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## The Diagnostic Odyssey of Autism Spectrum Disorder

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### Abstract

**OBJECTIVES**—Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by challenges in social communication and interaction and restricted or repetitive behavior, interests, or activities. Although ASD symptoms generally manifest in early childhood, many individuals experience delays accessing an autism diagnosis and related services. In this study, we identify the individual, social, and structural factors that influence parents' experiences of children's ASD diagnosis.

**METHODS**—Parents of 25 children with autism participated in 60- to 90-minute semistructured in-person interviews. Interviews were recorded and transcribed verbatim. Transcripts were analyzed using the method of grounded theory. This inductive method allowed analysts to identify key themes related to participants' experiences of children's ASD diagnosis.

**RESULTS**—The process of ASD diagnosis reflects an odyssey that includes 3 key phases: the prediagnosis phase, in which “Making Sense of Child Difference” is a primary characteristic of

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participants' experiences; the during-diagnosis phase, when "Navigating Diagnosis" suggests systematic barriers that influence the timing of ASD diagnosis; and the postdiagnosis phase, when participants' experiences of "Connecting to Services" point to the important role that personal efforts play in gaining access to care.

**CONCLUSIONS**—In this study, we highlight individual, social, and structural factors that influence parent experiences before, during, and after their child's autism diagnosis. Our findings indicate the need for more consistent and continuous support for autistic individuals and their families during the diagnostic odyssey, as well as resources that better represent the diversity of experiences and symptoms associated with autism across the life course.

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## THE DIAGNOSTIC ODYSSEY OF AUTISM SPECTRUM DISORDER

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by persistent challenges in reciprocal social communication and interaction as well as restricted or repetitive patterns of behavior, interests, or activities.<sup>1</sup> Symptoms of ASD generally manifest in early childhood and can typically be recognized by 24 months of age.<sup>2</sup> Early identification of ASD facilitates treatment planning and early intervention, which is reported to reduce children's long-term intellectual, behavioral, and functional impairments as well as improve family outcomes.<sup>3, 4</sup>

However, the process of obtaining an ASD diagnosis and connecting to early intervention and support services is often challenging. The processes involved in (1) identifying the need for an ASD diagnosis, (2) obtaining an accurate assessment by a trained professional, and (3) gaining the appropriate services for a child with ASD involve complex individual, social, and medical factors that can often be logistically, financially, and personally difficult to navigate. For example, ASD symptoms can often go unrecognized until an individual is older because of parental attributions of their child's symptoms to medical issues or nonautism-specific behaviors.<sup>5-7</sup> In addition, clinicians often experience challenges accurately recognizing and diagnosing ASD because of the heterogeneity of its symptoms.<sup>8-10</sup> Furthermore, community and geographic factors, including residence in a rural area and the capacity of the health system, have been associated with later ASD diagnosis.<sup>11-13</sup> In the United States, diagnostic delays are further exacerbated by racial, ethnic, and sociodemographic factors, with Hispanic and African-American children, children not born in the United States or whose parents were not born in the United States, and children of parents with fewer years of formal education all receiving diagnoses much later than their counterparts.<sup>8, 14, 15</sup>

These factors suggest some of the individual, social, and structural conditions that influence ASD diagnosis. We know that families can experience many challenges during the process of ASD diagnosis. We therefore liken this process to an "odyssey," which we define as a long and eventful journey.<sup>16</sup> For parents, this odyssey often introduces new diagnostic classifications, shifts perceptions and understandings of their child's development, and requires the navigation of complex social, educational, and medical systems. Family experiences during this process can influence the likelihood of gaining a timely diagnosis and the postdiagnosis actions taken. Significant delays and obstacles to obtaining an

accurate diagnosis may also erode a family's trust in and willingness to continue interacting with the health system.<sup>17</sup> This is consequential because effective postdiagnosis support for children and families has been found to be crucial in ensuring the implementation of effective intervention strategies to address ASD.<sup>18</sup>

The American Academy of Pediatrics recommends universal screening for ASD during 18- and 24-month well-child visits.<sup>2, 14, 19, 20</sup> Several standardized screening instruments (eg, Modified Checklist for Autism in Toddlers, Social Communication Questionnaire) have been developed to identify ASD, and the use of these screening instruments is associated with earlier identification of developmental concerns.<sup>2, 14</sup> However, some clinicians have been slow to adopt formal ASD screening tools, and studies indicate that many have not introduced ASD-specific screening as a routine part of the well-child visit. For example, documented ASD screenings occurred in only 15% of 18- and 24-month wellchild visits across 26 primary care practices in Utah that were enrolled in a learning collaborative from June 2009 through July 2011.<sup>21</sup> Similarly, only 55% of primary care clinicians in Wisconsin that were surveyed in 2012 reported routine use of developmental and autismspecific screening tools.<sup>13</sup> This lack of adherence to ASD screening guidelines is further complicated by the heterogeneity of ASD, which precludes the development of a single, simple method for identifying ASD across age groups and symptom presentations.

Given that pediatricians are often the first professionals with whom parents interact about their child's development and on whom parents rely for advice, their capacity to respond effectively to parent experiences related to ASD may significantly influence the diagnostic process.<sup>22</sup> However, some pediatricians report low self-efficacy, a lack of adequate training and resources to educate parents about developmental disabilities, and a reluctance to overwhelm parents by directly raising concerns about autism.<sup>9</sup> Notably, researchers have indicated that although parents of children with ASD were more likely to raise concerns at an earlier age compared with children with intellectual or developmental disabilities, health care providers were less likely to respond proactively. Proactive responses could include making a referral to a specialist, conducting additional developmental tests, giving psychosocial support, and providing resources that reflect the wide range of experiences and symptoms associated with ASD. However, research suggests that some pediatricians were more likely to respond passively to parental concerns when children had ASD compared with an intellectual or developmental disability, suggesting that the child might "grow out of it" or expressing that it was "too early" to indicate the need for a formal assessment.<sup>23</sup> These passive responses were associated with increases in diagnostic delays, while more proactive responses were associated with a decrease in diagnostic delays.<sup>23</sup>

Currently, 1 in every 68 children in the United States is estimated to be affected by ASD.<sup>24, 25</sup> It is therefore imperative to understand how parents experience the ASD diagnostic odyssey. To address this question, we used qualitative methods to analyze how parents of children with autism experience ASD diagnosis and their perceptions of the individual, social, and structural factors that influence this process. Although qualitative analysis does not allow us to define the prevalence of any opinion or attitude in the general population, we point to key themes expressed by our participants that may assist health professionals in

helping families gain accurate and timely diagnoses for their children and provide services to improve family and individual experiences of ASD.

## METHODS

We conducted semistructured interviews with 44 parents of 25 children diagnosed with autism in the greater Los Angeles area. In accordance with institutional review board approval, participants were recruited from clinics across the Los Angeles area. Parent participants ranged from 24 to 57 years of age and reported high socioeconomic backgrounds. Children were between 24 and 45 months and expressed a range of autism symptoms (see Table 1 and 2).

Interviews took place between 2013 and 2015 and were conducted at the University of California, Los Angeles by 1 of the study authors. Parents were interviewed individually or as a couple, depending on their availability and preference. After obtaining written consent, participants were asked a series of open-ended interview questions about their child's ASD diagnosis including: the initial signs they associated with autism; how interactions with friends, family members, and professionals shaped their understanding of their child's development; and the process of gaining an ASD diagnosis and navigating ASD-related services.

All interviews lasted from 60 to 90 minutes and were accompanied by a professional assessment of the child using the Screening Tool for Autism in Toddlers and Young Children–Expanded, the Autism Symptom Interview, and the Autism Diagnostic Observation Schedule. Interviews were transcribed verbatim and deidentified. All transcripts were analyzed in the analysis program Dedoose, a secure online program that enables both qualitative and quantitative analysis.

Data analysis followed the method of grounded theory, which includes a systematic process for developing a coding system to inductively analyze qualitative data and a method for making comparisons to ensure objective development of concepts and theories.<sup>26–28</sup> In line with the principles of grounded theory, data analysis was ongoing throughout the research process. This allowed the study team to triangulate our perspectives on key themes and to adjust the interview guide to capture a range of participant experiences during data collection. On the basis of this process and the coding strategy described below, thematic saturation was reached after interviews with parents of 20 children. Additional interviews were conducted to confirm key themes.

After all interviews were conducted, 3 of the authors independently coded a subset of the transcripts to ensure that our findings did not reflect individual bias. The authors discussed our interpretations of the data during weekly meetings that took place over 4 months, during which time we revised and tested the codebook that was originally developed by the lead author. The revised codebook was then used by all coders to analyze the original subset of interviews to assure intercoder reliability. After intercoder reliability was reached, the lead author used the finalized codebook to analyze all interviews, sharing analytic memos and emergent findings related to key themes with the study team throughout. This iterative,

collective, and ongoing analysis is the basis of the 3 processes involved in the diagnosis odyssey that we present below.

## RESULTS

Three key themes emerged related to the diagnostic odyssey. The first theme is “Making Sense of Child Difference,” which describes parents’ expectations of their children’s development and how those expectations shifted as they began the diagnostic odyssey. With this finding, we signal an introductory phase of the diagnostic odyssey, when parents’ understanding of their children’s development started to be articulated in relationship to the possibility of an ASD diagnosis. The second theme is “Navigating Diagnosis,” in which participant accounts point to the barriers and long waiting periods they experienced related to an ASD diagnosis. These included barriers within the health care system and emotional challenges that families faced. The final theme is “Connecting to Services.” Conveyed in this theme are parents’ experiences as they gained knowledge about and adjusted to the systems of care related to ASD. With these phases, we suggest that social contexts; parent and child interactions with pediatricians, peers, and other professionals; and structural barriers all influence experiences of ASD diagnosis.

### Making Sense of Child Differences

All participants discussed how their experiences with pediatricians, parenting books, online resources, and family and peer interactions helped them develop expectations for their own child’s development. However, some parents reported challenges making sense of differences their children exhibited compared with their peers and in relation to expected developmental milestones. These participants often did not initially view their child’s development as warranting medical attention, which led to challenges when an ASD diagnosis was introduced. One mother recalled the experience with her daughter:

She was my first [child]. I just figured she didn’t want to talk that much, I had nothing to compare to. I had some friends that had their kids, some were kind of aren’t supposed to compare your kids at that age so I thought nothing of it.

Another mother explained how she initially interpreted her son’s developmental trajectory in comparison with his closest peer. She said:

We have some close family friends and we were fortunate enough to be pregnant together and we raised our children together. Their baby was the girl in their family, so she was always quick to those mile markers: wow, she’s crawling, she’s talking, she’s doing all these things. And I always thought, she’s a girl and that’s probably why my son is just a little slower. But our son was always so sweet and calm and didn’t require much. It seemed like he was content that way. He never really fussed, he liked going down to bed. Up until my son was 14 months old, I thought everything was fine.

Rather than suggesting the need for a formal evaluation or diagnosis, these parents and others we interviewed initially interpreted their children’s behaviors as normal deviations from expected developmental milestones or reflections of their unique personalities.

Although others we interviewed communicated concerns about their children with their pediatricians, in these cases it was often the pediatrician who raised the possibility of an ASD diagnosis with parents. As a participant explained:

I didn't notice that my son was behind until my pediatrician said, "Look I think we have something that we are overlooking here." She asked me a series of questions on our well check...She pointed out he is not pointing, he's not making good eye contact, he's not talking, he had a very thick glaze in his eyes, it was just like a disconnected stare. Those really frightened me...But I kinda thought, really? There's something wrong? And at first, I questioned it. And every family member that we shared it with said, "That's ridiculous, he's just a baby, you can't think anything of that, he's going to grow out of it."

In this case and many others, parents felt conflicted as they reconciled professional advice and the perspectives of trusted friends or family members. Others we interviewed were frustrated with the response they received when they brought concerns about their child's development to their pediatrician's attention. A father explained:

I would tell [our pediatrician] these things, like little milestones that my son should be hitting. And he's just like, "No, don't worry about it. Boys are late. You overthink everything, you over analyze everything. Just relax, he'll get there." And my mother's intuition was like, "This is not good."

Although all our participants' children ultimately received a formal evaluation by a developmental specialist and an ASD diagnosis, these experiences suggest the important role that pediatricians, family members, social networks, and previous perceptions of child development all play in determining when and if autism is diagnosed. In addition, these accounts reveal the personal challenges that parents often experience reconciling different perceptions of their child's development before an ASD diagnosis takes place and the important role that a child's gender can play in this process. Understanding the influence of these contexts on caregiver experiences can assist physicians in supporting families through this initial phase of the diagnostic odyssey.

### **Navigating the Diagnosis**

The second phase of the diagnostic odyssey conveys how structural conditions can influence the diagnosis experience while it is taking place. Many participants remarked on the long waiting periods they experienced between their child's initial referral to a specialist and a formal ASD diagnosis. These extended periods of time caused parents to feel a profound sense of uncertainty and frustration as they waited. Although many participants reported that pediatricians provided timely referrals, families nevertheless often waited months to obtain a specialist's assessment. One father described the process, stating:

First, you need to go to your pediatrician and the pediatrician has to make the referral to a specialist, and after you see the specialist, that's when you get the diagnosis added. But that takes a while. The only thing I get very, very mad about is the process to get everything done takes so long. Like for my son, I had to wait months to get just an evaluation and I think it's just wasting time... you can't get the services during that time, because you don't have the evaluations yet.



Others expressed similar frustrations, as another parent explained:

I felt like... when you say I'll have to wait some months, it's killing me, because that is time that my child could be learning or at least you could be evaluating them. You could be doing more testing, but I have to wait months. It is something that I know he already has, it's torture, that we had to wait months.

Another parent explained the discrepancy between an emphasis on early intervention and the amount of time it took for his son to be diagnosed. He said, "The process took almost a year. So, the system is kind of bad, it's very bad...If you do the process soon, you can get more therapy and more help for my kid, right? But this doesn't happen."

Our participants explained that an ASD diagnosis ultimately gave their children access to in-home speech and behavioral therapies, school-based services, and helpful professional and personal networks. However, nearly all the parents we interviewed felt they had lost valuable time with these resources because of the long waiting periods between referrals, assessments, and access to ASD-related services. To circumvent these delays and the feelings of frustration that often accompanied them, several participants described paying out of pocket for services while they waited for confirmation of their child's diagnosis. This is an option that many others we interviewed could not afford.

### Connecting to Services

After their son or daughter was diagnosed with ASD, nearly all of our participants expressed emotional, financial, or social challenges navigating the complex ASD-related service system. This led many to feel they had to personally advocate for their child to receive adequate services. These efforts required extensive time and energy on the part of all the parents we interviewed. Many participants described adjusting their work schedules or leaving their jobs to accommodate the new responsibilities associated with their child's care. Others described moving to cities or school districts that had more reliable resources. Many also conveyed difficulty in gaining effective forms of personal and medical support during this period, including childcare and individual therapy. Although our sample was not varied enough to account for differences by education or socioeconomic status, reflected in this theme are experiences that are likely to be impacted by these factors. Even after parents secured services for their children, many felt they needed to remain vigilant to keep those resources in place, especially during school and life transitions.

Many of our participants described challenges navigating the systems related to autism care while juggling other responsibilities. One mother explained feeling overwhelmed after her daughter's ASD diagnosis, stating:

I have to do everything, so I have to work, I have to take care of my daughter, I have to talk to all these people to get all these assessments and appointments. Sometimes, I forget some of these appointments because there are so many appointments.

As the quote below reflects, other parents hoped their pediatrician would provide more guidance after their child's diagnosis:



Basically, I was the person investigating all the information, like how you get [services] and everything. My pediatrician never really told me, “Oh, you have to do this...” It’s more like I have to do everything. And I was thinking in the beginning that it’s the responsibility of the doctor to tell me what is right.

Even when medical professionals played a more central role in assisting families, the decentralized nature of ASD-related services meant that many parents felt personally responsible for coordinating their child’s care. Although some participants embraced this role, others felt uncertain about whether and to what extent they should engage with the services available to their child. One mother’s experience suggested the persistence she felt was involved in gaining access to ASD-related services. She explained, “You have to wake up, start walking, and start knocking doors to get the services. Because I think that the problem [is] you need to knock a lot of doors.”

After families gained access to services for their children, many described a period of adjustment not only to the complex systems of care related to ASD, but to the approach of some services. Because many interventions rely on caregivers’ active participation and reinforcement, some parents noted a personal transition that accompanied these new ways of interacting with their children. One mother described an experience that others also shared, recounting the challenges and opportunities associated with ASD-related therapy for her son:

Every child has their own personality and I thought my son’s autism was his personality. So, me trying to break into that world was something I was apprehensive to do...It was a challenge, it is the biggest blessing and the scariest thing at the same time.

In this instance and many others, participants conveyed the often conflicting feelings they had about providing the best care for their children as they experienced the autism diagnostic odyssey.

## DISCUSSION

With these findings, we suggest that the autism diagnostic odyssey begins before and continues long after an ASD diagnosis. As many others have observed, 17, 23 obtaining an autism diagnosis can be a long and drawn-out process that often involves uncertainty and competing understandings of a child’s development along the way. This process involves the interaction of multiple individuals including parents, children, pediatricians, specialists, therapists, social workers, and educators, as well as factors including the social and medical systems, family dynamics, and knowledge of autism. Suggested in our findings are the ways that this odyssey can be influenced by parents’ previous experiences and expectations of their children, their interactions with friends and family, their relationships with medical professionals, and the complex structures that accompany ASD diagnosis and services.

Experiences of ASD diagnosis are situated in these larger systems of meaning and structures of care. Recognizing parent and caregiver experiences as impacted by this broader landscape is therefore critical. Doing so may allow providers to see clinical encounters as an important but partial piece of the diagnostic odyssey. Parent experiences point to some important ways

that pediatricians might engage these factors to better assist families throughout the diagnostic odyssey. For example, clinicians can provide a clearer sense of the time period and process involved in gaining an ASD diagnosis, actively engage or help to expand a parent's social network when families are coping with the diagnostic process, or interface more fluidly with existing structures of care associated with ASD to improve this process. In addition, more public education about the variation in autism's presentation, types of services available, and forms of support for autistic individuals and families may alleviate some of the burdens that many families experience during the diagnostic odyssey. Our findings also suggest that more societal acceptance of autism and better understanding of its expression across the life course would aid families and autistic individuals alike.

These actions may be particularly helpful now, given recent discussions about universal screening for autism.<sup>29</sup> Our findings suggest that some parents and pediatricians may initially feel uncertain about ASD diagnosis, or unfamiliar with the behaviors that warrant additional assessment or monitoring, especially during early periods of child development. During this time, pediatricians and other professionals should therefore be aware of not only the need for assessing child development accurately but of caring for children and their families as they traverse the complex odyssey associated with ASD.

This study is limited by retrospective accounts and the inclusion of English-speaking participants from a single, large, urban center. As a qualitative study, our intent is to illuminate important experiences related to ASD diagnosis. These findings may not be generalizable to other populations, and our methods do not allow us to estimate the prevalence of these themes in the United States population. Additional researchers should therefore explore how the diagnostic odyssey differs for families who do not speak English, those in other regions, those with varying levels of comfort with the medical system, and those with different education and income status. Because of the participants in our study, we cannot speak to experiences across these important distinctions. However, many of the experiences parents shared are likely to be exacerbated by these differences. Finally, as awareness of autism increases and access and funding for developmental services shifts, experiences of the diagnostic odyssey may also change.

Nevertheless, critical insight into parent experiences of children's ASD diagnosis is provided in this study, and we point to the important role that pediatricians can play in this process. For example, if pediatricians are knowledgeable about community resources in their area, they can interact with schools and special education and meet with parents on a regular basis to provide support. More frequent interaction with families during the diagnostic odyssey could also assist families in receiving more timely access to medical, developmental, and social support. Future researchers should explore new and existing programs that provide these forms of support and assess how they impact individual experiences, social contexts, and structures of care associated with ASD before, during, and after diagnosis. Understanding the relationships between individual experiences and the contexts in which they are situated will be imperative to improving the autism diagnostic odyssey.

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## ABBREVIATION

**ASD** autism spectrum disorder

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TABLE 1

## Demographic Breakdown of Participating Families

Demographics	Children, <i>n</i> = 25 (19 Male, 6 Female)	Mothers, <i>n</i> = 22	Fathers, <i>n</i> = 22
Average age (range), y	3.06 (2.05–3.84)	35.76 (24.34–43.37)	39.94 (25.87–57.67)
Race and/or ethnicity			
White	7	6	8
African American	2	2	5
Hispanic	7	7	5
Asian American	7	5	5
Native American	1	1	1
Pacific Islander	0	2	0
Multiethnic	7	0	0
Other	0	2	3
Parental education level			
Some high school	—	0	1
High school graduate	—	1	5
Some college	—	6	5
College graduate	—	10	6
Graduate and/or professional training	—	5	5
Parental employment status			
Unemployed	—	10	0
Employed, part-time	—	5	0
Employed, full-time	—	5	16
Self-employed, part-time	—	3	1
Self-employed, full-time	—	0	5

—, not applicable

**TABLE 2**

## Demographic Breakdown of Families

<b>Demographics</b>	<b><i>n</i></b>
Family income, \$	
<10k	1
10–20k	1
20–30k	3
30–40k	2
40–50k	1
60–80k	5
80–100k	1
>100k	7
Family receiving aid (ie, Medicaid, food stamps, SSI, food pantry, TANF, unemployment, WIC, housing assistance, etc)	16

SSI, Supplemental Security Income; TANF, Temporary Assistance for Needy Families; WIC, Special Supplemental Nutrition Program for Women, Infants, and Children.

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