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Challenges in Assessing Children with Autism: Making Informed Choices to assess the Spectrum

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ABSTRACT

Autism is a neurodevelopmental disorder with a diverse presentation. Our understanding and theories of the diversity of the condition are constantly evolving. The clinical profile of symptomatology and behavioral challenges need to be taken into consideration during the assessment of their skills and abilities. Most manualized psychological assessments are normed to the majority of a population, which automatically puts the neurodiverse population at a disadvantage, especially Autism, and the entire spectrum of its clinical presentation. The challenges faced by the stakeholders (parents, teachers, therapists, prospective employers, and persons on the spectrum themselves) in home, clinic, and classroom settings need to be put together with the scores of the assessments conducted, otherwise, the numbers will always remain an arbitrary concept. The current article attempts to find avenues within manualized procedures to assess children with Autism, otherwise prematurely labeled as 'untestable'.

Keywords: *Autism, IQ assessment, VIQ, PIQ, FSIQ*

Autism, a neurodevelopmental disorder characterized by deficits in communication, socialization, and repetitive restrictive behaviors (American Psychiatric Association, 2013), has its presentation on a spectrum – where traits/symptoms are manifested in varying degrees.

Several areas of research, include etiological research and impact research, the effect of parenting (which has been subsequently disregarded), to the current focus on epigenetics and machine learning. Changes in the perspective of diagnostic manuals (DSM-5 and ICD 11), currently emphasize adaptive behavior, which helps understand the long-term impact of the diagnosis. However, the involvement of cognitive functioning is undeniable. Cognitive function, though a broad umbrella term, has its influence on daily adaptive functioning, learning, acquisition of skills, academic performance, and social adjustment. Understanding cognitive ability is one of the cornerstones in making a holistic plan for the child's therapeutic progress.

The assessment of intellectual ability (IQ assessment) is the most common method of assessing cognitive ability. It is a highly manualized and standardized method of testing to understand the level of the child's skills, in the context of peers of their chronological age. IQ assessment yields a score that is interpreted as the intellectual ability of the child. The benefits of IQ assessment include (a) diagnostic clarification; (b) obtaining a profile of strengths and weaknesses (Klin et al., 2005); (c) assessment of intervention efficiency (Estes et al., 2015) (d) long-term outcome predictions. Their latest revisions attempt to provide a profile of abilities instead of one absolute score. The advantage is a profile sheds light on the strengths and weaknesses of the child, which in turn lends itself to myriad benefits in areas of therapy and training, or even in formulating individualized plans.

Kanner (1943) postulated that autistic children tend to have 'good' cognitive ability. However, subsequent research studies have shown mixed results. Studies indicate they have the entire range of IQ, from Intellectual Developmental Disabilities (IDD) to extremely high IQ levels (Charman, 2010). The Autism & Developmental Disabilities Monitoring (ADDM) Network found among 8-year-olds, 31.6% had IDD, 24.5% had Borderline Intelligence, and 43.9% had average or above-average IQ ranges (Goldstein et al., 2008). However, these mixed results are likely due to symptomatology interacting with various testing factors, which may result in spuriously low scores (Brown, 2000).

IQ is a strong predictor of future outcomes (school, work, achievement) for not only the ASD population but amongst neurotypicals too (Holwerda et al., 2012). Testing of intelligence is part of the recommended interdisciplinary diagnostic evaluation for children with Autism (Volkmar et al., 2014). ICD 11 also has specifiers based on intellectual functioning for diagnosing autism (World Health Organization, 2018).

Cognitive profiles in autism have no definitive pattern, varying based on age, IQ level, symptom severity, and co-morbidities. People on the spectrum have "splinter skills" in areas of reading, memory, math skills, visuospatial skills, semantic knowledge, and various art forms (Meilleur et al., 2015). On the other hand, they have their own set of cognitive weaknesses including but not limited to, atypical perception, inattention, predictive cognition, cognitive inflexibility, and perspective-taking. Depending on the task or domain tested, the splinter skills and the weaknesses skew the child's performance, making interpretation of IQ scores a challenge. Comparably higher IQ scores and lower

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symptom severity have been seen as prognosticators of optimal outcomes in autism (Di Renzo et al., 2021).

One of the greatest limitations of focusing only on the IQ score as an absolute measure of a child's functioning is evidence that the same IQ score can be associated with varied cognitive profiles (Goharpey et al., 2009). Rommelse et al., (2015) attempted to understand if cognitive deficits in ASD were a function of the IQ, concluding that children with below-average IQs had more severe cognitive impairment, leading them to postulate that intelligence may be a moderator in the cognitive presentation of ASD. Volkmar et al. (2014) believed that IQ served as a frame of reference to evaluate the social, cognitive, and communicative difficulties of a child.

The three well-known cognitive theories implicated in Autism are Executive Dysfunction, 'Weak' Central Coherence (Frith & Happe, 1994), and 'Theory of Mind' difficulties (Baron-Cohen, 1985). Brunsdon et al. (2015) found a third had two or more areas of cognitive deficits, while most of them had impairments in one domain, also concluding that a higher level of symptomatology is associated with multi-domain cognitive deficits.

Assessing intelligence in autistic children has proven to be a challenge. This article attempts to list out the challenges and their reasons, as it would provide stakeholders involved in the child's care, to make informed decisions about the child's abilities.

The challenges will first be discussed in terms of test factors, and autistic symptomatology.

Difficulties with the instrument:

Interpretation of IQ tests relies strongly on norms. They provide meaning to raw data by converting it to scaled/standardized scores based on age, gender, and/or grade level. In simpler terms, it is comparing the individual's performance to the performance of others with similar demographics (Timmerman et al., 2020). Norming, despite several efforts to decrease error and keep it relevant, can pose several issues.

1. **Culturally or diagnostically appropriate norms:** The deliberation of assessment for culturally diverse populations has been ongoing. Several studies have acknowledged the lack of culturally appropriate norms for IQ assessment (Shuttleworth-Edwards, 2016), the absence of appropriate diagnostic and screening tools for Autism (Wallis et al., 2008), and relevant intervention modules for Autism (DuBay et al., 2018). Incidentally, Carter et al. (1998) established norms for the Vineland Adaptive Behavior Scale-II (VABS) for autism, where he provided percentile norms for four groups, based on chronological age and language development. Considering these well-researched viewpoints, it is postulated that existing normed IQ assessment tools are diagnostically and culturally not relevant to autism.

2. **Updated Norms:** The biggest difficulty of using norm-referenced tests is the lack of updated norms. The latest available Indian norms (Wechsler, 2013) for a standardized IQ test is the WISC IV (Wechsler, 2003), while the WISC V has been in use since 2014, internationally. The well-established concept of the Flynn effect postulates an increase of three points in the standard score every decade (Flynn, 1984). The lack of relevant norms has a far-reaching impact as the narrow, outdated choice of assessment tools available, severely limits the scope for a strength-based assessment, especially for a population as distinct as autism.

The available measures with autism included in the standardization sample are, (a) Bayley III (Bayley, 2005) (b) WPPSI-IV (Wechsler, 2012) (c) WISC-V (Wechsler, 2014) (d) Stanford-Binet-5 (Roid, 2003) (e) Vineland II (Sparrow, 2005) and Vineland3 (Sparrow, 2016); (f) Leiter International Performance Scale 3rd Ed (Roid, 2003) (g) Adaptive Behavior Assessment System – 3rd Edition (Harrison, 2015). The tests that have not included autism in the standardization sample, but have been well-researched with the population, are (a) Differential Ability Scales-II (Elliot, 2007); (b) Mullens Scale of Early Learning (Mullen, 1995) (c) WASI-II (Wechsler, 2014) (d) Kaufman Brief Intelligence Test-2nd edition (Kaufman, 2004).

Despite having about eleven cognitive measures, mentioned above, we, in India, have only one test –the WISC IV which has norms standardized on the Indian population.

Influence of ASD symptomatology on IQ assessment:

1. **Language Processing Impairments:** Language skills include receptive, expressive, pragmatic, and written skills; with every child having different levels of each skill. These are impaired in autism, especially when tasks involve speech. There is also a decrease in audio-visual integration (DePape et al., 2012).

Language deficits vary significantly along the developmental trajectory. Receptive and expressive language delay is a core diagnostic feature, where the presentation of the deficit varies with development and intervention. Also in autism, there is no simple presentation of 'language delay'; instead, there is the presence of the 'lack of intent to communicate' (Happe & Frith, 1996). Language Processing is also impacted by the severity of autistic features (Bavin et al., 2014).

The impact of language processing challenges is seen in the very first step of the assessment, which is understanding instructions. The diverse ways the same instruction is received and processed by each child

implies that every child understands what needs to be done differently.

2. **Attention Skills**: Attention deficit is an inherent feature of Autism. The absence of joint attention is a diagnostic indicator. Sustained attention and divided attention have been documented to be impaired (Shiri, et al., 2015).

Attentional hyper-focus is another feature, which influences repetitive, restrictive behaviors (Allen & Courchesne, 2001). In autism, attention is strongly based on their interest levels, and perform only if the task interests them.

Children who have not had any intervention, find participation in tabletop activities challenging. Children with impaired joint attention are unable to focus on the example/samples required to perform further tasks.

Taking attention abnormalities – joint attention, selective attention, divided attention, and shifting of attention – into consideration, some children have significant difficulties, especially on timed tasks, (Block Design, Coding, and Symbol Search tasks of the WISC IV), where more often than not they engage in the stereotypic play of blocks and writing tools, instead of the actual tasks.

3. **Sensory Processing Abnormalities**: These are flaws present in the process of understanding sensory stimuli – visual, olfactory, gustatory, auditory, vestibular, proprioceptive, and interoceptive (Mailloux et al., 2007). Over 90% of these children have sensory abnormalities ranging from hyposensitivity to hypersensitivity, and these differences in sensory processing may cause the various features of autism (Marco et al., 2011).

Haigh et al. (2018) argued cognition is impacted by sensory abnormalities. Additionally, sensory abnormalities influence attention skills and adaptive behavior (Dellapiazza et al., 2018). Leekam (2007), demonstrated sensory abnormalities persist irrespective of age or IQ range and the severity of sensory abnormality was higher in those with lower IQ scores.

4. **Motor Skill Deficit**: Motor Skills, broadly classified into two types – gross motor and fine motor skills – include coordination, balance, postural stability, locomotion, palmar grasp, and pincer grip.

As a group, autistic children exhibit poorer motor skills. More severe sensory symptoms and lower IQ were found to be the best predictors of motor ability (Surgent et al., 2020). The Verbal-Performance discrepancy has also been associated with motor skills, higher VIQ indicates poorer visuomotor and motor coordination, and higher PIQ indicates higher motor skills (Yu, 2018). Cognitive assessments require gross motor skills from core stabilization for sitting at the chair, to fine motor skills of grasping and manipulation of blocks and materials (Matheis, 2018).

5. **Repetitive and Restrictive Behaviors (RRBs)**: RRBs are a core diagnostic feature. The child displays behavior patterns that are repeated over and over again, and/or are circumvented to a limited interest area. Various behaviors come under this umbrella term – motor stimming (repetitive physical movements), verbal stims (repeating certain sounds, words, at times even sentences). Walking/running around and poor sitting tolerance can also be an RRB, rather than a feature of ADHD. The need for symmetry is another RRB that can interfere during assessment.

Higher the level of RRBs, the more challenging it is to engage the child in goal-directed activity. Like, a child with a high need for symmetry, finds the Block Design test significantly challenging, due to their intrinsic need to arrange the blocks in an idiosyncratic pattern. Poor sitting tolerance, and stimming, both verbal and physical, impact the process of assessment significantly.

6. **Executive Skill deficits**: Neurodevelopmental disorders are documented to have executive functioning (EF) deficits, manifested in varying degrees. EF is the efficient use of primarily the pre-frontal cortex functions, for goal attainment using appropriate problem-solving, involving higher-order processing like planning, decision-making, set-shifting, impulse control, and inhibition amongst others (Ozonoff et al., 1991). The different overlapping components include Attention Control, Cognitive Flexibility, Information Processing, and Goal Setting (Anderson, 2002).

Executive dysfunction is one of the cognitive theories explaining autism (Rao et al., 2016). The involvement of executive dysfunction was noted when the similarities were observed between those with traumatic brain injuries and frontal lobe dysfunction, and those with autism (Ozonoff et al., 1991). The main areas of EF deficit in autism have been noted in cognitive flexibility, planning, and working memory (Hill, 2004).

Cognitive flexibility is the ability to shift between tasks or actions based on demand (Geurts et al., 2009). Studies using the modified version of the Wisconsin Card Sorting Test (WCST) did find that autistic children had poorer scores on cognitive flexibility and disengagement (Yeung et al., 2016).

The clinical implications of these findings are seen when the sub-tests of the IQ test change without feedback. The child is expected to seamlessly move to the next task testing unrelated cognitive processes. Sometimes, even within a sub-test, the technique of reaching the solution changes, leaving the child to build upon recently acquired knowledge, and intuitively attempt various techniques for a successful resolution.

7. **Social factors**: A child with autism has an altered sense of achievement, accomplishment, competition, and motivation. All of these add to the drive to perform on a test and do their best, which is completely different in autistic children. Very often, young children need to be motivated with food or their favorite toy to elicit one response.

The Social Motivation Theory of Autism has been well-established and studied (Chevallier et al., 2012). When motivation is taken in its neuropsychological terms, it is completed by a continuous loop of monitoring and feedback (Stavropoulos & Carver, 2018). Autistic children find repetitive behavior and restrictive interests more motivating, rather than being motivated by any external factor.

Difficulties with IQ tests for children on the spectrum:

Amongst all available tests, autistic children do better on Ravens Progressive Matrices (Dawson, 2007), Leiter International Performance Scales (Grondhuis, 2013), and Stanford Binet-5 (Baum, 2014). The pattern of their performance on the Wechslers' scales has been studied intensively. Several studies have proven the Verbal-Performance Skew (PIQ>VIQ), which is typical of the ASD profile (Gilchrist, 2001; Charman, 2011). Analysis has further shown subtest-wise variance in their performance. Among the performance-based tests, they do significantly better on Block Design (Gilchrist, 2001; Takayanagi et al., 2021), Matrix Reasoning (Oliveras-Rentas et al., 2012; Mayes & Calhoun, 2008). On the verbal tests, they do relatively better on lexical-based tests like Information, Vocabulary, and Similarities, rather than Comprehension (Mayes & Calhoun, 2003), involving social reasoning and complex language processing. They have challenges in Working Memory and Processing Speed, as highlighted by poorer scores on Digit-Span (Mayes & Calhoun, 2003), Coding (Mayes & Calhoun, 2008), Symbol Search (Nader et al., 2015), and Letter-Number Sequence (Oliveras-Rentas et al., 2012). The relatively lower scores on the subtests of the Working Memory Index and the Processing Speed Index are due to the challenges in working memory, which is one of the main components of EF (Wang et al., 2017).

Working with the challenges:

The various challenges faced by autistic children have been elucidated until now, with decades of research that prove it. It is evident that children with diverse neurodevelopmental disorders such as autism are at a disadvantage when measured on tools standardized on the neurotypical population. While having an equating measure is important, it is also vital to work with neurodiverse strengths and challenges. Slight alterations in the testing procedure, without diluting the sanctity of the test administration, can help get the best performance out of these children.

Pilvang and Brown (2000) describe a phenomenon, they call 'blocking', a pattern of responses or behavior that aimed to avoid certain types of responding. It is postulated that autistic behavior patterns interfere with response to the stimuli presented and the behavior of blocking thwarts any abnormal response pattern. They concluded that children with ASD obtained average to high IQ levels when specific techniques to counter the 'blocking' behavior. Using the Peabody test, they obtained average–high IQs with children who previously were tested to have sub-normal intelligence or were considered untestable when a multi-sub-test battery was used.

Similarly, Koegel et al. (1997) explored how attention and motivation impact test scores in autism. Several IQ assessments were conducted in two conditions – the standardized condition, where the instructions in the manual were followed exactly; the motivation/attention design, where they accounted for the motivation/attention factors that could interfere in testing based on clinical observation/interview. They conclude that factoring in the motivational/attentional attributes resulted in a higher score on multiple standardized tests, such that some children deemed 'untestable' on the standardized condition, obtained scores in the adequate range on the motivation condition.

Several other techniques that are well established in the field of Special Education and therapy can be incorporated into the testing procedure.

Instructions: Existing standardized instructions could be given pointwise or step by step. Children can be made to repeat what is expected. In the sub-tests that have an example or sample item, it can be demonstrated or roleplayed with the parent, without any extra explanation. This will help the child observe what is expected of them. Use phrases or words the child is comfortable with, instead of introducing a new word and penalizing them for not understanding what is expected of them. Example: using the words 'matching' or 'same-same' instead of alike or similar, for the Similarities or Picture Concepts subtest; or even using a sentence stem, like 'both carrots and peas are…'; or coaching the parent to give the instructions, especially in cases where the child tends to listen only to the parent.

Priming: This technique can be used to help the child understand what is expected of them, without giving away the test materials or exposing actual testing items. Example: getting the child to imitate the assessor before the Block Design test. The imitation can be in the form of a game of hand tapping, which can then progress to

imitation with single block colors before the actual Block Design sub-test begins.

Visual Schedules: This is the best technique for preparing a child for work that is expected. As each sub-test is over, the child can score off or peel the item off the schedule. This can be done without divulging the nature of the test or the procedural rules of the sub-test (Dettmer et al., 2000).

Breaks and Stim-time: Some children with poor sitting tolerance and attentional difficulties tend to perform well with several breaks, just as children with RRBs and sensory issues do well with regulated stim-time or fidget-time. Having these incorporated within the visual schedule makes the rest of the assessment smoother.

Despite the planning that is required to try and make these techniques uniform and standardized, it is vital to be willing to act immediately when unforeseen events occur. An assessor should always be prepared to diffuse a meltdown before it occurs or deal with behavioral difficulties that can be unique to each child.

CONCLUSION

Intelligence as a construct is a relatively stable one; however, IQ scores vary based on several reasons that have been discussed. Standardized, manualized assessments have certain unwritten pre-requisite competencies that autistic children inherently lack. Low scores on cognitive assessment could be an artifact of decreased attention, social disengagement, emotional dysregulation, or any of the factors discussed above, rather than actual cognitive inability. The procurement of an IQ score requires several of the aforementioned factors to be in the optimal range, and disturbance of even one of the factors can make it almost impossible to get a score. This is the singular reason why it has always been difficult to obtain an IQ score for them, such that most research studies in the field control for IQ.

We acknowledge that the process of assessing a child with autism can be daunting. However, several techniques can be utilized to ensure the child is not penalized for the features of his diagnosis. Understanding that they lack the skills and continuing to put them through stringent assessment techniques is setting the stage to measure their incompetence. However, learning about the child's symptomatic and behavioral challenges and making allowances for them in a pre-determined method, keeping in mind what is permissible by the manual, is the means to obtain a strengths-based score of their abilities, as described in the previous section. Accommodating a child's physical challenges during assessment has always been in practice, where no Clinical Psychologist penalizes the child for physical disability. A process where accommodations are made, in a systematic and documented manner, is vital to ensure no autistic child is penalized during the assessment, for their symptom profile.

Unless assessment with autistic children follows a strengths-based approach, it is best that we (mental health professionals, therapists, educationists, and other stakeholders) refrain from treating the IQ score like an exalted absolute score, as it would not be truly reflective of the child's actual ability.

Conversely, having supplementary norms or norms specific to children with developmental disorders or autism could equate some of the variability and scatter in the profiles obtained.

It is also important to note that a valuable report of the child's abilities has a careful and detailed behavioral observation, even session-wise if need be, to interpret the scores in the light of the child's clinical symptomatology. Other factors like detailed adaptive profiles, cognitive profiles, learning profiles, and language and sensory profiles need to be used in conjunction with the IQ score to understand the abilities of the child in a diverse presentation like autism.

Disclaimer: The terms children with autism and autistic children are used interchangeably to take into consideration the current preference of autism self-advocates.

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Letter to Editor

Locomotor Capabilities and Quality of Life among Lower Limb Amputees

Dear Editor,

Quality of life is likely to be affected by amputation of a limb. However, little is known about the health-related quality of life of amputees. Authors assessed locomotor capabilities and quality of life among lower limb amputees, using cross-sectional design. The respondents were selected using a convenience sampling method. The data was collected from 75 lower limb amputees living in Chennai. A schedule of interviews was used to collect the relevant information from the respondents.

Authors observed that as a result of trauma, peripheral artery disease, or diabetes, several respondents had their lower arms amputated (transtibial). According to the findings, most respondents had better locomotor capabilities with prosthesis, as they could walk alone. There was a significant positive effect of prosthesis usage satisfaction, psychological adjustment, locomotor capabilities, life enjoyment, and quality of life. Respondents had better life enjoyment and overall quality of life. They had a lower level of stress evaluations with a presentation of better oral/emotional state.

Observations concluded the rehabilitation through aids and appliances facilitates the day to day living of persons with locomotor disability.

Thanks

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