

Assessment of Autism Spectrum Disorders in Children with Visual Impairment and Blindness

Moire Stevenson, Annie Chatillon & Mariah Lisi

CIUSSS West-Central Montreal

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*Correspondence:

*Dr. Moire Stevenson. CIUSSS West-Central Montreal; Email: info@moirestevenson.com.

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Abstract

Children with visual impairment and blindness (VIB) are consistently reported to show higher rates of autism spectrum disorder (ASD) or ASD-like features than sighted peers, yet the nature of this association remains unclear. A major source of ambiguity lies in the use of assessment tools developed for sighted populations, as these tools rely heavily on visual behaviours such as gaze following, joint attention, and eye contact. In children with VIB, these markers may reflect sensory differences rather than underlying neurodevelopmental disorders, increasing the risk of misdiagnosis. This commentary critically reviews recent adaptations of standard instruments, alongside the emergence of specialized measures. While adaptations and innovations show promise, their limited validation and integration into clinical practice hinder their impact. The present commentary builds on the findings of the scoping review by Stevenson & Tedone, 2024, which examined studies published between 1995 and 2020. The present work reflects on that body of evidence and notes that additional work since continues to shape understanding in this area. Taken together, these issues highlight the need for assessment frameworks that move beyond sighted developmental norms, prioritizing tools and training designed for non-sighted children. Only with rigorously validated instruments, longitudinal research and formalized guidelines can clinicians distinguish between neurodevelopmental disorders and expected development in children with VIB.

Introduction

There is a well-documented increased prevalence of autism spectrum disorder (ASD) or ASD-like features in children with visual impairment and blindness (VIB) compared to the general population of children^{1,2}. However, the true nature of the relationship between ASD and VIB remains ambiguous and under-researched. One of the central issues impeding clarity is the lack of assessment tools designed to account for developmental differences in children with VIB. This commentary builds directly on our previously published scoping review (Stevenson & Tedone, 2024)³, which systematically examined studies published between 1995 and 2020. That review provided the foundation to reflect on the broader implications of the challenges associated, examine recent modifications and innovations, and explore how future diagnostic strategies can be better aligned with the developmental trajectories of children with VIB.

Current Assessment Tools

Most widely used diagnostic tools for ASD such as the *Autism Diagnostic Observation Schedule - Second Edition (ADOS-2)*⁴ (12 months old through adulthood), the *Autism Diagnostic Interview - Revised (ADI-R)*⁵ (mental age of 2 years old), the *Childhood Autism*

*Rating Scale (CARS;)*⁶ (2 years old and above), and the *Modified Checklist for Autism in Toddlers (M-CHAT;)*⁷ (16 to 30 months old) were developed based on typical visual development. Additionally, these tools frequently rely on visual behaviours such as eye contact, joint attention, pointing to shared objects, and facial expressivity⁸. For children with VIB, these behaviours may be absent or atypical, and do not necessarily indicate an underlying neurodevelopmental disorder; they are better explained through a lack of visual input. As a result, behaviours such as lack of eye contact, reduced joint attention, echolalia and limited symbolic play, which are common indicators of ASD, may be misattributed in children with VIB⁹.

This is evident in 13 items included in the M-CHAT that require parents to evaluate their child's visual responsiveness¹⁰. This tool presumes that a child following a pointing gesture or making eye contact, has typical visual capabilities. A child with VIB may not demonstrate such behaviours, leading to scores that falsely portray a higher risk of ASD. Likewise, the CARS assigns important diagnostic weight to visual responsiveness. Consequently, a child may be inaccurately rated as exhibiting atypical visual responsiveness when they are, in fact, engaging with their environment appropriately. Therefore, a child with VIB who avoids eye contact or does not respond to visual cues is not necessarily demonstrating ASD behaviours. However, in the absence of tools that account for these differences, clinicians often rely on instruments that may fail to differentiate between neurodevelopment disorder symptoms and expected developmental variation due to visual impairment. Thus, without clear adaptation protocols or scoring adjustments, these tools risk conflating behavioural differences, thereby increasing the likelihood of misdiagnosis in this population.

Modifications and Innovations

To mitigate these issues, some researchers have responded by adapting existing ASD assessment tools for children with VIB. Modifications have included omitting visually dependent items, rewording questions, shifting cut-off scores, or substituting visual stimuli with tactile or auditory equivalents^{1,8, 11,12,13,14}. In one study⁸, the ADOS-2 was modified to include a Braille children's book and puzzles. These changes allowed for more meaningful responses from children with VIB. The same study¹⁴ also used a modified version of the *Developmental, Dimensional and Diagnostic Interview (3DI;)*¹⁵, omitting three questions directly related to vision and adapting five others involving shared attention. Hobson and Lee¹³ excluded visual items from the CARS and used verbal subsets of the WISC-III and the *Behavior Checklist for Disordered Preschoolers (BCDP;)*¹⁶ to assess changes in ASD symptoms over time. Similarly, Goodman and Minne (1995) altered the *Autism Behaviour*

*Checklist (ABC;)*¹² for use with blind children, through both its format and wording.

However, these adaptations were often implemented without rigorous validation. Modifying a diagnostic tool can heighten the risk of undermining its psychometric properties, including its reliability and validity. Importantly, omitting a visual response category from the CARS might eliminate behaviours that are significant in understanding developmental differences in children with VIB. Moreover, without proper validation, clinicians may be using tools that are no longer measuring the constructs they were originally intended to assess, thereby compromising the accuracy of assessments and potentially leading to misinterpretation of a child's developmental profile. These methodological limitations were identified as a recurring issue in the scoping review, emphasizing the need for future validation studies before adapted tools can be recommended for clinical use. While these adapted tools provide potential solutions, they also introduce interpretive risks that can unintendedly influence diagnosis and intervention.

The diagnostic complexity reflects a broader limitation being that developmental norms are strictly informed through sighted experiences. Eye contact, gaze following, visual play and imitation are standard markers of early social and communicative development⁹. However, these are not universally applicable as children with VIB often use alternative strategies to engage socially and communicate. Bartoli et al. (2019)¹¹ developed an audio and tactile version of the *Theory of Mind Storybooks*. These efforts move beyond merely subtracting visual components. They reimagine assessment in ways that accurately represent the experiences of non-sighted children. Therefore, to ensure accurate assessment, clinicians must learn to recognize and evaluate these alternative developmental trajectories. For this to be possible, there needs to be a shift from adapting tools designed for sighted children to developing tools designed for non-sighted children from the onset.

New Instruments

Recognizing the limitations of altering existing tools, some researchers have begun to develop entirely new diagnostic tools tailored to the needs of children with VIB. The *Visual Impairment and Social Communication Schedule (VISS)* was designed to identify early social communication difficulties and ASD in preschool children with severe to profound visual impairment. Preliminary studies showed high sensitivity (89%) and specificity (100%) when compared with clinical ASD diagnoses¹. The VISS was developed with input from professionals experienced in VIB and incorporates non-visual behaviours as markers of social communication, making it more appropriate for blind and visually impaired populations. Similarly, the

Observation of Autism in people with Sensory and Intellectual Disabilities (OASID) was created to assess ASD in individuals with sensory impairment such as VIB and deaf blindness, and intellectual disabilities. It is a semi-structured observational tool validated through comparison with the CARS and the *Pervasive Developmental Disorders in Mental Retardation Scale (PDD-MRS)*;¹⁷. It demonstrated strong content and construct validity, internal consistency and promising inter-rater reliability¹⁸.

Despite the development of tools such as the VISS and the OASID, their integration into clinical practice remains limited. While these tools show promise, they have not yet been incorporated into routine assessment procedures or widely adopted in professional training. This may be due, in part, to the lack of available clinical guidelines and consensus on their use, as well as insufficient detail in the literature regarding their administration and validation. Furthermore, there is a lack of elaboration on how tools are applied in practice, which hinders the integration of these findings into broader clinical use⁸. Until these tools are supported by standardized training, validated protocols, and clearly established practice guidelines, their practical impact remains limited^{8,19}.

Timing of Assessment

Recent research raises concerns about the diagnostic stability of ASD in children with VIB, revealing significant variation over time. Hobson and Lee (2010)¹³ conducted a longitudinal study of children with congenital blindness who were initially diagnosed with ASD between ages three and nine. Eight years later, only one of the nine blind children still met diagnostic criteria, whereas all sighted children retained their diagnosis. This suggests that what may appear as ASD traits in early childhood may attenuate with age. Furthermore, William et al.⁸, found that non-sighted children exhibited more ASD symptomatology prior to age four, with significant reductions observed between ages six to nine. The authors proposed that improvements were likely due to children becoming more comfortable exploring their environments and gaining greater communicative competence with age. Contrarily Parr et al.²⁰, 2010 found that ASD symptoms increased with age in children with severe VIB, with most diagnoses made between ages two years four months and four years six months. Thus, these findings suggest that early assessments in children with VIB may be particularly prone to overdiagnosis or misdiagnosis if not interpreted with caution. They also highlight the importance of repeated assessments over time and of diagnostic traits that are sensitive to development^{13,20}.

Access to Services

Adding to the complexities of diagnosis, access to essential services is frequently limited as it is contingent on a formal diagnosis. This reality can create incentives

that can unintentionally influence diagnostic practices. This may result in ASD labels being used to access essential services, even when a child's behaviours may be better explained by sensory differences or other developmental differences^{12,19}. Such pressure not only increases the risk of misdiagnosis but also undermines the credibility of the diagnostic process. A misdiagnosed child may receive inappropriate interventions, while a child who is underdiagnosed or not diagnosed at all may be denied access to much needed support. Thus, either outcome places the child at a disadvantage, particularly within a system that equates diagnosis with eligibility for services.

Given these complexities, expert clinical judgment becomes paramount, however the limited availability of adequate training means many clinicians are not fully equipped to distinguish between developmental traits associated with VIB and those indicative of ASD. As de Verdier et al.¹⁹ highlighted, parents of children with VIB often report frustration with professionals who lack experience recognizing the developmental trajectories of visually impaired children. Consequently, effective assessment of ASD in children with VIB requires interdisciplinary collaboration among professionals with expertise in visual impairment. Without such specialized expertise, assessments risk overlooking the nuances of sensory-based development and may conflate VIB traits as ASD. As a result, clinicians may mistakenly believe that it is not possible to assess ASD in this population² or may diagnose a child with ASD when their behaviour may be indicative of typical development for that child¹³.

Important Considerations

The diagnostic complexity reflects a broader limitation being that developmental norms are strictly informed through sighted experiences. Eye contact, gaze following, visual play and imitation are standard markers of early social and communicative development⁹. However, these are not universally applicable as children with VIB often use alternative strategies to engage socially and communicate. Bartoli et al.¹¹ developed an audio and tactile version of the *Theory of Mind Storybooks*. These efforts move beyond merely subtracting visual components. They reimagine assessment in ways that accurately represent the experiences of non-sighted children. Therefore, to ensure accurate assessment, clinicians must learn to recognize and evaluate these alternative developmental trajectories. For this to be possible, there needs to be a shift from adapting tools designed for sighted children to developing tools designed for non-sighted children from the onset.

Future Directions and Calls to Action

The literature on assessing ASD in children with VIB reveals several critical priorities that demand attention. Firstly, while modifications to standard diagnostic tools,

such as the ADOS-2, CARS, M-CHAT and 3DI, have been implemented to accommodate sensory differences, these adapted tools require systematic validation to ensure their reliability and diagnostic integrity are preserved. Without such validation, clinicians risk relying on tools whose psychometric properties may no longer be sound. Secondly, newly developed tools like the VISS and OASID, designed specifically for populations with VIB, show promise but are underutilized in clinical practice. Their integration of their administration into clinician and educator training programs is essential for widespread and effective use. Additionally, longitudinal studies tracking children with VIB are sparse but essential, as such research would clarify which ASD traits are persistent, transient, or developmentally normative within this population. Therefore, these priorities reflect the broader conclusion of the reviewed literature: that effective ASD assessment in children with VIB requires specialized tools, rigorous validation processes and an ongoing commitment to research.

Conclusion

The diagnostic procedure for ASD in children with VIB is not merely a question of clinical precision. It exemplifies which developmental norms are considered and whose experiences are considered in assessments. Current diagnostic practices, rooted in sighted behaviours, risk misrepresenting the neurodevelopmental profiles of children with VIB. This reveals a critical situation; we are often not diagnosing the children themselves, but rather their divergence from sighted developmental norms. The overreliance on visual markers such as eye contact and gaze following, coupled with the adaptation of assessment tools designed for sighted children, places children with VIB at a disadvantage. Without context-specific tools, appropriately trained clinicians and practical guidelines, behaviours that are developmentally typical for blind children may be identified as symptoms of ASD. Efforts to adapt or create tools such as the VISS and OASID signal a much-needed shift, but these innovations remain on the periphery of mainstream diagnostic practices. As highlighted previously, the practical utility of these tools is limited without standardized training, validated protocols, and clear practice guidelines. Until such structures are firmly in place, the risk of misdiagnosis persists. Therefore, diagnostic tools must be reimagined, not merely as instruments for categorization, but as frameworks that respect the distinct development of children with VIB. Only by embedding these tools within formal training and clinical standards can clinicians claim that these children are being diagnosed, rather than misdiagnosing their differences.

Conflict of interest statement

Declarations. Conflict of interest: The authors have no conflict of interest to declare.

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