# Barriers to an Information Effect on Diagnostic Disparities of Autism Spectrum Disorder in Young Children

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## Abstract

**Objectives:** Autism spectrum disorder (ASD) is underdiagnosed in children from minority and low socioeconomic status families, and reports indicate that parental "lack of awareness" of symptoms is a factor, which implicates the adoption of the category globally. However, parental knowledge of ASD has failed to explain emerging clusters of cases. The objective of the present research was to identify and describe barriers to an "information effect" in diagnosis.

**Methods:** Interviews were conducted with the parents of 54 children with ASD in Costa Rica, many living within clusters that appeared after a genetic study conducted an information campaign for recruitment. The interviews explored factors influencing symptom recognition and help-seeking behaviors. Several barriers were identified that prevent information about ASD or exposure to diagnosed cases from influencing parents' help-seeking behaviors.

**Results:** Early symptoms in most children gave parents no reason to suspect ASD. Later, parents' understanding of ASD depended on caricatures of the disorder. Parents often received unsolicited advice from strangers, although rarely from family, and it was always seen as critical of their parenting; furthermore, the advice was too late to influence the referral process, which was well underway by the time classical symptoms of ASD appeared, if they did at all. Postdiagnosis, the interviewees occasionally gave advice to other parents, mostly strangers, but none had apparently been diagnosed.

**Conclusions:** The results implicate efforts to educate parents about symptoms of ASD, where a focus on generic developmental delays and neurodevelopmental disorders in general may be more effective than ASD-specific information.

## Keywords

autism spectrum disorder, diagnostic disparities, help-seeking behaviors, qualitative research

# Introduction

Autism spectrum disorder (ASD) has long been underdiagnosed in children from minority and low socioeconomic status (SES) families.<sup>1,2</sup> On one hand, some clinics are more likely than others to diagnose ASD or refer children to specialists, and minority and low SES families have inferior access to diagnosing clinics. On the other hand, various reports indicate that parental "lack of awareness" of ASD symptoms is a primary factor, again, with minority and low SES families experiencing poor outcomes, presumably because of a lack of information.<sup>3</sup> This assumption has been used to justify expensive public health programs, such as the Centers for Disease Control and Prevention's "Learn the signs. Act early" campaign,<sup>4</sup> where the hope is that exposing parents to health-related information will be a panacea for diagnostic disparities.<sup>5,6</sup> Yet in the first sample of parents of children with ASD living within spatial clusters of low severity cases<sup>7</sup>—the very cases for which information should be especially helpful—our previous research found that exposure to information had little effect on the diagnostic disparities.<sup>3</sup> The present report examines barriers to an

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information effect on parental help-seeking for ASD diagnosis, which implicate underdiagnosed populations globally.

#### **Materials and Methods**

This study was part of a larger project on the adoption and diffusion of ASD in Costa Rica. With approval from the institutional review boards at the University of Wisconsin and the Hospital Nacional de Niños in Costa Rica, interviews were conducted with the parents of 54 children with ASD, including many cases within the spatial clusters that appeared after a genetic study conducted an information campaign for case recruitment.<sup>8</sup> Medical files of these cases, including referral information, were also reviewed.

Briefly, the Hospital Nacional de Niños has the sole public clinic for ASD, and children, who have universal health care, must receive a diagnosis (not necessarily ASD) in the public health-care system to receive services. Parents of patients were recruited from the hospital in 2013 when the parents attended a follow-up appointment for a previous ASD diagnosis (the vast majority) or arrived for an informing interview after their children underwent an Autism Diagnostic Observation Schedule assessment. All parents agreed to participate. The parents were told about the study before signing informed consent. Semi-structured interviews lasting 30 to 60 minutes were conducted in Spanish in a private room at the hospital.

The interviews focused on factors influencing parents' symptom recognition and help-seeking behaviors, including contact with parents of children with neurodevelopmental disorders and clinical encounters prior to diagnosis. Parents were asked to discuss what led them to notice developmental anomalies in their children, who they talked to after they developed concerns, and whether anyone influenced their decision to obtain medical advice. They were asked to create a timeline of their referral pathways and elaborate on referral information in the medical files. They were also asked if they had ever seen other children who might have ASD and whether they had said anything to the parents. Finally, they were asked whether they recalled knowing children with ASD from before or after their child was diagnosed, including how often and in what circumstances they had spoken to the children or the parents; if applicable, they were asked to provide names for later crosschecking in the medical records. Two interviewers took detailed notes during the interviews and resolved any differences immediately afterwards. Upon discovering the absence of an information effect on clusters of cases we had previously identified,<sup>7</sup> we sought commonalities as well as conspicuous differences among parents who were exposed to health-related information or other children with the disorder, at first attempting a purely descriptive thematic analysis of information barriers, and later producing more generalizable theory from those themes. Memo-writing was conducted throughout the process as themes were developed.9

#### Results

The children in the sample represented as much as 10% of the diagnosed population in Costa Rica. The average age at the time of symptom recognition was 16 months, and the average time from recognition to diagnosis was 45 months. Forty percent of the sample of children were classified as low severity cases.

#### First Concerns

With few exceptions, parents, and typically the mothers, were the first to recognize the first symptoms in their children. When it was not the parents, it was a teacher (n = 3), clinician (n = 1), grandparents (n = 2), or babysitter (n = 1); it was never a stranger or neighbor who first noticed symptoms.

Only 16.7% of families were initially concerned about unusual behaviors or social delays commonly associated with ASD. The remaining 83.3% of families were concerned about generic developmental delays or difficult behaviors. For example, Alberto's family was 1 (24.1%) of 13 for which crying was a primary symptom that provoked concern. Alberto began crying intensely in the middle of the night at 6 weeks of age. The symptom was actually related to a hernia, but it stuck with Alberto's parents as he developed. Then, at 18 months, his crying came back; he also displayed language regression and anger, and he began hitting himself and others.

Other parents were also influenced by early problems that were likely unrelated to ASD. Carlos's mother was concerned at birth because he was so big and he slept too much and hardly cried. She became even more concerned about his health at 6 months of age when a pediatrician was providing information about sudden infant death syndrome, and she took the advice to mean that Carlos was specifically "prone to sudden death." At that point, she "fought with the doctors every time...to try to get a test for his condition."

## Knowledge and Advice-Seeking

Nearly half of the families, 26 (48.1%) of 54, knew nothing about the disorder before their children were diagnosed. Of the remaining parents, 25 (46.3%) knew very little about ASD or had only heard of the category (typically only from watching the 1988 movie *Rain Man*), and only 3 (5.6%) parents knew about specific symptoms and the heterogeneity of the disorder. The 3 parents who had considerable knowledge of ASD were university educated. One of the parents had worked in a US hospital and another was a trained physiotherapist who had treated patients with ASD. The remaining parent had heard of ASD on a radio program.

After their diagnoses, many of the interviewed parents were positioned to influence parents of undiagnosed children. Alberto's parents, unbeknownst to them, were part of a cohort of children in their small town who would be diagnosed with ASD in the coming years, establishing one of the country's primary spatial clusters of ASD diagnoses. His parents were never aware of this fact, or that 2 interviewees, who were both diagnosed after Alberto, lived down the road. The older of the 2, the son of an accountant, was first taken to the local clinic for developmental delay. He had been having trouble crawling and walking by 1 year of age. The parents were uncomfortable with the advice from the clinic to give him time, but instead of consulting with friends and family, they consulted a private physician in San Jose. The physician shared their concern and guided them through the public system, beginning with a pediatrician at the local hospital.

The younger of the 2 nearby children lived in a different neighborhood in the town. At 2 years old, he was still not talking and laughed for no apparent reason. A local pediatrician said to give him time, but after 4 visits over a year, the problem was not improving. The pediatrician referred the child to the local hospital where a psychologist mentioned ASD and referred directly to the Hospital Nacional de Niños. At this point, the child was well over 4 years old and was talking in the third person and presenting with obsessive behaviors and interests. The parents never consulted with their friends and family about these behaviors.

#### Unsolicited Advice

Only one respondent recalled a stranger mentioning ASD specifically. At 8 months old, her child was banging his head on the window of a public bus. A woman asked if he had ASD, but the respondent thought little of this interaction until she recalled it after receiving the diagnosis. In fact, at the time of the head-banging incident, her child had already begun early stimulation treatment, and even though the mother saw children with ASD at the early stimulation clinic, she did not suspect her son of having it. He behaved too differently from the other kids.

When respondents' children were seen to be behaving in public in inappropriate ways, strangers were uninhibited about commenting on the behaviors. One respondent's child routinely waved his arms and was "very corky," always running back and forth. On several occasions, passersby approached the mother and asked why she did not go to the doctor. The mother was annoyed by these chance public encounters and was later influenced by a language therapist to pursue medical help.

Many respondents reported providing unsolicited advice after their children's diagnoses. Carlos's mother became a kind of lay expert on ASD and reported having "telepaticos" for detecting other children with ASD. She attended talks at the Hospital Nacional de Niños and found literature about the disorder and she began talking with other people about the diagnosis to warn them of Carlos's behaviors, beginning with his teachers at school. When people on the street would ask about his behaviors, she would tell them about ASD. One time, she thought a boy on a playdate at her house had ASD; she told the mother her suspicion, but the mother was "stubborn and didn't believe" her. Alberto's parents also had opportunities to spread information about the diagnosis to other parents. She talked about the diagnosis with Alberto's teachers and her family, and then her husband's nephew displayed suspicious behaviors. She would not dare mention ASD to the parents, though, or any others. She was afraid of how they would react. Other parents were similar: as a cautious alternative to mentioning ASD, one respondent pointed out to her sister-in-law that her child acted a lot like her son, but she "wouldn't dare" be more direct. Another respondent told her sister to take her 17-year-old daughter to a specialist because she was "too dependent."

In all, 31 (57.4%) of 54 parents reportedly suggested the need for a medical evaluation to a parent of a symptomatic child. More than half of those 31 did not recall having mentioned ASD. Remarkably, we cross-checked names in the Hospital Nacional de Niños database (from 2007-2013) to locate evidence of subsequent diagnoses: no matches were confirmed.

# Caricatures of ASD

When parents were exposed to multiple children with ASD who displayed different behaviors or developmental delays, parents were uniformly hard-pressed to make a connection. One parent-the university educated mother who had previously worked in a US hospital-already had a child with ASD when her second one started presenting symptoms, but she was "in denial" even after the diagnosis. The first child, 15 months senior, was nonverbal, asocial, and acted "like a storm," displaying difficult behaviors in public that regularly elicited offensive comments from strangers. His difficult behaviors aside, he was independent. The parents already knew about autism when he was evaluated in the United States at the age of 3, although they were surprised by the diagnosis. The second child, a girl, was also language delayed but was extremely social. She was also "naive" and "not afraid of anyone," and she was dependent on her parents. She was behind in kindergarten when her teachers suggested seeing a private clinician.

Likewise, it turns out that Carlos's mother, the one with "telepaticos," had a nephew who was diagnosed with ASD. However, she believed that her nephew, who was 2 years older than Carlos, had problems in the mental domain, whereas Carlos's problems were "more of a social issue." She never imagined that the boys had the same problem.

When respondents were willing to initiate conversations about other parents' children, the respondents reported conspicuously similar symptoms between their children and the other children: there was a nephew whose main symptom, like the respondent's child, was extreme language delay; a daughter of a colleague who had the "same features" as the respondent's daughter; and a female acquaintance whose female child was "equal" to the respondent's daughter. A neighbor encounter involved a close friend whose child, curiously like the respondent's child, also displayed stereotyped behaviors, hit his mother, and had epilepsy. In another, the neighbor child was seen running out in the street, apparently oblivious to the danger of cars. The respondent told the mother that her child had done the same thing and that they "had something similar."

# Discussion

Parents—including the ones on the slow side of the spectrum of identifying or showing concern for anomalous behaviors—were aware of problems long before opportunities arose for parent-to-parent information spread. When parents did turn to friends and family for advice, they were encouraged to wait and were reassured that the symptoms would pass.

With this in mind, we note that efforts to encourage the early identification of ASD have been thwarted by the finding that early symptoms are poor predictors of later symptomology,<sup>10</sup> and many of the stereotypical symptoms of ASD, such as hand waving, are typically not present in younger children.<sup>11-14</sup> If it does present at all, classical ASD often does not appear until around 5 years of age.<sup>15-17</sup> In our sample, stereotypical ASD behaviors did emerge in many cases, but not before other generic symptoms were noticed at an early age. This is consistent with research from before<sup>18,19</sup> and after<sup>10,20</sup> the US ASD "epidemic," and in other low- and medium-income countries<sup>21-23</sup> and in the United Kingdom<sup>24</sup>: parents consistently report the identification of anomalies at an early age, before 2 years, and the early symptoms are primarily related to language delay. When problems are social in nature-a step closer to classical ASD-many people still do not consider ASD.<sup>25</sup> Like in our sample, many children provoke concern because of general medical concerns or day-to-day challenges, such as sleeping problems.<sup>26</sup> Consistent with a wide range of reports in the early diagnosis literature, our data suggest that these types of generic developmental problems do not require information from other parents to elicit concern.

But given the small number of parents in our sample who reported being influenced by incoming information, the prevalence of reported outgoing referrals is higher than would be expected, and with no apparent effect on subsequent diagnoses. The most plausible explanation is that the incoming referrals occurred but went unnoticed, which implies that the reported outgoing referrals had little effect. This would explain respondents' complaints that other parents do not want to hear "criticism" about their children. The implication here is that the respondents know that telling a stranger she should take her child to the clinic for a diagnosis is likely to be seen as criticism.

Yet these awkward encounters do occur, and not only in Latin America. In an ethnography about parents of children with ASD in New York, de Wolfe<sup>27</sup> documents several such encounters. The US parents were routinely inundated with unwanted attention, and they often chose to mention the diagnosis as a way to account for inappropriate public behaviors and complete "meltdowns." Strangers would commonly interject to propose solutions or to criticize the actions (or lack thereof) of the parents. The author points out the difficulty for these parents when they were seen by others as not doing good parenting, such as when common forms of discipline were known by the ASD parent to be ineffective. One parent became

so frustrated with these encounters—often occurring at moments when he was already flabbergasted—that he printed business cards to describe ASD and settle misunderstandings about his parenting choices, saving himself from the conversation. Another parent thought mention of the diagnosis to account for "bad" behavior was futile, as other parents would never understand until they were in the situation themselves.

Stranger encounters aside, the primary barrier to an influential information effect was that parents' understanding of ASD depended on caricatures of the disorder, either from other children they had encountered or from the movie Rain Man. When parents were exposed to information about ASD or other children with the disorder, incongruities between the caricatures and their own children led them to conclude that their children "had something else," actually forming resolve that ASD was not the cause. The likelihood that parents of symptomatic children would be exposed to other children with ASD, and that the symptoms between the two children would then overlap to suggest for a reasonable-but-naive person that they had the same condition, was slim at best.

Research on prototypes is relevant: Eleanor Rosch<sup>28</sup> pointed out that categories of natural objects are determined by one's experiences and then organized into prototypes. Prototypes, then, are used in the classification of disease and illness categories. For novices of those categories, such as young people with no professional experience in health or medicine, the categories have high distinctiveness, and there is little agreement between individuals; on the contrary, for experts of those categories, such as clinicians who have seen hundreds of patients with the particular condition, the categories become less distinctive but agreement increases.<sup>29</sup> For ASD, this means that increased knowledge of the category blurs its boundariesexperienced clinicians know from experience the aphorism, "if you know one child with autism, you know one child with autism," whereas people with little exposure to it are more likely to have strict boundaries based on idiosyncratic features.<sup>30</sup> Novices associate ASD with the classical symptoms that spring to mind from limited exposure to individuals with the disorder. It is conceivable that they think of Raymond Babbitt (Rain Man), reciting baseball facts or counting toothpicks, or they remember the child running out in the street, oblivious to passing cars.

# Conclusions

Theories that account for parental symptom recognition and help-seeking behaviors in ASD tend to put the onus of early detection on parents, which is unfortunate given a history of blaming mothers for ASD (eg, Bettelheim). Our data indicate that ASD-specific information may play a smaller role in diagnostic disparities of young children than previously thought. Our Costa Rican families were primed to be influenced by ASD-specific information: they were relatively uninformed about ASD, ASD-specific information had been recently disseminated by the genetic study authors, and their children were expressing symptoms of ASD. However, parents were uniformly good at detecting developmental delays and bad at attributing those delays to ASD, partially because their impressions of ASD were based on caricatures of the disorder largely dissimilar to their children's symptoms.

The overwhelming pattern was that parents had reasons very early that were suggestive of atypical development. These factors made parents scrutinize their children's development, although as they first sought help from friends and family and primary care physicians, they were told to wait and see if the delays disappeared. Parents were comforted, temporarily, often believing the issues would resolve, but as new developmental milestones passed by, they became increasingly concerned. They received unwanted advice from strangers in public, but it was always seen as critical of their parenting, and always too late to influence the referral process, which was well underway by the time classical symptoms of ASD appeared, if they did at all. After the diagnosis, all parents were informed about ASD, and some of them began spreading information about the disorder to other parents when they saw other children behaving similarly to their own. These encounters apparently had little effect on the other parents' health behaviors-in part, at least, for the same reasons that strangers failed to influence the interviewed parents.

This study represents a sample of Costa Rican families of children with ASD. The sample likely has considerable overlap with families of children in other Latin American countries in which the ASD category is currently being adopted. The results suggest that efforts to disseminate ASD information through a population with low levels of ASD knowledge will not resolve diagnostic disparities, as there are considerable barriers to an information effect on parents' health behaviors. A more effective approach may be to focus information on the heterogeneity of symptoms of ASD, as well as generic developmental delays that can indicate neurodevelopmental disorders in general.

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