

RESEARCH ARTICLE

Early Identification of Young Children with ASD and Other Developmental Disabilities: Areas for Improvement

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Abstract

There continues to be an ongoing effort in pediatric practice to improve screening and referral rates of children with potential developmental disabilities including Autism Spectrum Disorder (ASD). Successes have been seen in practices relative to broad developmental screening efforts and increasing improvement in screening for ASD. However, gaps continue to occur in screening, referral for further evaluation, and follow-up that allows the practice (and treating provider) to know the outcome of the referral. This type of “closing the loop” between providers and referral sources is necessary for the practice to function as a medical home for the child and family. In addition, caregivers have highlighted many challenges in the early identification process in working with their primary care provider. This manuscript discusses some of the barriers to early identification for children and their families, successful strategies for more consistent screening and closing the loop following referral, and highlights parental perceptions about identification and referral. Further, practical approaches that could be used by pediatric providers are highlighted.

Key Words: early identification, screening, referral, developmental disabilities

Early Identification and Screening

Over the last few decades, efforts in primary care have focused on early identification of young children with developmental disabilities including Autism Spectrum Disorder (ASD). The initial focus was on screening for developmental disabilities with increasing attention in recent years on screening for ASD.^{1,2} Early identification is critical to a child with developmental disabilities to ensure the child is referred for appropriate services to enhance their development and learning. Early intervention services are associated with improved outcomes in communication, social interaction, play, and cognitive development.^{3,4} As noted by the American Academy of Pediatrics, early identification is viewed as the responsibility of pediatric professionals as a primary function of the medical home.¹

Despite significant progress in developmental screening rates (tripling from 2002 to 2016),⁵ the top rate continues to be around 63%.⁵ Further, the rate for ASD screening ranges from 30% to 80%⁶⁻⁸ with one recent study indicating a rate of 93% at 18 month visits.⁹ In addition, when children receive a positive ASD screen, they are more likely to receive an ASD diagnosis and are diagnosed at a younger age compared with children not screened.⁸ Even in practices that screen for ASD, however, some do not follow the AAP guidelines of ASD screenings administered at 18 and 24 months.^{1,8}

A second issue is the lack of consistent use of ASD screening tools. The most commonly used tool is one of the versions of the Modified Checklist for Autism in Toddlers, Revised, with Follow-

Up (M-CHAT-R/F),¹⁰ however, some practices are unaware of this most recent version or do not use the follow-up questions.^{8,11} The evidence is strong for the use of the M-CHAT-R/F as an ASD-specific screener for 18 and 24 months, but only if used with the follow-up questions.^{12,13} Administering the follow-up questions to caregivers for the “failed” questions promotes discussion of those behaviors in more detail and allows more clarity on whether they are actually of concern. Use of the follow-up questions has been seen to reduce the number of false negatives and could be especially important for children of color and those from lower-income households as their screen positive rates at times are two to three times higher than those of white, higher income children.¹⁴ In addition, earlier work pinpointed that the use of at-risk scores on the M-CHAT with the follow-up questions and the pediatrician’s concerns for ASD, resulted in high levels of identifying children with ASD.¹⁵ Even when using the follow-up questions, however, only 48% of the children who fail the screening will receive a diagnosis of ASD, but a more important number is that 95% of these children will be diagnosed with some type of developmental disability including ASD.¹⁶ Thus, there is an imperative for ALL children who fail the MCHAT-R/F to be referred for an evaluation.

Referral Practices

Another issue in primary care is referral of children with or at-risk for developmental disabilities. Recent data indicate that only 59% of children who were at-risk were reportedly referred by

pediatricians.⁵ Two recent studies place that percentage at 31% and noted that despite early concerns some children were not referred until three years of age.^{8,9} Indeed in focus groups, healthcare providers indicated they (a) use their instincts instead of relying on the screening results, (b) do not always refer children who have failed an ASD screen due to not being sure the child needs referral, (c) need more information about children with ASD, and/or (d) have concerns about parental reactions to a failed screen.¹¹ In addition, some providers shared dissatisfaction with their interactions in the past with parents about sharing ASD screening results.¹¹ Therefore, current gaps exist both in screening consistently and referring children who fail a screening.^{8,9,11} In addition, screening rates of Hispanic children lag well behind White children.⁸ In parallel, Hispanic children continue to be under-identified when it comes to ASD (as much as 50% less often as White children),^{8,17} therefore much greater attention needs to be paid to these children and families. Language issues (lack of Spanish speaking professionals, lack of well translated tools), cultural interpretations, low literacy levels, and lack of awareness of developmental milestones may be factors.^{8,11,12}

A key issue within referral is the nature of the referral sources that primary care providers use routinely. There is a range of sources utilized including early intervention, ASD-specific agencies/organizations, other specialists (e.g., developmental pediatrician, psychologist, neurologist, speech-language pathologist, audiologist), and less frequently local family navigation and support

organizations/agencies (e.g., Family Support Program, Autism Society).⁸ Some providers refer to early intervention simultaneously with referral for ASD specific evaluation, whereas others refer directly to other specialists.⁸ Although referring to a specialist may get a diagnosis (e.g., psychologist) or treatment (e.g., speech-language therapy), the service that is typically lacking from specialists is family navigation services. In focus groups with caregivers with children with ASD, the number one need expressed was for navigation services to help guide families in decision making.¹⁸ Some early intervention systems provide service coordination, however, not all. Therefore, if a local early intervention program or specialist does not provide navigation services, practitioners may want to simultaneously refer to early intervention/specialist and local navigation services.

Caregiver Views on the Early Identification Process

When considering early identification of children in primary care, it is also important to examine caregivers' views of this process. From a survey of over 400 caregivers of young children (birth to nine) diagnosed with ASD, fewer than half reported their child was screened for ASD, 25% were initially told that their child did not have ASD, over half of the children were initially diagnosed with other autism-related conditions, and almost one half of the caregivers saw three or more professionals before their child was diagnosed with ASD.¹⁹ As these results imply, the system was not as effective as it could have been for these

children and their families, and clearly an ASD diagnosis and access to ASD intervention were delayed. Indeed, the gap between first concerns and diagnosis was 18 months.¹⁹ In a large study of over 36,000 children screened across a large health system, the children who were screened for ASD were more likely to be diagnosed with ASD and received an earlier diagnosis.⁸

Further attempts to gain perspectives of caregivers have included a focus group study with 55 caregivers of children with ASD from birth to nine.¹⁸ The participants were asked about facilitators and barriers to screening, diagnosis, and identifying and accessing other services. In terms of who had the first concerns about the child, two thirds (37) of the caregivers reported that they or a family member had. However, for 23 of them, when they raised concerns with their primary care provider, they were reassured with language such as, “He’ll talk when he’s ready.” OR “I think you’re looking for something that’s not there.”; OR “He is fine.”, thus often delaying a diagnosis. These results are similar to the work of Zuckerman and colleagues who compared the survey responses of parents of 1420 children with ASD and 2098 children with intellectual disability/developmental delay (ID/DD).²⁰ The caregivers reported on their conversations with their healthcare provider about early concerns. Although the caregivers of children with ASD reported earlier conversations than the parents of children with ID/DD, they were more likely to be reassured than those parents with children with ID/DD. In fact, half of the parents with children with ASD received reassuring responses and these reassurances

led to delays in diagnosis compared with children with ASD whose pediatricians were more receptive to parental concerns.²⁰

In contrast, there have been positive reports from caregivers about the steps healthcare providers have taken to help identify early developmental or ASD issues in their children.¹⁸ Some providers listened carefully to caregivers, helped them explore their concerns, and promoted getting an evaluation for the child. One caregiver from the focus group study noted “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.”¹⁸ Therefore, some caregivers were grateful and appreciated the time providers spent with them helping address concerns about their child. There are also caregivers who when providers raised developmental or ASD concerns were angry or disbelieving, but some later realized that helping raise their awareness had prompted an earlier evaluation and entry into early intervention services. One physician from a recent focus group with healthcare providers suggested when meeting resistance from caregivers about concerns, saying “You know this might be overcalling it, but we should start early because it might take a while!” So it’s better to be ahead of the game than to wait until it’s too late.”¹¹ In this way, healthcare providers may ease caregivers into taking the next step to get the child evaluated without turning them off to conversation.

Follow-up after Referral

The last issue addressed within early identification in primary care is related to the lack of follow-up after referral. Both

healthcare providers and caregivers report a lack of follow through after screening and referral.^{11,20} Reasons provided for why providers do not complete this process are time constraints, lack of knowledge of area resources, frequent turn over in early intervention agencies, as well as not having a clear system in their practice to follow children after referral.¹¹ Thus providers are unable to partner with caregivers in the ongoing process of monitoring the child's progress and helping make decisions that could impact the child's development. In the spirit of a medical home, this type of follow through is critical and part of the role of the provider.

Conclusions and Recommendations

Increasingly professionals and caregivers are calling for additional modifications in primary care practice in the ways children who are at-risk for developmental disabilities or ASD are screened, referred, and followed-up.^{1,2,8,10,18-20} Recommendations range from an increased focus on early identification in both traditional and continuing education of medical professionals to practice-based changes. The types of changes encouraged

include enhancing the knowledge and skills of providers about ASD redflags, gaining greater adherence to the screening guidelines of the AAP, using electronic means to prompt for ASD screening and to offer the follow-up questions for the MCHAT-RF, improving the consistency of referral to include all children with a failed M-CHAT-R/F, and developing an effective means to follow-up with caregivers and referral sources after a referral. In addition, some providers have spoken of their uncertainty when talking to caregivers about the results of a failed screening or their concerns about the child.¹¹ Several sources have excellent recommendations for practices, including working with Spanish-speaking families.^{5,20,21} In addition, Table 1 provides recommendations to providers when bringing up or hearing developmental or ASD concerns from caregivers. The recommendations were collated from a variety of sources.^{1,2,8-10,18-21} Finally, careful listening to caregivers about their concerns and about their suggestions for potential improvements in primary care for early identification and referral can help guide practices as they consider possible modifications.¹⁸⁻²¹

Table 1. Recommendations for healthcare providers when bringing up or hearing developmental or ASD concerns from caregivers.^{1,2,8,10,11,18,19,20,21}

1. Thoughtful active listening is paramount.
2. Always discuss results of any screening performed.
3. Always talk first about strengths before moving to concerns.
4. Use the words that caregivers use about their child (e.g., in own world, very active, not talking) can be helpful in gaining more information from caregivers.
5. Ask caregivers for examples of the concerning behaviors reported.
6. You may want to ask if others in the child's family or among the child's caregivers (e.g., childcare providers, teachers) have concerns.
7. When talking about your concerns, refer to any related behaviors mentioned by caregivers or family members or other caregivers.
8. False negatives can be reduced with use of the MCHAT-R/F follow-up questions.
9. A failed CHAT-R/F screen indicates high potential of ASD or other developmental delay/disability, so always refer for evaluation.
10. Let family know you may not be "expert" on ASD, but you can help refer & identify resources.
11. Partner with caregivers to decide on next steps to promote shared decision making.
12. Assure caregivers you will follow-up with call/visit (some experts are encouraging an early return follow-up visit).
13. Later, have staff watch for reports from referral sources.
14. If needed, enhance your own knowledge of signs and characteristics of ASD through readings, CEUs.
15. When making referrals, the AAP guidelines suggest simultaneous referrals to evaluation and diagnosis, early intervention services, and audiology evaluation.
16. Be sure you or someone else in the practice know about area resources, particularly ones that can provide family navigation services.

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