

UNDERSTANDING AUTISM: Medical Model Versus Neurodiversity

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Introduction

Autism is an area of research that has been approached with a range of perspectives and models that either build on or remain at odds with one another. This essay provides an overview on how the subject of Autism has been established since its inception in Disability Studies, beginning with the Medical Model Perspective, and branching out to the contemporary alternate approach of Neurodiversity, influenced by the Social Model of Disability.

The original perception on disability has progressed over time. This development relies on the advancement in research and is influenced by socio-cultural factors impacting legislative changes. As a result, various models of disability have been presented, two of which have played a vital role in the transformation of the perception causing a paradigm shift. These constitute the Medical Model and the Social Model.

The first section of the paper provides the historical background of Autism beginning with how it became nuanced from the once misunderstood assumption of Childhood Schizophrenia to a spectrum of complex manifestations outlined within the Medical Model Perspective. This section outlines the definition proposed by the Medical Model and the variations of Autism that can be understood from that definition.

The second section of the paper introduces the emerging perspective of Neurodiversity and its distinct understanding of Autism.

The third section presents a comparison between the two perspectives i.e., the Medical Model and Neurodiversity. This segment analyses the critical aspects that inform the differences between both perspectives.

The concluding section reflects on the debate on Autism within the field, inferred from the arguments presented in this paper.

A Brief History and Introduction to the Medical Model Perspective on Autism:

Autism Spectrum Disorder, previously confused with Childhood Schizophrenia and misunderstood as Schizotypal Personality Disorder in some adults is classified as a neurological/developmental condition characterized by persistent social and communication deficits that adversely affects all important aspects of an individual's day to day life.

Autism was first described by Leo Kanner in 1943, who in his article presented a brief history of eleven children (eight boys and three girls) and discovered that despite the remarkable similarities, this condition differs in many respects from all other known instances of Childhood Schizophrenia (Sean Cohmer, 2014). He also mentioned children with delayed Echolalia exhibiting the desire to maintain uniformity in their lives and resistance to change. He further stated that these children were also gifted in terms of intelligence and possessed extraordinary memory. This led Kanner to mark Autism as a psychiatric condition that is a manifestation of an emotional disturbance rather than a cognitive one. It

is said that Kanner had borrowed the term 'Autism' from Eugene Bleuler who used it to describe self-absorbed aspects of Schizophrenia in adults. He then coined the term 'Infantile Autism' – however, never considered it an early prodrome of Schizophrenia. This realisation was a breakthrough which led to the evolution of the clinical definition and diagnostic criteria of Autism. Currently professionals use the Fifth Edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) to perform diagnosis. DSM-5 is a publication of the American Psychiatric Association (APA) which has included Autism in a broad category of pervasive developmental disorders. This revised edition presents a more precise and scientifically applicable way of diagnosing Autism.

Another term that plays a critical role in articulating our understanding towards Autism is '*spectrum*'. Spectrum signifies the variation of social, communication and behavioural characteristics of Autism, ranging from mild to moderate or severe.

The resulting variation is classified in the following levels of severity:

Level 1- Requiring support

Level 2- Requiring substantial support

Level 3- Requiring very substantial support (American Psychiatric Association, 2013).

The criteria "B" of DSM-5 from American Psychiatric Association (2013) consists of the behavioural aspects of Autism which are as follows:

'Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history

1. Stereotyped or repetitive motor movements, use of objects, or speech (simple motor stereotypies, lining up toys or flipping objects, Echolalia, idiosyncratic phrases).
2. Insistence on uniformity, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper/Hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).'

These behaviours are often referred to as 'Restricted and Repetitive Behaviours' (RRBs), some of which serve no social function however play a vital role in relieving stress whilst compensating for any fluctuations in sensory experiences. RRBs are a core diagnostic feature of Autism and according to the criteria set by DSM-5, any two of the above-mentioned types must be present to pertain diagnosis.

It has also been observed that these behaviours may differ significantly from each other. However, the only binding factor is the inflexibility in thinking which can be dealt with by acting with prompt efficiency through early intervention.

Since the term 'Restricted and Repetitive' refers to a broad range of diverse behaviours, RRBs have been divided into two clusters: 'Lower Order'- Motor Actions; and 'Higher Order' - Behaviours.

Lower Order - Motor Actions

Lower Order motor actions entail:

- a) Repetitive Manipulation of Objects (RMO)
- b) Stereotyped Motor Movements (SMM)

RMO is the prolonged engagement of squeezing, rubbing, flicking, spinning, lining up, stacking, swiping, or moving objects in a repetitive manner. In addition, it is considered as one of the early signs indicating the presence of Autism.

As far as SMMs are concerned, they involve flapping of arms and hands, pressing, rubbing, or patting a body part and stiffening fingers, hands, or arms (Elison et al., 2014). It is also important to note that SMMs are prominent and potentially permanent clinical characteristic of Autism.

These bodily movements are also commonly known as Motor Stereotypies.

A more troubling form of Motor Stereotypies is Self-injurious Behaviour (SIB) which involves the occurrence of an action that leads to physical harm directed towards self, typically in the form of tissue damage (Matson & Turygin, 2012). The frequency and intensity with which SIB can occur varies from person to person, ranging from mild and irregular to chronic and severe (Summers et al., 2017). The most common form of SIB is head banging, other forms include head hitting, scratching, slapping, picking, or pinching the skin, biting, eye poking, hair pulling, vomiting, and ingesting non-edible substances - a condition known as "Pica" which drives an individual to compulsively swallow items that are not food, (Shawler et al., 2019). Self-injury can eventuate due to a variety of reasons; it might be associated with a biochemical abnormality or a seizure activity in the brain while some researchers have suggested that level of arousal plays a vital role in triggering these behaviours (M. Edelson, 2022). Other reasons can include

1. Sensory sensitivities
2. Frustration due to poor receptive or expressive communication
3. Escape from an aversive social encounter
4. Presence of co-occurring medical health related issues.
5. Difficulty in regulating emotions.

Repetitive vocalization also falls under category of L-RRB (Lower Order RRB). Constant humming or monotonous iteration of phrases, also known as Vocal Stereotypy, may serve a distinct function of gaining auditory stimulation or attention (Kahveci & Serin, 2019).

Higher Order - Behaviours

Higher Order behaviours which include insistence on uniformity, fixation on idiosyncratic routines and manifestation of circumscribed interests are linked with a distinct cognitive framework that adhere to a rule which compels individuals on the spectrum to have everything in their surroundings in order or in a certain preferred way (Nichols, 2021). These behaviours have been reported to be more detrimental than L-RRBs (Lower Order) to both Autistic individuals and their families as they reflect extreme rigidity and inflexibility (Emily, 2021).

In addition to interfering with the areas of learning, such behaviours also have a significant impact on sleeping patterns, ability to explore play and hold conversations beyond their fixed interests. This results in the Autistic individual having poor academic performance, prolonged isolation periods and minimal reciprocation with family members. (Lin & Koegel, 2018)

The remaining attributes of Autism, required as a criterion of diagnoses, are ‘Social Communication’ and ‘Social Interaction’.

Social Communication and Interaction

Social communication, also known as Pragmatics, refers to the way language is used in social contexts. To assimilate the concept behind the term “Social Communication” it is important to discuss its three prime components.

1. Appropriate use of language for distinct instances such as greeting people, sharing information, making a request, or giving command.
2. Modifying language according to the need of the listener or different social conditions for example adopting a formal tone in a professional setting, being aware of the listener’s knowledge and providing or withholding information as per the requirement, adjusting the tone in accordance with the noise present in the environment. This adjustment of tone is also called “Prosody” that refers to a set of variables in speech such as pitch or rhythm that affect how a message is communicated.
3. Following conversation rules which includes turn taking, choosing different words to explain a point, using appropriate gestures, facial expressions, eye contact or body language when needed. (National Institute on Deafness and Other Mental Health Disorders, 2022)

Upon establishing that the combination of aforementioned components is essential to develop ideal Social Communication skills, the next phase is to outline instances where the Autistic Individuals lack certain elements of these components, and the resulting deficit affecting their interpersonal skills. These are explained in the Criterion “A” definition of DSM-5.

The criterion “A” of DSM-5 consists of the interpersonal aspects of Autism which are as follows:

“Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers”

It is important to note that according to DSM-5 complete absence of language or its delayed and atypical development is no longer a criterion for Autism. However, a child must have persistent deficit in each of the afore-mentioned areas to pertain diagnosis.

Furthermore, it is critical to mention that a fluently verbal Autistic individual might have extensive vocabulary but could struggle with the nonverbal aspects of language like using or comprehending the partner’s gestures or facial expressions or maintaining eye contact endorsing the fact that people on the spectrum behave differently in a social setting than what is expected by society.

Some individuals on the spectrum might also display rigidity or repetition in their language such as using stock phrases every time to start a conversation. For example, saying “My name is Jack” even when talking to friends or family or simply repeat others’ words or sentences. This rote and literal

repetition of the speech of others is known as 'Echolalia' and can be classified into either Immediate or Delayed. (Kanner, 1943).

Immediate Echolalia occurs when an individual responds by mimicking words or phrases of his/her communication partner, with some, or no mitigation, and affirmation is also communicated by literal repetition of the question. (Mcgee, 2012). While Delayed Echolalia occurs when an individual has heard something before (can vary from hours to years) and later repeats it.

Experts use the term 'Social Communication' to shed light on the fact that Neurotypicals might face issues with language or speech but not with 'Social Interaction'. However, Autistic individuals encounter challenges in social contexts regardless of how fluent they are with words. Diminished or inequitable tendency to share interest has commonly been observed; either the individuals would abstain from sharing enthusiasm on their subject of interest, or the sharing would be unequal (perseverate on their topic of interest without comprehending their communication partner's active or lack of interest.

An important aspect of Social Communication is Social Interaction, a process by which we act or react to the people in our surroundings during a social encounter. Even though the two terms are often used interchangeably, there is a slight difference. Social Communication signifies the act of sharing information while in the case of Social Interaction, the information being shared, proactively affects others, and generates a response.

Individuals on the spectrum might experience a decline in social connectedness and often face difficulty in understanding or recognizing mental states of other people. This complication ultimately makes it difficult for such individuals to navigate within the expected societal conventions.

In addition to this, they also lack the social qualities that are associated with play like being flexible and spontaneous with toys, engagement in pretend play or playing in a group setting. (Grant, 2016).

It is apparent from the facts stated above, that the Medical Model focuses on symptoms of the condition and puts emphasis on 'fixing' the individual through medication and or by therapy.

The next section elaborates the Social Model. Contrary to the Medical Model, the Social Model instead of pathologizing the challenges, focuses on the goals, strengths, and experiences.

A Brief History and Introduction to the Neurodiverse Perspective on Understanding Autism:

Post 1990s, the field of Autism Research experienced an emerging paradigm shift in its conventional approach of the Medical Model towards Autism. This shift of perception is referred to as Neurodiversity.

Neurodiversity formulates the idea that no standardized model of a brain exists against which all other human brains must be compared and conditions like Autism, Attention Deficit Hyperactive Disorder (ADHD), Dyslexia or Dyscalculia etc, should be regarded as naturally occurring cognitive variations with strengths. It advocates the proposition that by substituting the disability prototype with a diversity perspective that reckons both strengths and challenges we allow more room to eliminate the barriers imposed by societal norms that are causing social exclusion and inequity.

A Neurodiverse perspective dismisses the existing notion outlined by the Medical Model under which Autism has been recognized as a disorder with a set of impairments and deficits. Instead, the Neurodiverse Perspective claims to understand Autism as a neurological difference advocating

strengths to prevent social exclusion. The term Neurodiversity was first coined by an Australian sociologist, Judy Singer in the late 1990's who in her thesis argued that Neurodiversity must be considered a new category represented by the marginalized groups that should and would be worthy of making its way alongside other categories for political action effecting change. (Disabled World, 2014) Neurodiversity Movement instils an idea that challenges the deficit-based stereotypes and misconceptions about neurological differences and focuses on replacing them with an approach which highlights the positive aspects of Autism and other subsequent groups.

Neurotypical - a term used to refer to an individual, who lies within the typical range for human Neurology is in fact a construct subjected to a contentious issue which claims that a standardized human brain does not exist therefore considering someone Neurotypical would be misleading. This idea, also known as "Cerebral Pluralism", played an important role in laying the foundation of the Neurodiversity Movement. (Planning Across the Spectrum, 2020)

Advocates of this movement believe in a strength-first approach to understanding Autism. They have raised voice against the functioning labels (high/low functioning) which has resulted in the elimination of these terminologies, consequently substituted by different levels of Autism (1,2,3) in the DSM V. According to them functioning labels don't do justice in describing an Autistic individual's needs because those needs are not dependent on one's IQ. (Planning Across the Spectrum, 2022).

A Neurodiverse Perspective talks about how creative Autistic individuals can be with their distinct imagination. Their ability to pay attention to detail helps them to stay focused without being distracted while excellent retention of facts with an outstanding long-term memory can help them reach higher levels of skills sharpening their expertise. Being visual learners, they have the tendency to retain information for longer periods of time. Having a literal perception of the world they tend to be non-judgemental and honest. Their loyalty and commitment are unquestionable which help them build strong bonds with others making them dedicated in both professional and social circumstances. Keeping in view the qualities one can conclude that according to the Neurodiversity point of view; Autistic individuals are not a distorted impression of the 'normal'. They are different, not less - *Temple Grandin*

Comparison Between the Medical Model and Neurodiversity

It seems evident from the discussion above that there are two ways of understanding Autism; the first is the Medical Model, which views Autism as a set of symptoms and deficits that require treatment. The second is the Social Model, which fosters Neurodiversity and considers Autism as an identity that can be celebrated and must be accommodated by society regardless.

The first difference between the two perspectives pertains to societal implications. The Medical Model focuses on identifying the causes and the interventions required to reduce the symptoms so that the individual can function as normally as possible in society. However, Neurodiversity argues the Medical Model has a discriminatory approach. This is reflected in society being structured in a way that leads to the marginalisation of Autistic individuals. It claims that a 'diagnosis' must not determine how an individual will fit into society.

The second difference can be attributed to the debate of seeking a cure. The Medical Model aids in determining how the disability affects an individual's life and could be used to initiate a better understanding. However, Neurodiversity challenges the Medical Model approach in seeking a cure as its advocates celebrate Autism as an inseparable aspect of an individual's identity, requiring no antidote for reversal.

The third aspect to consider is the importance of professional help versus the importance of social attitudes in nurturing a conducive environment. The Medical Model proclaims that an Autistic

individual must approach a professional for help, while Neurodiversity talks about how help is embedded within society and approaching Autistic individuals with respect and equality can bring about a positive change in their lives.

The final point of debate between the two perspectives pertains to the alteration of a Neurodivergent individual's behaviour to the Neurotypical societal standards. It is a common misconception that the Neurodiversity Movement denies medical treatment or is based on the belief that Autistics are individuals who do not require any assistance. This assumption is misleading as the Neurodiversity Movement believes that treatment is required only if it benefits the individual rather than changing their behaviour to suit the conventions of society. The practice of behavioural therapy is a good example that clarifies the aforementioned misconception. If the goal of the therapy is to eradicate hand flapping or to force eye contact, then according to the advocates of Neurodiversity it is unjust to do so as communication is possible without eye contact. In addition, hand flapping should only be regarded as a distinct trait that is neither causing harm to self nor to others. Therefore, it is society that must adjust according to the unique needs of every individual. The Neurodiversity Movement uses this example to validate its claim that the Medical Model forces Neurodivergent individuals to adjust neurotypically by eradicating certain traits that are distinct to their identity.

Conclusion:

The transformation of Autism diagnosis, from its discovery as it was first described by Kanner, to its present-day understanding, as narrated in the Diagnostic Statistical Manual of Mental Health Disorders has seen significant evolution. The amalgamation of the role played by the advancement in research and several social reforms has given rise to various perceptions and approaches that presently inform the well-established Medical Model and relatively recent Neurodiversity. As for now the Medical Model is the most prevalent approach to Autism, with a focal point to treat Autism by interventions or medication while the Neurodiversity Movement's target is to restructure society so it can be more inclusive and respectful of the neurological differences present within. However, it is critical to understand that there is no universally acceptable way of perceiving Autism, and the model that is more likely to achieve full Autism emancipation remains inconclusive.

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