity for the ABA industry, which is beginning to catch up belated now even in India [76-80].

### **Legal, ethical & political concerns**

Engaging persons with autism with the criminal justice system either as victims or as perpetrators is an area of study that is not studied. Every aspect of autism can fall under the scanner of ethical, legal, or political concern. When the British Prime Minister showed vaccine hesitancy, his personal decision became a public affair with a setback to the country-wide immunization program [81]. There are ethical concerns related to the clinical code of conduct, including professional training, competence, certification of expertise, respect for others regarding privacy and confidentiality. In reality, there are narratives of horror stories in autism [82, 83]. For example, the practice of ABA requires the official endorsement as Board Certified Behaviour Analyst. There are reports that some persons with autism had to endure "sticky hands," where their hands were stuck down with tacky glue as a form of punishment. Some argue that the commercialization of ABA has reduced it to something like teaching dog tricks. Most often, it is noted that what the child learns in the

settings of ABA does not generalize to the real world. ABA views autism as some kind of a tragedy like cancer. If they are not treated ethically, they will be doomed [84-86]. On occasions, ethical issues may transgress or transform into medico-legal issues during the practice of ABA [87].

## CONCLUSION

It is high time that the myths of autism are laid threadbare and openly discussed. Suppose the epidemic myth requires to be reconstructed at one end. In that case, the vaccination myth needs burial along with the concepts of "refrigerated mothers," claims for their "cures" debunking the "savant syndrome claims," or that it is an inherent behaviour or mental disorder with communication and social skill deficits. Equally abominable are the notions that persons with autism do not want friends or are asexual creatures. The driving themes currently engaged in autism vary across a wide range of topics. They include stress, mental health, impact, behaviour problems, parents' experience, families, social support, and quality of life. With the advent of the corona, tele-applications for diagnosis and interventions are a growing concern. Other questions like whether the heterogeneity of autism is a fact or artifact due to the conceptual ambiguity or due to the happening of genetic variations, the "gold standard" and "best practices" continue to be scrutinized repeatedly. The obsession over themes or topics like gut microbial regulation, biomarkers, risk genes, and "new" gene discoveries, epidemiology, the role of consanguinity, and gifted individuals in autism continue to engage researchers in autism in a relentless reinvention of the wheel even today.

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