

# Autism Spectrum Disorder Identification, Diagnosis, and Navigation of Services: Learning From the Voices of Caregivers

Focus on Autism and Other  
Developmental Disabilities  
2020, Vol. 35(4) 246–256  
© Hammill Institute on Disabilities 2020  
Article reuse guidelines:  
sagepub.com/journals-permissions  
DOI: 10.1177/1088357620922165  
focus.sagepub.com



Elizabeth Crais, PhD<sup>1</sup>, Cara S. McComish, PhD<sup>1</sup>, Emily F. Kertcher, PhD<sup>2</sup>,  
Steve Hooper, PhD<sup>1</sup>, Rebecca Pretzel, PhD<sup>1,3</sup>, Lucia Mendez, PhD<sup>4</sup>,  
and Michelle Villalobos, PhD<sup>5</sup>

## Abstract

This study explored caregivers' perspectives on facilitators and barriers to screening, diagnosis, and identifying and accessing other services for young children with autism spectrum disorder (ASD); and caregivers' suggestions for improving the process. Eight focus groups with 55 caregivers were conducted. Four groups had a mix of White, African American, and Asian caregivers, and to gain broader populations, we recruited two groups of Spanish-speaking and two groups of American Indian caregivers. Some caregivers reported that their child and they received excellent services; however, the majority reported concerns about the services they and their child received. The findings also indicated a lower age of diagnosis and a smaller gap between concerns and diagnosis for White non-Hispanic children compared with Hispanic non-White children. Caregivers had many suggestions for ways to improve the process.

## Keywords

ASD, caregiver perspectives, screening, diagnosis, access, service systems

Many families of young children diagnosed with autism spectrum disorder (ASD) report challenges with one or more phases of moving from first concerns, to diagnosis, to identifying and accessing other ASD services (Crane et al., 2016; Grant et al., 2015; Montes et al., 2009), including those families from Latino cultures (Zuckerman et al., 2014). Despite a national focus on early identification, the achievement of early and consistent screening, diagnosis, and identification and access to ASD services that are positive for families is inconsistent. Providing superior services is clearly the aim of all professionals. However, most published studies aimed at gathering evaluative data have focused on the nature of the dissatisfactions rather than the views of caregivers on how services could be improved. Out of more than 30 studies we reviewed, although some professionals offered suggestions for change, only three (Carlsson et al., 2016; Osborne & Reed, 2008; Zuckerman et al., 2014) specifically sought caregiver's suggestions. In the current study, we set out to gain the perspectives of caregivers on both the barriers to services and their ideas on how to improve them in the belief that caregivers themselves can guide the field in making real progress toward change.

In terms of professionals improving services, enhanced early screening in primary care has been one means targeted (Miller et al., 2011; Pierce et al., 2011; Richards et al.,

2016). Despite these efforts, some providers continue to rely on observation (Radecki et al., 2011), do not screen even when caregivers raise concerns (Arunyanart et al., 2012), may not use up-to-date screening tools (e.g., using the Modified Checklist for Autism in Toddlers [MCHAT]—Robins et al., 2001, 2014—without the follow-up questions), and fail to refer despite a positive screen (Crais et al., 2014). Others report they are not well prepared to identify children or comfortable talking with families about ASD concerns (Crais et al., 2014), including those from Latino families (Zuckerman et al., 2013). Despite high self-reports of pediatric screening (Self et al., 2015), in a recent survey of caregivers of young children with ASD, only half reported their child was screened for ASD (Martinez et al., 2018). However, some families may not be aware of screening if they do not complete a form and are asked questions

<sup>1</sup>The University of North Carolina at Chapel Hill, USA

<sup>2</sup>UNC Hospitals, Chapel Hill, USA

<sup>3</sup>Carolina Institute for Developmental Disabilities, Chapel Hill, NC, USA

<sup>4</sup>The University of North Carolina at Greensboro, USA

<sup>5</sup>Asheville TEACCH, NC, USA

## Corresponding Author:

Elizabeth Crais, Division of Speech and Hearing Sciences, The University of North Carolina at Chapel Hill, CB 7190, 3126 Bondurant Hall, Chapel Hill, NC 27599-7190, USA.

Email: bcraiss@med.unc.edu

orally. Furthermore, although 80% of Self et al.'s pediatricians were screening, only 17% were following American Academy of Pediatrics (AAP) screening guidelines.

Another barrier to services is the gap between parent report of concern and diagnosis. As noted in Zwaigenbaum et al.'s (2015) introduction to their meta-analysis, parental concerns are commonly noticed before 18 and 28 months, whereas the Centers for Disease Control (CDC) epidemiologic data note the median age of diagnosis is over 4 years (Baio et al., 2014). Two recent studies (Crane et al., 2016; Zuckerman et al., 2015) reported the gap from the first provider conversation about concerns to ASD diagnosis is often 3 to 3½ years. Zuckerman et al. (2015) revealed that over half the parents initially received a "reassuring" response from their physician (e.g., child will outgrow, too early to tell). Moreover, parents of children with ASD reported earlier conversations compared with parents of children with other disabilities. They were also much more likely to be reassured, and reassurance led to delays in diagnosis compared with children with ASD whose pediatricians were more receptive to parental concerns (Zuckerman et al., 2015). Thus, some caregivers feel not listened to, frustrated, and that their physicians ignored their concerns or were not prepared to recognize ASD (Brookman-Frazee et al., 2012; Tomlin et al., 2013).

Many studies have also documented caregiver dissatisfactions with diagnostic services. Across studies, families describe unfamiliar settings for the child, diagnostic inconsistencies, overwhelming amounts of information, limited support following evaluation, frustrating paths to access services, varied availability and a "fight" for resources, and a resulting emotional toll on families (Abbott et al., 2013; Carlsson et al., 2016; Chamak & Bonniau, 2013; Coogole et al., 2013; Reed & Osborne, 2012). Some caregivers feel isolated and unsupported during the process (Carbone et al., 2010; Freuler et al., 2014; Russell & McCloskey, 2016).

Despite initiatives aimed toward lowering the age of identification, diagnosis, and accessing other ASD services, few studies have examined caregivers' perspectives on the facilitators and barriers to the process, and their thoughts on how one or more phases could be improved (Carlsson et al., 2016; Osborne & Reed, 2008; Zuckerman et al., 2014, are exceptions). Across these studies, caregivers have suggested professionals need more ASD knowledge and skills; professionals need to provide caregivers with a clearer path, more time, guidance, and information after diagnosis; and families could use a coach to help with decision making. Caregiver feedback about the quality and effectiveness of identification, diagnosis, and identifying and accessing other ASD services could be beneficial. The current study was designed to gain a deeper understanding of those perspectives. In addition, we canvassed a broader array of ethnic populations than most studies. We also chose to utilize focus groups because they can be helpful in gaining consumer feedback about a process, and group interactions can

promote a range of ideas and experiences (Krueger & Casey, 2008; Nassar-McMillan & Borders, 2002). Of the multiple studies we reviewed, only one solely used this methodology (Osborne & Reed, 2008), whereas two others (Grant et al., 2015; Zuckerman et al., 2014) included a mix of focus groups and individual interviews.

## Method

### Study Design

Focus groups were utilized because of the richness of detail they can provide about the experiences and perspectives of caregivers (Colton & Covert, 2007; Fowler, 2014). Quantitative data were also collected on some details (i.e., county, race, ethnicity, number of children in family, number of children with ASD, age of all children, age of diagnosis).

### Participants

In total, 55 caregivers of young children diagnosed with ASD participated in eight focus groups with an average size of six to seven participants, in seven areas in eastern, western, and central North Carolina. Caregivers were primarily mothers with a few fathers and grandmothers. Although four groups had a mix of White, African American, and Asian caregivers, to gain broader populations, we recruited two groups of Spanish-speaking caregivers and two groups of American Indian caregivers. The caregiver self-identified racial breakdown was 38 Whites, nine American Indians (plus four White mothers married to American Indian fathers), three Black/African Americans, and one Asian; 18 caregivers identified as being of Hispanic ethnicity. In terms of urban/rural distribution, 34 lived in counties labeled "urban" (more than 50.1% of population live in urban locale), 15 in counties labeled "rural-50" (50–99.9% live rurally), and six in counties labeled "rural-100" (100% population live rurally) ("American Community Survey 2013-2017," 2018).

The mean number of children/family was 2.51 (range = 1–7), and the mean number of children with ASD/family was 1.25 (range = 1–5). Among the 55 caregivers were 69 children with ASD. Although our recruitment targeted families with children up to eight, five families with 9-year-olds attended and were included. Mean age of the children with ASD was 4.7 years (range = 19 months–9 years), whereas a few parents had other children with ASD as old as 23. Families who had an older child/youth with ASD were asked to speak only of their experiences with their child/ren, 9 years and younger.

### Procedures

Four focus group questions were developed based on current literature and revised through an iterative process

with qualitative experts from the University of North Carolina's Institute for Research in Social Science and other caregivers of children with ASD. These caregivers were recommended by local and state ASD organizations. The questions were as follows: What helped and what were barriers in moving toward getting an ASD diagnosis for your child? Once diagnosed, what helped in identifying needed Early Intervention (EI) services? and What ways could the process have been better for you and your family? The study was approved through the university's Institutional Review Board.

The participants were recruited through the Autism Society of NC (ASNC), one of the largest statewide networks of caregivers of children with ASD. Local parent advocates sent recruitment flyers to their area lists and used "word of mouth" to set up each group. To maximize recruitment, our ASNC contacts urged us not to gather caregiver socioeconomic status (SES) information because some caregivers may not have had legal status and/or were unemployed, and we agreed. The first two authors facilitated the six English-speaking groups and the sixth author, a native Spanish speaker, the Spanish groups. All three had focus group training, had conducted previous groups, and used standardized guidelines. Each group lasted approximately 1½ hr and was held in a central location in each community. Participants completed a consent form, a brief data form on their children, had a light snack, and received a US\$25 gift card.

After introductions were completed and the purpose was stated, the four questions were asked in succession with time allowed for participants to respond to each. Each session was audio recorded for later transcription. A note-taker transcribed each speaker's first few words and nonverbal responses, and at session end reviewed the main points expressed which served as a form of a "member check" to give participants a way to validate the accuracy of the information gathered.

### Data Analysis

The audio recordings were transcribed by graduate research assistants and confirmed by the authors through use of the audiotapes. Inconsistencies were discussed and edited for context. After reading the transcripts, the first three authors developed a coding system using a grounded theory approach (Krueger & Casey, 2008), with systematic steps to identify main topics ("open" codes) and subthemes ("axial" codes) (Faggiolani, 2011). The first three transcripts were then independently coded. Through discussion and resolution of discrepancies, the three authors reached consensus on the code names, definitions, and example quotes for each code. Several of the codes were easily named and coded (e.g., first concerns: age, concerning behaviors, who first noticed), whereas others (e.g., caregiver reactions) were more nuanced and took more discussion to narrow the operational definitions.

Once the coding system was confirmed, all transcripts were entered into ATLAS.ti (Scientific Software Development GmbH, Berlin, 2013) for coding and analysis. The second and third authors independently coded all transcripts, with consensus gained on disagreements. The data were analyzed in ATLAS.ti to identify common codes, the variety of participant responses within each code, and to identify representative caregiver quotes. Throughout the remainder of the article, following recommended focus group conventions, modifiers such as a few, some, many, most, or all will be used to describe proportionally how many people talked about an issue in a particular way (Krueger & Casey, 2008). This commonly used data analysis strategy is preferred to actual counts because not all caregivers may respond about each topic. See a copy of the codes and representative quotes in the Supplemental Material.

## Results

The study's purpose was to gain caregivers' in-depth perspectives on early identification, diagnosis, and accessing other ASD services, and, in particular, how the process could be improved. We also sought to gather perspectives from a broader array of racial and ethnic populations than most studies and used focus group methodology to identify representative themes. Across groups, there were far more barriers identified than facilitators, and five main themes emerged: first concerns, diagnosis, identifying and accessing other ASD services, additional barriers, and what would help.

### First Concerns

Within first concerns were five axial codes: age of first concerns, concerning behaviors, who first noticed concerns, caregivers' reactions to the actions taken/not taken, and ASD screening.

*Age of first concerns.* Of the 49 caregivers who reported they or someone had concerns about their child/ren, the age range was similar across racial/ethnic groups. Some caregivers reported concerns as early as 12 months, about a third at or before 2 years of age, most of the rest between 2 and 3 years (preschool), and several between 3 and 5 years.

*Concerning behaviors.* The most frequent concern was the child not meeting milestones, particularly talking. Dysregulation issues (e.g., tantrums, aggressiveness, hyperactivity, need for sameness) were next most common, followed by limited eye contact; repetitive behaviors; poor or no response to name; lack of or limited social interactions; concerns about the child's hearing; regression that included loss of: words, eye contact, or babbling; toe walking; and unusual play. Most caregivers noted multiple concerns.

*Who first noticed concerns.* Most caregivers were the first to notice, whereas a third noted “others” had, and several did not report who noticed. The most frequent “others” were preschool teachers or EI professionals, followed by grandmothers and babysitters, and a handful of physicians. For caregivers with multiple children with ASD, subsequent children were often recognized earlier than first-borns.

*Caregivers’ reactions to the actions taken/not taken.* Most caregivers who had concerns shared them with their physician (mostly pediatricians, a few family practitioners), with mixed responses. Some helped caregivers explore their concerns and move toward evaluation, and these caregivers felt fortunate to have support. A few whose physician brought up concerns reported being angry and did not initially agree; however, when a preschool teacher or EI provider raised concerns, most caregivers were grateful.

For most caregivers who raised a concern with their physician, reassuring language was often used (e.g., “He’ll talk when he’s ready”; “He’s fine, don’t worry”). Some negated caregiver’s concerns, “I think you’re looking for something that’s not there,” or in a perceived condescending tone, “He passed the MCHAT at 2, so what makes you think he has autism?” Some professionals told caregivers they were sure the child did not have ASD, thereby delaying diagnosis. Also worrisome was the number of caregivers who had to continue over multiple visits to convince their physician to make a referral or who changed physicians because they did not feel supported. One reported,

He’s meeting all these milestones . . . but why is he still having meltdowns? Finally, I called the doctor and [said] “I need a referral for a child psychologist,” [and at the evaluation] within five minutes he said, “Your child has Pervasive Development Disorder-NOS.”

*ASD screening.* Caregivers were not specifically asked about ASD screening, and those who mentioned screening reported completing the MCHAT or a “checklist” for ASD. Some commented they were asked about their child’s development, and others noted they followed their child’s milestones themselves.

## Diagnosis

These codes reflected three subtopics: age of diagnosis, behaviors observed, and caregiver reactions to the diagnosis and process (e.g., how professionals interacted with the child/caregivers, shared information, and provided guidance afterward, especially identifying other ASD services).

*Age of diagnosis.* Fifty caregivers reported age of child diagnosis as a mean of 3.74 years (range = 15 months–9 years). Non-Hispanic White caregivers reported a mean of 2.55

years, whereas Hispanic caregivers reported a mean of 4.97 years, despite similar ages of first concerns.

*Behaviors observed.* The key diagnosis behaviors were similar to first concerns with the addition of repetitive behaviors, social deficits with peers, and behaviors seen in early care or preschool (e.g., need for routine, sensory reactions to materials/routines).

*Caregiver reactions to the diagnosis and process.* Several caregivers were satisfied with the diagnostic process, as exemplified by this comment: “A great panel of specialists came out and did a great job working with him.” For some, receiving a diagnosis was positive in bringing clarity to what was happening with their child and/or confirming their suspicions. One described, “Our family’s been so stressed, and now we’re understanding why. So, there are positives out of finding out because you can do things differently.” Another said, “I was concerned more that they would tell me he’s fine, and then I would have no help,” and also expressed, “But you still have your moments where it’s like you don’t wanna hear that.”

In contrast, some caregivers were initially told the child did not have ASD. Some saw multiple providers and received varied diagnoses (e.g., language, developmental, behavioral, or sensory processing conditions) before an ASD diagnosis. These alternate diagnoses were confusing and frustrating for families as this quote illustrates: “Ellen [all names are pseudonyms] was diagnosed [with ASD] last November . . . which was a blessing because she had been labeled everything else.” Caregivers also reported some professional’s hesitance to diagnose ASD: “I had to chase the diagnosis. They want to label him as developmental delay. They do not want to label autism. If I had a nickel for every time someone said, ‘Oh, he looked in my eyes today.’” Others felt professionals were too interested in making an ASD diagnosis: “The autism team was excited. They had this 2½-year-old and people were excited to diagnose. Fun was what it felt like for them. I was the only one mourning at the funeral.” For the majority of caregivers, the process was far from smooth or positive.

For some, the diagnosis was devastating: “It’s REALLY hard, like your D-Day—Diagnosis Day—SUCKS! Cuz all your dreams or what you thought that you didn’t even know you HAD.” These kinds of emotions surfaced through all eight focus groups and multiple caregivers cried when talking about their experiences, as did others while listening. Others tried to counter the negative view of the diagnosis, noting, “You know, it’s not a death sentence . . . and I think that’s what so many people are afraid of . . .” Another added, “My son’s whole life was going through my head. He’ll never be able to get married . . . Then the more you educate yourself, you realize that it’s not the ending, it’s actually the beginning . . .” Another point of dissatisfaction was how

professionals shared information. One physician reportedly said, “Your child has PDD-NOS and you need to start immediately to RESCUE him from autism.” Others gave caregivers little time to process or understand the information shared: “They recommended that we move forward with treatment. But because of the way it was presented, I backed up . . . because I was overwhelmed with what they had said.”

One of the biggest issues was the lack of guidance provided post-diagnosis. Only a handful of caregivers felt they had gotten what they needed from professionals about next steps or available resources. Some agencies/organizations were seen as supports for families. Other caregivers talked about how much they relied on the parent advocates from ASNC, or early services received from the Children’s Developmental Service Agency [CDSA, statewide evaluation agency]. One caregiver shared how fortunate she felt to have someone reach out every 3 to 4 months and let her know where her child was and what supports he needed. The majority, however, felt overwhelmed and underprepared to tackle what came after, as evidenced by this comment:

The other thing that’s so hard is that now you have this [diagnosis], you don’t know where to start and you’re drinking from the fire hose. I KNOW I have to do it, but I don’t know what. There’s no quarterback to help you figure it out.

Because of limited guidance, a number turned to the internet. Others avoided the internet, cautious about unproven therapies and “dead ends.” Some noted that although written or online information was helpful, that alone was not enough, “*The Autism Speaks: One Hundred Day Kit* is great, it has a lot of information, but . . . I needed SOMEBODY who could’ve told me THAT DAY, ‘Here’s support if you need to speak to somebody right now.’” Some were frustrated at the long wait for follow-up information. Many caregivers shared the need for more guidance, better resource materials, and human “navigators” to help them through the next steps. Some noted there were helpful resources available, but one difficulty was finding them.

Common facilitators mentioned were other parents in support groups such as those ASNC sponsors or links made through area programs. The following comment reflects many caregiver’s experiences: “I’m a fairly educated person. I don’t live under a rock, but it felt like the best resource that I got was from other confused mothers.” The need to lean on other caregivers for information was exhibited many times in each group. Often caregivers mentioned a person or resource others were unaware of it. A further demonstration of the need for support was that after each focus group ended, caregivers stayed at least one additional hour (one group stayed almost 2 hr) to network and share information.

### Additional Barriers

Across identification, diagnosis, and accessing other ASD services, caregivers endorsed four additional barriers: (a) professional lack of ASD-specific knowledge and skills; (b) caregiver lack of ASD knowledge, their attitudes and beliefs, and those of family/friends and community; (c) cultural issues; and (d) limitations in the systems around them.

**Professional’s lack of ASD-specific knowledge and skills.** All the caregivers spoke of the frustratingly common experience encountering professionals who were not well prepared to recognize ASD characteristics, screen for ASD, talk about concerns, know when to make a referral or diagnosis, or intervene. Some caregivers felt the burden of needing to help “educate” professionals. If their physician or teacher had missed concerns about their child, some caregivers made sure to inform them of the diagnosis.

**Caregivers’ lack of knowledge, their own attitudes/beliefs, and those of others around them.** Caregivers at times noted their own lack of knowledge about ASD and “denial” (term used by caregivers, not the authors) in not recognizing some of their child’s concerning behaviors, their disbelief in others’ concerns, or not listening to their own internal voices. The following illustrates this ambivalence: “[Looking at the milestone chart], I’m thinking not really, like kinda, and every one was kind of, BUT . . . there was always a but.”

Some caregivers related the difficulty of getting their spouse “on board”; however, given the few fathers present, these comments may reflect gender roles in their households:

There’s no family support, like my husband. I bet everyone else has the same story. Husbands don’t know about any of this until their kids can’t participate on a soccer field [others say “yes” or “amen” in agreement] because they’re working and don’t see it.

Family and community members also lack knowledge. Some caregivers faced judgments from strangers when out with their child: “I couldn’t go anywhere—he would scream and have a meltdown anywhere I went. People look at you as a parent like ‘You guys are terrible parents.’” Several talked about onlookers giving advice about the need to spank the child, help them learn manners, or self-control. A number talked of the isolation from family, friends, and community resulting from having a child with ASD: “You’re faced with a disorder that tries to isolate you.” Caregivers talked often about the need to educate the community: recreation staff, store personnel, faith-based staff, and family and friends.

One father described how he and his wife deal with community members who may not be aware of ASD

characteristics: “When we go shopping with Levi, we know he’s gonna flap and scream, it’s inevitable. So we say in a loud voice walking in the store: ‘Let’s go spread some autism awareness, son!’” Due to difficulties finding a babysitter, some caregivers do not go out as a couple anymore. One caregiver said, “I think what’s really sad is that we ARE the experts. Even though we’re not really experts, we are the experts eventually and nobody knows them better than we do.”

**Cultural barriers.** Resistance by fathers seemed particularly common for a number of Hispanic/Latina mothers: “There is a certain machismo and they say ‘No! You are probably not raising him right. You are probably the problem. You have spoiled him.’” Another suggested, “I think the problem is cultural.” A few felt their husbands had delayed their child’s diagnosis and others felt unsupported by family and friends. For Hispanic/Latino families, the need for more Spanish-speaking professionals (across systems) and transportation limitations hindered early identification and accessing services. Both Hispanic and American Indian caregivers especially noted the stigma of having a child with a disability, and family/community being dismissive a “problem” existed, although some non-Hispanic White caregivers experienced this too. Other cultural barriers included limited information and availability of services in their communities. For some American Indian caregivers, resources were not viewed as high quality. In addition, some noted seeking support outside the tribal community was seen as unnecessary: “[We’re] from a community where we are considered a country within a country . . . where everything is isolated.”

**System limitations.** Many spoke of the difficulties accessing services, in particular long waits for a diagnosis or finding certain professionals (e.g., occupational therapists) or appropriate interventions (Spanish-speaking services). Waiting for an evaluation ranged from a few months to 1½ years. Other than a few caregivers who seemed satisfied with their child’s services, most talked of the limited type and frequency of intervention services available. Some talked of changing preschools, and the frequency their child was sent home (or asked to leave) or suspended or expelled. Those with school-aged children recounted the limited services their child received due to shortages of related service providers (e.g., speech–language, occupational, and physical therapists), especially in rural areas.

### *What Would Make the Process Better*

Caregivers provided many suggestions to improve the process. The most frequent revolved around the lack of clear guidelines for caregivers to know what steps to take and the limited and inconsistent guidance to help them “navigate”

the process. Many talked of the need for 1:1 guidance throughout the process, not just after the diagnosis.

It was clear even *within* a focus group that caregivers knew about certain resources, whereas others did not. In every step in the process, caregivers longed for ongoing support: “Then you’re alone. And five years later I’m still alone.” Caregivers spoke of the need for help: identifying ASD-knowledgeable professionals across service systems, managing the Individual Education Plan (IEP) process, identifying appropriate interventions, and prioritizing next steps for their child and family. In talking about her child’s first IEP, one caregiver related,

[I needed help] to navigate the IEPs . . . because my first IEP meeting, I didn’t know what the heck it was . . . and what it is for. His teacher was like, “Okay, is this good, is this good?” and I’m like “Okay, yea, I don’t know what I’m doing.” So if there was an IEP class for parents to understand how this process works and what you can get . . . I think that would be helpful.

Caregivers also noted it would be helpful if all agencies/programs used the same guidelines or materials so families would be informed of all available services and supports: “I do think that the state should do better in making sure that each family has a road map and has connections [to services].” Caregivers also argued for more state-level preparation and monitoring of professionals across service systems. Others also highlighted the need to develop more community awareness of the characteristics of ASD and better integration across service systems from health providers through evaluation and access to other ASD services.

## **Discussion**

The purpose of the focus groups was to gather the perspectives of a broad array of caregivers of young children diagnosed with ASD on the process of early identification and accessing other ASD services, and on how the process could be improved. Focus group methodology was used because it is ideal for gaining feedback about a process, and group interactions can promote a range of ideas and experiences (Krueger & Casey, 2008; Nassar-McMillan & Borders, 2002). The discussion will first highlight the “good news” and the aspects working well for children and families, and then address the barriers and the many suggestions these caregivers provided (and later those we have) that might spur needed changes.

### *The Good News*

Despite the volume of caregiver comments describing barriers, there were some positive responses that reflect well on the systems that support families. Although the range of when first concerns were raised was 12 months to 5 years,

many caregivers noted concerns at or before 2 years of age and most had concerns by 2 to 3 years. Thus, with these caregivers, they and/or others were recognizing concerns well before diagnosis. In addition, the age of first concerns was similar between White non-Hispanic and non-White Hispanic caregivers, indicating at least the equal potential for early identification. Furthermore, the average age of diagnosis was 3.74 years, compared with over 4 years in other studies (Baio et al., 2014), and for White non-Hispanic children, the average age was 2.55 years (similar to Mandell et al., 2002). In addition, the gap between first concerns and diagnosis was close to 1½ years for White non-Hispanic children compared with 3 to 3½ years in some studies (Crane et al., 2016; Zuckerman et al., 2015). Similar to some studies (Bickel et al., 2015; Oswald et al., 2015), in the current sample there was a slightly lower age of diagnosis, and substantially lower for White non-Hispanic children.

Some caregivers had positive journeys: Physicians heard their concerns and made referrals, caregivers were guided by knowledgeable professionals, and children received timely and accurate diagnosis and access to other ASD services. These families' experiences mirror aspects of the caregiver interviews two years post-diagnosis by Carlsson et al. (2016) and reflect positive aspects of some services. This good news is possibly a result of increased attention to early screening and diagnosis, and the history of EI services provided to children with ASD and their families in parts of our state.

### *Barriers and Suggestions to Address Them*

In contrast to the good news, the many barriers reported indicate that the majority of caregivers did not encounter a timely or smooth process from first concerns to accessing ASD services. The primary barriers shared by caregivers were professional's lack of ASD-specific knowledge and skills; caregivers' own lack of knowledge, attitudes and beliefs, or those of family/friends and community; cultural barriers; and system limitations.

Caregivers shared their perceptions that some professionals were not well prepared to screen and diagnose ASD. This perception was confirmed by the relatively late age of identification of many of the children (compared with age of first concerns), the multiple diagnoses some received, and the number of times caregivers were told their child did not have ASD before a final ASD diagnosis. Similar to other studies of caregivers who reported sharing their concerns with their physician (Brookman-Frazee et al., 2012; Oswald et al., 2015; Zuckerman et al., 2015), the majority were given reassuring responses, resulting in delayed referral for diagnosis. Furthermore, following diagnosis, many families found themselves on a rocky road, unsure of what to believe or how to figure out what was best for their child.

Despite the barriers, many caregivers were resilient and persistent throughout the process, tenaciously continuing to bring up and finally insist on action. They fought to get professionals and family members to "buy into" their concerns. Although most non-White Hispanic caregivers reported many of the same barriers as White non-Hispanic caregivers, there were some who felt that professionals lacked both cultural awareness and Spanish skills that delayed their child's identification.

To help improve the process, caregivers recommendations included enhancing professionals' knowledge and skills related to ASD, as has been recommended by researchers to promote ASD education at both preservice and in-service levels for health care, EI, and school professionals (Crais et al., 2014; Golnik et al., 2009; Matheis & Matson, 2015; Miller et al., 2011; Self et al., 2015). From our perspective, it may also be time to examine the way evaluations are conducted and how information is shared. The literature on family-centered evaluations and encouraging active roles for caregivers may provide guidance for enhancing ASD surveillance, screening, and diagnosis (Crais et al., 2006; Summers et al., 2005). When caregivers are offered more active roles (e.g., completing parent-report tools, observing their child in daily routines), there are more opportunities for consensus building around concerns and diagnosis. As the work of Crais et al. (2006) indicated, following the evaluation of children birth to 5 across disabilities, few caregivers were asked to complete an evaluation tool about their child and less than one third were asked their reactions to the diagnosis. Furthermore, as noted by Carlsson et al. (2016), single evaluation sessions may not be the best means to deliver potentially upsetting news or talk about follow-up steps. Thus, consideration could be given to follow-up sessions (or contacts) after diagnosis to address caregivers' questions/concerns and have time to fully discuss next steps.

A unique barrier confronting non-White Hispanic families was that despite similar ages of first concerns, these children were not diagnosed until 4.97 years, well beyond the age for White non-Hispanic children, similar to Baio et al. (2014). Hispanic caregivers also identified barriers that included a lack of caregiver and community information about ASD, limited access to health care (including transportation and child care), cultural beliefs about ASD and other disabilities (especially issues of machismo), and more recently, immigration concerns. Zuckerman and colleagues (2014) in their focus groups with Hispanic caregivers also identified some of the same reasons for disparities. In addition, Birkinin et al. (2008) in interviews with minority families in New Zealand learned that a variety of methods of communication, especially culture-specific ones, were key to reaching minority families. These collective results argue that additional resources should be provided to

Hispanic communities to increase awareness and early identification.

Among American Indian caregivers, the issues raised included limited services in their rural and remote areas and resistance (as other groups) to recognition and acceptance of ASD concerns or diagnosis. These populations may need greater engagement with available community services and more awareness by tribal leaders of the isolation felt by some caregivers in their communities, and the need for additional education and awareness of ASD characteristics.

Some caregivers felt that their own hesitance to believe there might be an issue may have delayed diagnosis. Across cultural groups, some caregivers, especially Hispanic caregivers, noted the resistance of fathers and other family members to an ASD diagnosis. Many noted the need for extra supports for fathers, including the formation of support groups and more attention to fathers throughout the process, similar to those around father engagement in ASD EI services proposed by Flippin and Crais (2011). In addition, caregivers spoke of the shame and frustration of taking their child out in public (even to outings with family or friends) because of the reactions and intolerance they experienced. Some talked of the need to build community awareness and to educate others. From our perspective, increased public awareness is needed about typical milestones, ASD characteristics, and red flags. Excellent materials developed by the CDC (i.e., *Learn the Signs. Act Early.*) could be made available where young children spend time, including pediatric, Women, Infants, and Children Clinic (WIC), child care, library, and recreational settings. Efforts working with faith-based organizations around ASD (e.g., *Autism Speaks*, CDC) could be especially useful in identifying typically hard to reach children and caregivers.

Although a range of system barriers were reported, the main issue raised by caregivers was the need for personal navigators to provide guidance in both the short and long term. Many spoke of feeling lost, clueless, and desperate for help. Of concern from a system adequacy perspective, many caregivers indicated that their best information came from other caregivers. As indicated in a meta-analysis of challenges for caregivers of children with ASD (Ooi et al., 2016), caregivers not only gain support from other caregivers but also learn ways to cope and manage issues surrounding their child. Although the current study showed that some caregivers were able to make connections with other families, for others it was a lonely pursuit, and the lack of information and the need for both informal and formal supports were striking. To provide additional supports for families, developing partnerships among physicians, parent organizations, and EI services could be an effective means to connect families.

The suggestions to address system barriers included greater access to evaluations, increased availability of

navigators, greater availability of service providers with expertise in ASD, more Spanish-speaking professionals, the need for intensive intervention services, and more consistency across programs. Only system enhancements will address greater access to evaluations or navigators, but perhaps alternatives could include information gathering and observations while families wait for evaluation, brief early sessions with families to assess current needs, and access to family organizations. The disparity in information or lack of information provided to caregivers demonstrates the lack of consistency in messaging from state agencies. In considering that these caregivers were already “connected” because they were part of area support groups, additional disparities likely exist. The results of the current study indicate, at least for children with ASD, that a more systematic navigation model and consistent content at a state level should be considered. In addition, the positive supports provided to caregivers through ASNC and the CDSA (statewide evaluation agency) appear to be strong models and should be considered for expansion. In addition, as documented by Grant et al. (2015), caregivers need different information at different points, further supporting the need for navigators to provide ongoing services rather than brief post-diagnosis sessions. There is growing evidence that when caregivers are supported after diagnosis and provided with strategies to address the issues they face, there are subsequent decreases in caregiver stress, increased confidence in caregiver abilities, and enhanced caregiver decision making (Farmer & Reupert, 2013; Keen et al., 2010; Tolmie et al., 2016).

## Limitations

We recognize that our sample was limited to caregivers who agreed to participate and that our sample was entirely from North Carolina; therefore, the results may be less generalizable to other states. We attempted to engage families from all regions of the state, including rural, urban, and suburban regions, although we have a smaller number who reside in significantly underserved areas of the state. In addition, we did not verify diagnosis of the children (as is common in most focus group/interview studies), instead using parent report and confirmation by the ASNC parent advocates who helped us recruit. From caregiver descriptions of first concerns and diagnostic behaviors, the authors felt assured the children were on the spectrum.

Furthermore, we recognize that our sample was somewhat selective as our recruitment was primarily through the local ASNC support groups and caregivers were those already “connected” with ASD services. From the advice of our parent advocates, we did not ask caregivers about their income, education, or employment, because of the uncertain legal status of some of our participants. Despite this limitation, from the language styles and type



of information shared by families (e.g., private insurance vs. Medicaid, details about family life, geographic areas), it was clear there was a cross-section of caregivers represented across the eight groups. We also asked our ASNC advocates to recruit a range of caregivers for each group, and specifically Hispanic and American Indian for two groups each. As a result, fewer White non-Hispanic and African American, and more American Indian and Hispanic caregivers participated than the census indicates are present in North Carolina (United States Census Bureau, 2016). Furthermore, some may be concerned about the influence of other caregiver's responses during the groups; however, the stories and emotions of these families, although similar at times, are also unique in their own ways and very personal. Finally, we did not ask specifically whether children had an ASD screening or the age of first concerns (although 49/55 caregivers provided that information). In future studies, these two key questions would be helpful to include. Despite these limitations, a number of caregiver perceptions were reflective of other studies of caregivers. Furthermore, we provided additional perspectives from a broader array of families than previous studies and highlighted additional caregiver suggestions for improvements in the process.

### Clinical and Research Implications

From the current study and others targeting aspects of the early identification and accessing services process, we have a growing body of caregiver feedback about ways the process could be improved. From a clinical perspective, pediatricians and family practice providers continue to need support and additional education on the red flags for ASD, screening, ways to share concerns about ASD with families, and more coordinated referral mechanisms. Evaluation programs could actively seek caregiver's perspectives to reshape their processes into being more family-responsive, including caregivers more actively in the evaluation process, and using more sensitive ways to share information and provide follow-up. Agencies responsible for navigation (and the policy makers who fund them) should consider additional resources for navigators and providing more consistent messaging and guidance across programs. Furthermore, insurance coverage for service coordination should be explored. An excellent compilation of recommendations for practice (particularly related to working with Latino caregivers but applicable to all groups) can be seen in Zuckerman et al. (2014).

From a research perspective, we need more studies of evaluation and navigation processes to identify the most effective as viewed by families and professionals. Furthermore, evaluating the linkages among early identification, diagnosis, and EI services could help shape future services. We now know many components that need

modification and have potential ideas for change but need systematic study of alternatives with caregiver input. The voices of caregivers provide clear messages to professionals. The important question will be whether we professionals will listen to the information they have to share.

### Authors' Note

The opinions expressed are those of the authors and do not represent views of the Health Resource and Services Administration (HRSA).

### Acknowledgments

The authors wish to thank all the caregivers of the focus groups and the regional Parent Advocates from the Autism Society of North Carolina who so graciously helped us recruit participants.

### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported by Health Resource and Services Administration (HRSA) Grant No. H6MMC26248-01 to Drs. S. Hooper and R. Pretzel.

### Supplemental Material

Supplemental material for this article is available online.

### References

- Abbott, M., Bernard, P., & Forge, J. (2013). Communicating a diagnosis of autism spectrum disorder: A qualitative study of parents' experiences. *Clinical Child Psychology and Psychiatry, 18*(3), 370–382.
- American Community Survey 2013-2017 5 year data release. (2018). Office of State Budget and Management. <https://www.census.gov/newsroom/press-kits/2018/acs-5year.html>
- Arunyanart, W., Fenick, A., Ukritchon, S., Worarachanee, I., Northrup, V., & Weitzman, C. (2012). Developmental and autism screening a survey across six states. *Infants Young Child, 25*(3), 175–187.
- Baio, J., & Autism Developmental Disabilities Monitoring Network Surveillance 2010 Year Principal Investigators. (2014). Prevalence of autism spectrum disorder among children aged 8 years: Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report, Surveillance Summaries, 3*(2), 1–22.
- Bickel, J., Bridgemohan, C., Sideridis, G., & Huntington, N. (2015). Child and family characteristics associated with age of diagnosis of an autism spectrum disorder in a tertiary care setting. *Journal of Developmental Behavioral Pediatrics, 36*(1), 1–7.

- Birkini, C., Anderson, A., Seymour, F., & Moore, A. (2008). A parent-focused early intervention program for autism: Who gets access? *Journal of Intellectual Developmental Disability, 33*(2), 108–116.
- Brookman-Frazee, L., Baker-Ericzén, M., Stadnick, N., & Taylor, R. (2012). Parent perspectives on community mental health services for children with autism spectrum disorders. *Journal of Child and Family Studies, 21*(4), 533–544.
- Carbone, P., Farley, M., & Davis, T. (2010). Primary care for children with autism. *American Family Physician, 81*(4), 453–460.
- Carlsson, E., Miniscalco, C., Kadesjo, B., & Laakso, K. (2016). Negotiating knowledge: Parents' experience of the neuropsychiatric diagnostic process for children with autism. *International Journal of Language and Communication Disorders, 51*(3), 328–338.
- Chamak, B., & Bonniau, B. (2013). Changes in the diagnosis of autism: How parents and professionals act and react in France. *Culture, Medicine, and Psychiatry, 37*(3), 405–426.
- Colton, D., & Covert, R. (2007). *Designing and constructing instruments for social research and evaluation*. Jossey-Bass.
- Coogle, C., Guerette, A., & Hanline, M. (2013). Early intervention experiences of families of children with an autism spectrum disorder: A qualitative pilot study. *Early Childhood Research & Practice, 15*(1), Article 1016155.
- Crais, E., McComish, C., Humphreys, B., Watson, L., Baranek, G., Reznick, S., Christian, R., & Earls, M. (2014). Pediatric healthcare professionals' views on autism spectrum disorder screening at 12-18 months. *Journal of Autism and Other Developmental Disabilities, 44*(9), 2311–2328.
- Crais, E., Poston Roy, V., & Free, K. (2006). Parents' and professionals' perceptions of the implementation of family-centered practices in child assessments. *American Journal of Speech-Language Pathology, 15*(4), 365–377.
- Crane, L., Chester, J., Goddard, L., Henry, L., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20*(2), 153–162.
- Faggiolani, C. (2011). Perceived identity: Applying grounded theory in libraries. *Italian Journal of Library Science and Information Science, 21*(1), Article 4592.
- Farmer, J., & Reupert, A. (2013). Understanding autism and understanding my child with autism: An evaluation of a group parent education program in rural Australia. *The Australian Journal of Rural Health, 21*(1), 20–27.
- Flippin, M., & Crais, E. (2011). The need for effective father involvement in early autism intervention: A systematic review and recommendations. *Journal of Early Intervention, 33*(1), 24–50.
- Fowler, F. (2014). *Survey research methods* (5th ed.). SAGE.
- Freuler, A., Baranek, G., Tashjian, C., Watson, L., Crais, E., & Turner-Brown, L. (2014). Parental reflections of experiences of participating in a randomized control trial of a behavioral intervention for infants at-risk for ASD. *Autism, the International Journal of Research and Practices, 18*(5), 519–528.
- Golnik, A., Ireland, M., & Borowsky, I. (2009). Medical homes for children with autism: A physician survey. *Pediatrics, 123*(3), 966–971.
- Grant, N., Rodger, C., & Hoffmann, C. (2015). Intervention decision-making processes and information preferences of parents of children with autism spectrum disorders. *Child: Health, Care and Development, 42*(1), 125–134.
- Keen, D., Couzens, D., Muspratt, S., & Rodger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders, 4*(2), 229–241.
- Krueger, R., & Casey, M. (2008). *Focus groups: A practical guide for applied research* (4th ed.). SAGE.
- Mandell, D., Listerud, J., Levy, S., & Pinto-Martin, J. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(12), 1447–1453.
- Martinez, M., Thomas, K., Williams, C., Christianson, R., Crais, E., Pretzel, R., & Hooper, S. (2018). Family experiences with the diagnosis of autism spectrum disorder: System barriers and facilitators of efficient diagnosis. *Journal of Autism and Developmental Disorders, 48*(7), 2368–2378.
- Matheis, M., & Matson, J. (2015). Autism spectrum disorder screening refusal rates: Findings from a statewide early intervention program. *Developmental and Physical Disabilities, 27*, 755–770.
- Miller, J., Gabrielsen, T., Villalobos, M., Alleman, R., Wahmhoff, N., Carbone, P., & Segura, B. (2011). The each child study: Systematic screening for autism spectrum disorders in a pediatric setting. *Pediatrics, 127*(5), 866–871.
- Montes, G., Halterman, J. S., & Magyar, C. (2009). Access to and satisfaction with school and community health services for US children with ASD. *Pediatrics, 124*(Suppl. 4), S407–S413.
- Nassar-McMillan, S., & Borders, L. (2002). Use of focus groups in survey item development. *The Qualitative Report, 7*(1). <http://www.nova.edu/ssss/QR/QR7-1/nassar.html>
- Ooi, K., Ong, Y., Jacob, S., & Khan, T. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment, 12*, 745–762.
- Osborne, L., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism, 12*(3), 309–324.
- Oswald, D., Haworth, S., Mackenzie, B., & Willis, J. (2015). Parental report of the diagnostic process and outcome: ASD compared with other developmental disabilities. *Focus on Autism and Other Developmental Disabilities, 32*(2), 152–160.
- Pierce, K., Carter, C., Weinfeld, M., Desmond, J., Hazin, R., Bjork, R., & Gallagher, N. (2011). Detecting, studying, and treating autism early: The one-year well-baby check-up approach. *Journal of Pediatrics, 159*(3), 458–465.
- Radecki, L., Sand-Loud, N., O'Connor, K. G., Sharp, S., & Olson, L. M. (2011). Trends in the use of standardized tools for developmental screening in early childhood: 2002–2009. *Pediatrics, 128*(1), 14–19.
- Reed, P., & Osborne, L. (2012). Diagnostic practice and its impacts on parental health and child behavior problems in autism spectrum disorders. *Archives of Disease in Childhood, 97*(10), 927–931.

- Richards, M., Mossey, J., & Robins, D. (2016). Parents' concerns as they relate to their child's development and later diagnosis of autism spectrum disorder. *Developmental Behavioral Pediatrics, 37*(7), 532–540.
- Robins, D., Casagrande, K., Barton, M., Chen, C., Dumont-Mathieu, T., & Fein, D. (2014). Validation of the Modified Checklist for Autism in Toddlers, Revised With Follow-Up (M-CHAT-R/F). *Pediatrics, 133*(1), 37–45.
- Robins, D., Fein, D., Barton, M., & Green, J. (2001). The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 31*(2), 131–144.
- Russell, S., & McCloskey, R. (2016). Parent perceptions of care received by children with an autism spectrum disorder. *Journal of Pediatric Nursing, 31*, 21–31.
- Scientific Software Development GmbH, Berlin. (2013). *ATLAS.ti* (Version 7.1).
- Self, T., Parham, D., & Rajagopalan, J. (2015). Autism spectrum disorder early screening practices: A survey of physicians. *Communication Disorders Quarterly, 36*(4), 195–207.
- Summers, J., Hoffman, L., Marquis, J., Turnbull, A., & Poston, D. (2005). Relationship between parent satisfaction regarding partnerships with professionals and age of child. *Topics in Early Childhood Special Education, 25*(1), 48–58.
- Tolmie, R., Bruck, S., & Kerslake, R. (2016). The Early Intervention Readiness Program (EIRP): A post-ASD diagnosis family support program. *Topics in Early Childhood Special Education, 36*(4), 242–250.
- Tomlin, A., Koch, S., Raches, C., Minshawi, N., & Swiezy, N. (2013). Autism screening practices among early intervention providers in Indiana. *Infants and Young Children, 26*(1), 74–88.
- United States Census Bureau. (2016, July 1). QuickFacts. <https://www.census.gov/quickfacts/XX>
- Zuckerman, K., Lindly, O., & Sinche, B. (2015). Parental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. *The Journal of Pediatrics, 166*(6), 1431–1439.
- Zuckerman, K., Mattox, K., Donelan, K., Batbayar, O., Baghaee, A., & Bethell, C. (2013). Pediatrician identification of Latino children at risk for autism spectrum disorder. *Pediatrics, 132*(3), 445–453.
- Zuckerman, K., Sinche, B., Mejia, A., Cobian, M., Becker, T., & Nicholaidis, C. (2014). Latino parents' perspectives on barriers to autism diagnosis. *Academic Pediatrics, 14*(3), 301–308.
- Zwaigenbaum, L., Bauman, M., Stone, W., Yirmiya, N., Estes, A., Hansen, R., McPartland, J., Natowicz, M., Choueiri, R., Fein, D., Kasari, C., Pierce, K., Buie, T., Carter, A., Davis, P., Granpeesheh, D., Mailloux, Z., Newschaffer, C., Robins, D., & Wetherby, A. (2015). Early identification of autism spectrum disorder: Recommendations for practice and research. *Pediatrics, 136*(1), 41–59.