

So Called Autistic-Like Behaviors in Children with Visual Impairments: is it the Right Label ?

Andrea URQUETA ALFARO¹

A subgroup of children with visual impairments display behaviors that some authors label “autistic-like.” These include: stereotyped behavior, difficulties in social interaction and pre-linguistic communication, egocentric language, delayed and restricted symbolic play, delays in joint attention, and difficulties in developing a theory of mind. A debated question is whether these are truly autistic behaviors or only superficially similar to those found in children with autism. To explore this question, this paper reviews findings regarding three of these so called autistic-like behaviors in children with visual impairments: stereotyped behaviors, difficulties with pre-linguistic social interaction and communication, and difficulties in joint attention. The reviewed findings underscore the significance of going beyond superficial similarities in order to consider functional interpretations of these behaviors; etiological factors derived from the challenges visual impairments place on children with visual impairments and their social partners; and the need to advance our understanding of what behaviors and developmental timelines are normal for this population.

Keywords : **Haptic, Visual impairment, Autism, Stereotypia, Joint attention, Theory of mind**

¹ *Andrea Urqueta Alfaro is graduated in psychology from Pontificia Universidad Católica de Chile. While working as a vision impairment specialist for 6 years for the Blind Babies Foundation in California, she obtained a master’s and preliminary teaching credential in special education visual impairments from San Francisco State University. She is a psychology doctorate candidate at the University of California, Berkeley, working under the supervision of optometrist Dr. Deborah Orel-Bixler.*
urqueta@berkeley.edu



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INTRODUCTION

According to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013) autistic spectrum disorder is characterized by persistent deficits in social communication and interaction and restricted, repetitive patterns of behavior, interests or activities. According to the International Statistical Classification of Diseases and Health Related Problems - 10 (World Health Organization, 1992), childhood autism involves impairments in reciprocal social interaction and communication, and restricted, stereotyped, repetitive behavior. In both diagnostic systems, symptoms are to be present since early childhood.

The report of behaviors in children with visual impairments similar to those associated with autism started within psychoanalytic research. In 1958, Keeler described behaviors such as social isolation, non-functional play, frequent use of imitation and formulaic speech or stereotyped behaviors in children with retrolental fibroplasia (as cited in Pérez-Pereira & Conti-Ramsden, 2005, p.99). During the 1960s and 1970s researchers including Selma Fraiberg contributed further reports of behaviors such as delayed and reversed use of personal pronouns, high rate of echolalia, frequent use of verbal routines and formulaic speech, abundance of egocentric speech, scarcity or absence of initiation of conversation, and difficulties with symbolic play (Fraiberg, 1977). More recent reports mention difficulties in social interaction and pre-linguistic communication and difficulties in joint attention and theory of mind (Baron-Cohen, 1995; Brown, Hobson, Lee, and Stevensen, 1997 ; Hobson, 2005).

Some accounts have linked these autistic-like behaviors to particular diagnoses such as retinopathy of prematurity and Leber's congenital amaurosis; however, there is also evidence that refutes a connection to particular visual impairment etiologies (Andrews & Wyver, 2005 ; Hobson, 2005; Rogers & Newhart-Larson, 1989).

A debated question is whether these are truly autistic behaviors or only superficially similar to those found in children with autism.

Hobson (2005) concludes that in children who are blind or have only light perception from birth,

there is no clear boundary between those who are diagnosed as having co-morbid autism and those who despite showing autistic-like behaviors do not meet the diagnostic criteria for autism. Hobson postulates a likely kinship in the pathogenesis of autistic features and autism in blind and sighted children. In Hobson's view, two requirements are needed in early childhood for the normal development of mind and personality. One, children must perceive people's emotional reactions and attitudes towards the external world. Second, children must be able to establish empathy or identification with other's emotional reactions and attitudes. Blindness impairs the first requirement, while autism impairs the second (Hobson, 1993). Despite this proposed kinship in the pathogenesis, Hobson (2005) predicts that blind children who are diagnosed early and receive treatment will tend to overcome the autistic features to a greater degree than sighted children with autism. The reason for this differential prognosis is that in the case of children who are blind, there can be strategies for circumventing the vision-dependent handicaps and for taking advantage of these children's relatively intact potential for social engagement.

However some authors question the diagnostic and clinical value of labeling these behaviors as autistic since they could be explained as consequences solely of visual impairments (Pérez-Pereira & Conti-Ramsden, 2005). This criticism does not deny the possibility of co-morbid autism in children with visual impairments. It also does not deny the presence of these behaviors and how they can superficially resemble autism; rather it questions autism as their etiology, and points out differences in the developmental pathways of children with visual impairments who show so called autistic-like behaviors and sighted children with autism (Andrews & Wyver, 2005).

In this paper I will review literature that debates three of the reported autistic-like behaviors in children with visual impairments specifically, stereotypic behaviors, difficulties in pre-linguistic social interaction and communication, and difficulties in joint attention. I have chosen these areas because as we will see, they highlight the difficulties determining comorbidity of blindness and autism. I will also draw from my six years of experience as an early interventionist for the Blind Babies Foundation.



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STEREOTYPIC BEHAVIORS

Stereotypic behaviors are characterized by repetition, rigidity, invariance and tendency to be inappropriate. These behaviors include repetitive motor mannerisms or use of language—e.g., hand flapping, toe walking, body rocking, sniffing, spinning objects, running objects across one’s peripheral vision, and echolalia. They also include restricted and stereotyped patterns of interest or the demand for sameness—e.g., attending solely to specific parts of objects, or insistent playing with objects in the same fashion such as lining blocks up in identical rows (Cunningham & Schreibman, 2008).

Unlike children with autism, those with visual impairments show a subset of specific stereotypic behaviors including body rocking and eye pressing (Andrews & Wyver, 2005). The early expressive language of some profoundly visually impaired and blind children has also been characterized by frequent use of stereotyped speech. However, Pérez-Pereira (1994) points out that in comparison to their sighted peers, blind children show a greater number of modified stereotyped speech—i.e., a child uses part or all of a previous utterance as a model but introduces changes—and that for both populations modified stereotyped speech serves language development.

Functionality

There are several considerations when determining if a behavior is stereotypic in children with visual impairments. First, the core characteristics of stereotypic behaviors do not consider whether these behaviors serve a functional purpose for the child (Cunningham & Schreibman, 2008). However, in children with visual impairments these behaviors can be explained as responses to sensory/social deprivation, perceived lack of environmental control, and as means to self-regulate (Cass, 1998).

Let’s consider two examples of stereotypic behaviors I have encountered both in the literature and professional practice: eye pressing and running objects across one’s peripheral vision. Children with

visual impairments can engage in eye pressing as a way to obtain visual sensations. Children whose visual impairment involves better peripheral than central vision will naturally look at objects with their peripheral visual fields. And those whose visual impairment entails better vision of motion than vision for stationary objects will understandably move objects in their field of view in order to see them better (Lueck, 2004). I have observed many visually impaired children engage in repetitive behavior when there is no other available sensory stimulation to them, whether physical or social. However, once alternative stimulation is provided such as bids for social interaction, these children would stop these repetitive behaviors and engage with social partners. Compare that with a child who engages in stereotypias despite accessible alternative stimulation. We find here a superficial similarity in the behaviors observed in both cases. However, the differential contexts and functional interpretation should be weighted when deciding whether these behaviors are truly stereotypic.

Developmental Appropriateness

Second, and in connection to behaviors’ functionality, there is the issue of determining what constitutes behaviors that are developmentally “inappropriate.” For example, mouthing is a primordial mean of exploration for infants. As children develop manual exploration, it replaces mouthing. As an early interventionist I observed children with visual impairments continue to use mouthing as a primary means of exploration—even if they had started manual exploration—beyond the age at which it is replaced by tactual exploration in the sighted.

If an analysis of the mouthing behavior reveals that it continues to function as an information gathering mechanism, it should not be considered developmentally inappropriate. Children with visual impairments might use mouthing to pick up more refined haptic information about objects, particularly when first introduced to them. This might continue beyond childhood at least in some adults who are blind (Villay, 1930). In my professional experience, I have observed other haptic means by which children with visual impairments explore objects that can seem developmentally inappropriate when the unique ways these children



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learn from the environment are disregarded. For instance, some children like to tap objects on their noses or foreheads, and would do so along with tactual manipulation.

Prognosis

Third, there is evidence that a wide array of stereotypic behaviors are observed in children with visual impairments during their first and second year of life, but many decrease from the third year onward (Troster, Brambring & Beelman, 1991). The reduction in stereotypic behaviors in this population's developmental pathway brings into question interventions aimed at extinguishing these behaviors as they might represent adaptive rather than maladaptive functioning (Warren, 1984).

DIFFICULTIES IN PRE-LINGUISTIC SOCIAL INTERACTION AND COMMUNICATION

Other types of autistic-like behaviors mentioned in children with visual impairments refer to difficulties with social interactions and pre-linguistic communication. For instance, it has been reported that these children have difficulty initiating communication with others (Kekelis & Anderson, 1984). However, this finding can be an artifact of caregivers' higher incidence of interaction initiation. Caregivers of children with profound visual impairments and blindness have been found to initiate communication at a higher rate than those of sighted peers. When data is presented as proportions between caregiver/child initiations, visually impaired children appear as less likely to initiate interactions. However, if data is presented in terms of frequencies, no differences are found between blind and sighted infants (Perez-Pereira & Conti-Ramsden, 2005).

In the development of pre-linguistic social interaction and communication, caregiver and child engage in dyadic interactions (mother-child) characterized by face-to-face interactions, mutual eye gaze and contingent responsiveness. Sighted infants display a variety of affective expressions in response to interactions. They can also appreciate

the emotional meaning of social partners' affective expressions. By tuning into each other's emotional expressions infants and caregivers regulate their interactions (Tronick, 1989).

It is within these contingent dyadic interactions that children first perceive themselves in relation to other individuals. In the case of children with visual impairments this development can be at risk depending on both caregiver's and child's ability to relate to each other using touch and auditory cues (Bigelow, 2003). Therefore, in order to assess the clinical significance of observed difficulties in pre-linguistic social interaction and communication it is imperative to consider the history of interactions between children with visual impairments and their caregivers.

Significance of early dyadic social interactions in children with visual impairments

The development of pre-linguistic social interaction and communication can present challenges to both children with visual impairments and their caregivers. When compared to their sighted peers infants who are blind have been reported as less responsive, less aware of mothers' bids for interaction, and as having a more limited repertoire of facial expressions (Cass, 1998). Infants with visual impairments can manifest interest in social partners and objects in idiosyncratic ways. For instance, instead of making eye contact the child might become still and silent, or even look down in order to pick up the caregiver's non-visual cues. Depending on the type of visual impairment, children might use their residual vision to attend to and navigate their environments, yet do not make eye contact.

Understandably, these behaviors challenge caregivers' ability to identify and respond to their children's states and can be misinterpreted as a sign of apathy. In this line, Fraiberg (1977) warned against considering facial expressions the sole source of emotional/communicational cues in children with visual impairments. She recommended attending to infants' whole body responses. Indeed, she reports blind infants who did not express much emotion with their faces but who demonstrated interest in people and objects by their motoric responses and tactual exploration (i.e., active tactual exploration



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of the caregiver's face compared to fleeting or lack of tactual exploration of non-familiar people). This and other strategies to aid caregivers read the non-visual emotional and communicational cues are nowadays common within early intervention strategies for this population (Lueck, Chen, Kekelis, & Hartman, 2008).

A child with visual impairments has limited or no access to caregivers' gestures and facial expressions. Thus it is crucial for the caregiver to achieve emotional non-visual rapport with their infants. This is exemplified by Fraiberg's findings regarding the development of smiling in 10 blind children. Concordant with what is observed in sighted infants, these blind infants smiled in response to their mother's voice by their 4th week of life. However, unlike the response that the sight of the caregiver's face triggers in the sighted child, the response of blind children to mother's voice was neither automatic nor regular, and required lots of vocal stimulation from the mother. Indeed, Fraiberg (1979) reports that the most consistent way to elicit a smile in these children was gross tactile or kinesthetic stimulation.

Non-visual cues from social partners are also crucial for visually impaired children's ability to identify their main caregivers and to differentiate them from non-familiar people. For instance, it has been reported that young blind or severely visually impaired children show a differential response to main caregiver versus non-familiar adult when the latter not only talked to the baby but also held him, thus providing haptic cues (Cass, 1998; Fraiberg, 1977).

The history of social interactions experienced by children with visual impairments must be taken into account when determining the etiology of their difficulties with pre-linguistic social interaction and communication. The clinical understanding of a child with visual impairment who has a history of social interactions that have successfully made use of non-visual senses should be differentiated from that of a child who has lacked successful opportunities to engage in mutually regulated interactions with social partners (Hobson, 2005).

DIFFICULTIES WITH JOINT ATTENTION SKILLS

Difficulties with joint attention skills are also reported among autistic-like behaviors in children with visual impairments. Joint attention refers to the child's understanding that he and another person can attend to the same object/event in the environment. Before the emergence of joint attention at around 9 to 12 months of age, sighted infants seem to attend to objects and people separately but do not integrate them within the same interaction. In joint attention episodes the child engages in a triadic interaction (child-object-social partner) and exhibits attention to both the object and the social partner's attention to this shared focus (Bruner, 1995).

Joint attention skills refer to the specific behaviors through which children demonstrate joint attention. For instance, infants can follow others' already established focus of attention—e.g., following others' direction of gaze to share their focus of attention. Or they can direct others' focus to what the infants themselves are attending—e.g., pointing out an object to a social partner and checking the other person's gaze toward it (Carpenter, Nagell, & Tomasello, 1998).

As with dyadic interactions (child-social partner), joint attention relies on each participant's ability to recognize the other's attentional focus from his overt behaviors. And likewise, difficulties identifying non-visual attentional cues and/or responding to them using the sensory channels available to each participant can impair the dyad's ability to follow or direct each other's focus of attention. For instance, a child with visual impairments can demonstrate interest in an object by touching it in an active way or by leaning his body towards it, rather than by pointing or gazing at it. If the caregiver cannot correctly identify the child's focus of attention, she won't be able to share such focus and would have to rely more heavily on directing the child's behavior toward a focus determined by the caregiver. Else, caregivers might talk to the child about objects that are not the child's current focus of attention. The challenges in early social interaction and communication faced by children with visual impairments and their caregivers can



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lead to difficulties establishing interactions that incorporate objects/events within which language and cultural use of objects can be scaffolded (Bigelow, 2004; Bruner, 1995; Carpenter et al., 1998).

Limited understanding of non-visual joint attention

In order to assess the joint attention skills of children with visual impairments one must first understand the developmental trajectory and behavioral indexes of joint attention in this population. However, there is limited research on this, which can be related to the low incidence of this population as well as to the behaviors most researchers use as indexes of joint attention. Such indexes must demonstrate that the child is not merely alternating attention from object to social partner but attending to the social partner's focus of attention. In research with sighted children this is commonly indexed by the child's shifting of gaze between the common focus of attention and the social partner's face, granted that the look at the social partner is not caused by stimuli from the adult, such as verbalizations to the child (Carpenter et al., 1998).

Nevertheless, by definition joint attention can be established using non-visual cues. For instance, when a child feels his and an adult's hand exploring the same object. Indeed, there is evidence that sighted children can identify their caregiver's attitude toward a potentially threatening situation—a social interaction that entails joint attention—using vocal cues alone (Leekman & Wyver, 2005). Yet in most studies, auditory or tactual means to achieve joint attention are not considered.

An exception is Bigelow's (2003) longitudinal study of joint attention development in two congenitally blind children with no other disabilities. Both children were diagnosed and had supportive services early in life. The children were observed once a month interacting with people and objects, between the ages of 13-21 months in one case, and 23-30 months in the other. By analyzing the monthly videotapes of these infants interacting with their mothers, Bigelow identified actions that incorporated non-visual abilities suggestive of joint attention, and further categorized them according to their strength as indexes of joint attention.

"Preliminary behaviors" include infants' use of adults as social tools—e.g., the child uses an adult's body to find an object—and acts by the infants that could be construed as communicative gestures about objects. A stronger category, "liberally construed joint attention behaviors," involves interactions in which the child's language or symbolic gestures affect the way in which the child and the adult engage each other with objects. For example, the child changes the way he is engaged with an object at an adult's verbal request. However, these interactions could be construed as "passive joint attention", in which children use adults' behavior as verbal scaffolding for their own actions on objects but demonstrate little awareness of the other's involvement or presence (Bakeman & Adamson, 1984).

In the strongest index category, "conservatively construed joint attention behaviors," children more clearly indicate their awareness of the adults' role in their mutual interaction with objects (yet in the absence of visual behaviors, some ambiguity in interpretation can remain for the sighted observer). Characteristic of these behaviors is the game-like context in which they occur and the child's attention to both object and social partner as integral parts of the interaction. For instance, the child cooperates with an adult in the manipulation of an object. The context involves the child's awareness of the adult's actions on the object with which the child is engaged (Bigelow, 2003).

Results indicated that blind children develop joint attention initially by touch. Later, they can use language to direct other's attention using words such as "see" and "look"; they can also understand when others use those words to direct children's attention to specific objects/events in the environment (Bigelow, 2003).

The age range within which the two blind children demonstrated the emergence of joint attention was markedly behind the reported time for sighted children (end of second year to third year, vs. 9 to 12 months). The emergence of liberally construed and conservatively construed attention behaviors occurred in close parallel timing, suggesting that both categories may indicate similar joint attention skills. It was also observed that all conservatively construed joint attention behaviors were initiated

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by the mother. Once the episodes had been initiated by the mother, blind children were active in maintaining the interaction (Bigelow, 2003).

Determining developmental delays in children with visual impairments

Is the fact that some children with visual impairments achieve joint attention at a later age than sighted peers relevant for assessing autistic-like behaviors in this population? I posit that it is not only non-relevant, but hazardous.

In talking about the issue of testing intelligence in children with visual impairments by comparing them to sighted norms, Warren (1978, p.408) reasons that intelligence relates to a person's ability to adapt to his environment. Given that the environments of visually impaired and sighted children are different, their "...adaptive needs are different. The question of whether adaptation is equally adequate cannot be approached by simply administering a common test."

Joint attention skills in children with visual impairments should be assessed using indexes tailored to the adaptive needs this development entails for this population. Determining whether a child with visual impairments is delayed in this or any other skill should be done in comparison to normative times for this population.

Given the wide array of visual levels included within visual impairments, normative times should be sensitive to group variations such as diverse levels of visual impairments. The study of normative times for these children is tied to the question of appropriated indexes. Due to the limited knowledge about joint attention when vision is degraded or absent, researchers/clinicians may fail to recognize the unique ways these children manifest joint attention skills.

Prognosis

Evidence suggests that joint attention is a precursor of theory of mind. Theory of mind refers to the understanding that humans have mental states such as beliefs and desires, which influence their behavior (Charman, Baron-Cohen, Swettenham, Baird, Cox, & Drew, 2001).

One way to assess theory of mind tests children's understanding that other people can have beliefs that do not correspond to the reality the child himself is aware of, that is, people can have false beliefs. In one paradigm, the child is presented with an object such as a candy box and asked what he thinks is inside. Typically children would say "candy." Then the child is allowed to see that instead the candy box contains sand. The child is asked what would a peer say is inside the candy box when first presented with it. Children who understand false belief will say the peer will believe it contains candy. If delays in joint attention in children with visual impairments are not found simply to be the normative timing in this population, then difficulties in the development of theory of mind would be expected. However, research shows mixed results regarding the development of theory of mind in these children. In a study 20 children with congenital blindness aged between 4 and 12 years performed lower in false belief tasks than a comparison group of sighted peers (Roch-Levecq, 2006). Yet another study found no differences in the way 24 children with visual impairments aged between 6 and 13 performed in tasks that involved the understanding of second-order Theory of Mind, i.e., the understanding that other people have beliefs about beliefs (Pijnacker, Vervloed, & Steenbergen, 2012). Aging has been found to significantly predict better performance in 4 types of false belief tasks in children who are blind or severely visually impaired; in this study, most 6-year-olds fail all tasks, most 8-year-olds do not perform above chance, but 90% of 12 years old pass 3 out of the 4 false belief tasks (Peterson, Peterson, & Webb, 2000).

In general, blind and visually impaired infants show worst results in tasks that involve unfamiliar situations, i.e., asking the child about the content of a teapot, which arguably is a dangerous activity not readily available to children. They also show poorer performance in situations that do not provide all sensory information, i.e. a "hamburger" that is not warm or has its typical smell. In contrast, these children have better results when tasks involve familiar situations and are rich in tactual information (Pérez-Pereira & Conti-Ramsden, 2005).



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CLOSING THOUGHTS

This paper has reviewed a number of so called autistic-like behaviors that have been identified in some children with visual impairments. Beyond discussing specific behaviors related to autism, it is important also to consider the overall clinical profile presented by this subgroup of children. Indeed, authors have noticed differential patterns of impairment between profoundly visually impaired or blind infants who show autistic-like behaviors and sighted children diagnosed as autistic. Specifically, unlike children diagnosed with autism, visually impaired children that show autistic-like behaviors usually exhibit intact attachment behavior, self-recognition, and the ability to respond differently to different people (Cass, 2006). Overall, children with visual impairments identified as having autistic-like behaviors do not show the affective impairments that are commonplace in children with autism (Andrews & Wyver, 2005; Cass, 1998; Hobson, 1993).

Further questions arise from this debate: how do we diagnose autism? Do we base it solely on behaviors? Or do we consider the possible etiologies for the clinical picture we are presented with? How does this impact intervention? I would argue that etiological considerations should inform intervention. A child who shows difficulties with joint attention due to visual impairments might not benefit from the same interventions as sighted children whose difficulties with joint attention arise from issues conceiving of people as possessing mental states.

Lastly, the question addressed in this paper ultimately underscores the tremendous need for longitudinal naturalistic research on the early development of children with visual impairments. When a baby is born with a visual impairment, he is not born with a handicap. Rather, he is born with a qualitatively different way to perceive, relate, and learn—one that can afford him the experiences to actualize his fullest potential through alternative means. This positive developmental outcome is not a given. From birth on, social partners must understand the idiosyncratic patterns of development that constitute the norm for visually

impaired infants. It is this understanding that will help us identify special needs, such as autism, that go beyond the expected adaptive demands derived from visual deficits.





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Editor's note:

The book *Insights from the blind* by Selma Fraiberg is available in French in the collection Corpus Tactilis, Les Doigts Qui Rêvent: Fraiberg, S. (2013). *Clins d'œil à perte de vue*, translated by F. Massard-Bobin, collection Corpus Tactilis, Talant, Les Doigts Qui Rêvent.

The original French version of *World of the Blind* by Pierre Villey is distributed in the collection Corpus Tactilis, Les Doigts Qui Rêvent: Villey, P. (1984, 1st ed. 1914) *Le monde des aveugles*, Paris: Librairie José Corti.