Exploring the Barriers and Possible Improvements for Routine Screening of Autism Spectrum Disorder in Pediatric Primary Care

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Senior Honors Thesis
School of Education
University of North Carolina at Chapel Hill
2017

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Abstract

Background: The American Academy of Pediatrics (AAP) recommends the routine screening of Autism Spectrum Disorder (ASD) in pediatric primary care at the 18- and 24-month well-child visit. Literature reveals that the ASD screening practices of pediatric primary care providers is often noncompliant with this recommendation.

Objective: The purpose of this study was to understand the barriers to ASD screening in pediatric primary care that may prevent pediatric primary care providers from screening as recommended by the AAP.

Methodology: A literature review of 23 peer-viewed research studies was conducted to identify themes in current literature regarding screening for ASD in pediatric primary care. Barriers and proposed implementations were identified to inform the field of ASD identification and management in pediatric primary care.

Results: The literature review revealed that there exists two domains of barriers inhibiting the routine screening for ASD in pediatric primary care. The first set of barriers concerns the logistics and procedures of screening for ASD in primary care. Barriers resulting from system-wide procedural barriers such as access to early intervention services is also included in this set of barriers. The second set of barriers are those that result from pediatric primary care providers’ education, attitudes, and efficacy regarding ASD screening and management. Identified improvements to ASD screening address both of these domains of barriers.

Conclusions: The routine screening of ASD in pediatric primary care is inhibited by an array of barriers originating from various components of ASD screening. Although these barriers exist, literature has revealed interventions that may help to integrate routine ASD screening in pediatric primary care.
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Exploring the Barriers and Possible Improvements for Routine Screening of Autism Spectrum Disorder in a Pediatric Primary Care

In 2016, the Centers for Disease Control and Prevention estimated that the prevalence of children diagnosed with some form of Autism Spectrum Disorder (ASD) was 1 in 68 during their most recent surveillance year in 2012 (Christensen, 2016). This estimate is an increase from the estimate made for the 2008 surveillance year which was about 1 in 88 children, and is more than double the estimate of about 1 in 156 children in 2002 (Baio, 2012). This increase in the prevalence of children with ASD has created the necessity for the field of primary care to evolve in order to meet the unique needs of this growing population of children. Specifically, pediatric primary care practices have the unique opportunity to integrate supportive measures for children with ASD, particularly the way in which ASD is identified and screened for in children.

Defining Autism Spectrum Disorder

*The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*, otherwise known as the DSM-5, outlines five major diagnostic criteria for ASD. The first criterion is the presence of “persistent deficits in social communication and social interaction across multiple contexts (p. 50).” These deficits can potentially manifest themselves through a variety of ways including difficulties with nonverbal communication (i.e. eye contact and body language), a reduced ability to develop, maintain, and understand relationships, along with challenges regarding social-emotional reciprocation (i.e. an inability to maintain a back-and-forth conversation). These deficits in social communication are accompanied by “restricted, repetitive patterns of behavior, interests, or activities (DSM-5; American Psychiatric Association, 2013, p. 50).” The DSM-5 describes that the fulfillment of this criteria is contingent on the existence of two or more of the following: “stereotyped or repetitive motor movement, use of objects or speech,” (p. 50), a
necessity for consistency marked by notable distress upon minor changes, a fixation on very specific interests or objects, or an abnormal reactivity (hyper- or hypo-) towards sensory input which may include an abnormal preoccupation for specific forms of sensory information (i.e. excessively licking an object to taste it). These two diagnostic criteria are used to categorize the severity of ASD.

The DSM-5 outlines three levels of severity of ASD. These levels are based on the extent to which deficits in social communication and the presence of repetitive, specific behaviors exist, require the necessity of supportive measures for the child. The severity levels for ASD range from level 1 to level 3. Level 1 is denoted by “deficits in social communication that cause noticeable impairments” along with an “inflexibility of behavior causing significant interference with function in one or more context” (DSM-5; American Psychiatric Association, 2013, p. 52). With each level of severity, the existence of social deficits and restrictive behaviors are exacerbated such that children with level 3 ASD are characterized as having “severe deficits in verbal and nonverbal social communication skills that cause severe impairments” and “inflexibility of behavior, extreme difficulty coping with change or other restricted/repetitive behaviors markedly interference with functioning in all spheres” (DSM-5; American Psychiatric Association, 2013, p. 52).

Each increasing level of severity of ASD also indicates the level of support the child needs to function given their social deficits and restricted behaviors. Children with level 1 ASD are seen as requiring support, level 2 as requiring substantial support, and level 3, the most severe level, is noted as requiring very substantial support (DSM-5; American Psychiatric Association, 2013, p. 52).
The third criterion for ASD diagnosis indicates that the previously described indicators of ASD must be present during the child’s early development period, and the fourth criterion expands upon this declaring that said symptoms must “cause clinically significant impairment in social, occupational, or other important areas of current functioning” (DSM-5; American Psychiatric Association, 2013, p. 50). The fifth and final criterion makes the distinction that these symptoms cannot be better attributed to an intellectual disability. There does exist the possibility of a comorbidity diagnosis, as intellectual disabilities and ASD have been known to frequently co-occur. This comorbidity diagnosis requires the existence of lower than expected social communication for the child’s general developmental level.

The symptoms of ASD typically arise between 12-24 months of age, however, children with very severe ASD may exhibit symptoms before they are 12-months old. ASD is not considered a degenerative disorder and these symptoms manifested in early childhood are typically accompanied by developmental gain later in childhood. Still, “only a minority of individuals with ASD live and work independently in adulthood” (DSM-5; American Psychiatric Association, 2013, p. 56). As such, children with ASD are amongst a vulnerable population that requires support and care throughout the various contexts and timelines of their life.

**Screening Children for ASD**

The diagnosis of ASD is a two-part process that initially begins with a developmental screening. The Centers for Disease Control and Prevention (2016) describes a developmental screening as a “short test to tell if the child is learning basic skills, and can help identify if there might be a delay” (p. 1). ASD-specific screening tools are designed to specifically identify children who are at risk for ASD. Formal screening is a more structured method to gain insight into a child’s behavior than behavioral surveillance which is essentially a provider’s observation
of the child’s behavior only while they are in clinic (Centers for Disease Control and Prevention, 2016). These developmental screenings are typically conducted by the child’s primary care provider during a well-visit and may require the child’s primary caregiver to answer some questions regarding the child’s development. The second component of ASD diagnosis involves a comprehensive developmental evaluation which can be conducted by an array of professionals including “teachers, social workers, nurses, psychologists, doctors, speech-language pathologists” (Centers for Disease Control and Prevention, 2016, p. 1). These comprehensive evaluations are a more thorough and holistic review of the child’s development and may include “clinical observations, parental reports of developmental and health histories, psychological tests, and speech and language assessments” (Centers for Disease Control and Prevention, 2016, p. 1). The child’s primary care provider may refer the child to a specialist in the field of ASD such as a developmental pediatrician, a child psychologist, psychiatrist, or neurologist for the completion of such an evaluation and subsequently a final diagnosis. Still, the primary care provider’s role in ASD-specific screening is immensely important in the identification and diagnosis of ASD (Centers for Disease Control and Prevention, 2016).

As the first step in the diagnosis process, these specific ASD screenings at the child’s primary care provider act as some of the preliminary opportunities to identify children who may be exhibiting characteristics of ASD. Through the screening of ASD at primary care, there exists the potential for early recognition of children exhibiting signs of ASD and as such, the ability to connect them with supportive resources as soon as possible (Crais et al, 2014).

The Modified Checklist for Autism in Toddlers (M-CHAT)

The Modified Checklist for Autism in Toddlers (M-CHAT) is one of the most common formal screening tools used in screening children for ASD in primary care. The M-CHAT was
developed with a sixth-grade reading level and consists of two parts (Arunyanart et al., 2012). The first part of the M-CAHT consists of 23 “yes/no” questions to be completed by the child’s caregiver. These 23 questions ask the child’s caregiver to consider their child’s behavior, with the questions designed to reveal whether or not the child exhibits behavior that may be indicative of ASD (Robins, Fein, Barton & Green, 2001). See Appendix A to view the first part of the M-CHAT.

In the traditional paper delivery of the M-CHAT, the child’s primary care provider, or whomever may have administered the M-CHAT, scores the screener (Robins, Fein, Barton & Green, 2001). See Appendix B to see the scoring guide for the M-CHAT. A “positive” screen means that the child is “at-risk” for ASD. If a child receives a “positive” screen in the first part of the M-CHAT, then the second part of the M-CHAT, the follow-up interview, should be administered (Robins, Fein, Barton & Green, 2001). The follow-up portion of the M-CHAT allows the primary care provider to have a conversation with the child’s caregiver to clarify their answers to the failed questions on the first part of the screener. See Appendix C for an example of a follow-up interview question for the M-CHAT. If the child continues to screen positive after completion of the M-CHAT follow-up, the provider should conduct or make a referral for a comprehensive ASD diagnostic evaluation (Robins, Fein, Barton & Green, 2001).

The Modified Checklist for Autism in Toddlers Revised (M-CHAT-R) is a revision to the M-CHAT. The M-CHAT-R is also a two-part screener but instead of 23, it includes 20 questions (Robins et al., 2014). Three of the questions from the M-CHAT that the developers found problematic were removed and the remaining questions were clarified. The administration of the M-CHAT-R is similar to that of the M-CHAT with follow-up to be administered if the initial screen was positive (Robins et al., 2014). See Appendix D to view the M-CHAT-R, Appendix E
to see the M-CHAT-R scoring guide, and Appendix F to see an example of an M-CHAT-R follow-up interview.

**Early Intervention and Improved Outcomes for Children with ASD**

Literature suggests that early intervention for children with ASD can lead to improved outcomes. A 2009 literature review of eleven studies regarding effective interventions revealed that early intensive behavioral intervention for young children with ASD improved their future outcomes, which came in the form of a higher IQ compared to their peers who did not receive such treatment (Howlin, Magiati, & Charman, 2009).

Other studies focused on examining the effectiveness of specific intervention programs. The Early Start Denver Model (ESDM) is a behavioral intervention program for children with ASD as young as 12-months of age. The program utilizes “applied behavior analysis with developmental and relationship-based approaches” (Dawson et al., 2010, p. 18). Children involved in this program saw “improvements in IQ, adaptive behavior, and autism diagnosis” (Dawson et al., 2010, p. 18). A 2015 study conducted by Estes et al. suggested that the children involved in the ESDM program “maintained gains made in early intervention during the 2-year-follow-up period in overall intellectual ability, adaptive behavior, symptom severity, and challenging behavior” (Estes et al., 2015, p. 152).

These studies point to the utility of early intervention, however, in order for early intervention programs to be implemented, children with ASD need to be identified as soon as reasonably possible. To accomplish such, entities like the American Academy of Pediatrics have created structured ASD-specific screening recommendations.
Recommendations from the American Association of Pediatrics

In a 2007 publication of their journal, *Pediatrics*, The American Association of Pediatrics (AAP) recommended that autism-specific screening should be conducted at the 18-month and 24-month well-child preventive care visit. The AAP describes that one of the benefits of the repeated developmental screening at the 24-month well-visit lies in the finding that “most parents of children with ASDs become concerned when the child is between 17 to 19 months of age but do not seek advice until they are 21- to 25- months old” (Gupta et al., 2007, p. 152). The repeated screening at 24-months allows for guardians to express the concerns that they may not have had at the 18-month well-visit to the pediatric primary care provider. Although the recommendation suggests autism-specific screening be performed at specific well-visits, it also emphasizes the importance of routine developmental (non-autism specific) at the 9-, 12-, and 18-month well-child visits (Johnson & Myers, 2007).

This recommendation is also reinforced in a 2007 publication from the AAP’s Council on Children with Disabilities. In this publication, the council emphasizes the importance of routine screening and provides an algorithmic model through which pediatric primary care providers should schedule and follow up on ASD-specific screening in the primary care setting (Johnson & Myers, 2007).

Notable Non-Compliance

Meeting these recommendations from the AAP and the Council on Children with Disabilities comes with its challenges. In a 2004 survey, it was revealed that only 8% of pediatric primary care providers performed routine screening of ASD despite 44% of the same providers reporting that they care for at least 10 children with some form of diagnosed ASD (Dosreis et al. 2006). A 2009 survey of 51 pediatric primary care physicians from Alabama and Mississippi
discovered that only 28% of these providers routinely screen for ASD even though they expressed knowledge regarding the increasing prevalence of ASD amongst American children (Gillis, 2009).

Some research appears to suggest that the rate of ASD-specific screening at 18- and 24-months of age has increased. In a 2012 survey of 281 pediatricians who were fellows of the AAP and represented six different states, it was revealed that 59.8% of these pediatricians screened for ASD at the 18-month visit and 50.2% at the 24-month visit (Arunyanart et al. 2012). These results indicated a 72.2% increase in the frequency of ASD-screening conducted by these physicians five years prior (Arunyanart et al. 2012). Even with this noteworthy increase, the rates of screening in this study express the fact that almost 40% of these pediatricians were not conducting ASD-screening at the 18-month visit and nearly half of the surveyed pediatricians did not screen for ASD at the 24-month visit. These rates of compliance become even more perplexing given the consideration that each of the pediatricians surveyed were affiliated with the AAP, the very entity that created such recommendations for ASD-specific screening.

As such, it is apparent that there are inhibitory factors that may prevent the implementation of routine ASD-specific screening in a pediatric primary care setting. This research seeks to explore the barriers to early screening in a pediatric primary care setting and the extent to which these barriers stand in the way of routine screening and adherence to the recommendations set forth by the AAP. Along with barriers, this research seeks to explore possible improvements to overcome such challenges. A review of current literature will seek to understand the current identified barriers to screening for ASD in pediatric primary care and the proposed implementations to overcome such barriers.
Methodology

This study is a literature review of journal articles that discuss potential barriers to screening for Autism Spectrum Disorder (ASD) in pediatric primary care and perspective methods to mediate these identified barriers. In this survey of literature, barriers to ASD screening are defined as anything that may prevent the consistent screening of ASD as recommended by the American Academy of Pediatrics (AAP), and implementations are defined as methods or interventions that contribute to recommended ASD screening.

Scope of Literature Review

The studies reviewed were obtained through Academic Search Premier, CINAHL Plus with Full Text, PubMed, and Google Scholar.

The following searches were used to obtain the studies featured in this review:
“ASD+primary care”, “Autism Spectrum Disorder+primary care”, “ASD+screening”
,“ASD+pediatrician”, “ASD+screening tools”, “ASD+screening+barriers”,
“ASD+screening+tools”, “ASD+screening+improvements”,”ASD+provider perspectives.”

Additionally, the examination of the references of selected studies and literature reviews was utilized to access a greater number of studies.

Criteria for Inclusion and Exclusion

Only peer reviewed studies that were published between 2007 and 2017 were included in this analysis. This was implemented for two reasons. The first being that limiting the research to the last decade identifies the most current themes in the field. The second was that setting the requirement that that studies be published after 2007 means that the studies included in this literature review were published following the AAP’s ASD screening guidelines.
For a study to be included in this literature review, it needed to address some aspect of screening for ASD in pediatric primary care. This included articles that assessed the ASD screening tools used in pediatric primary care, the way in which ASD screening was conducted in pediatric primary care, and primary care providers’ perspectives on ASD screening. Only articles that discussed ASD screening in the context of pediatric primary care were included.

For the purpose of this study, “pediatric primary care providers” were defined as an array of professionals and specialties, including, but not limited to, pediatricians, family medicine physicians, family nurse practitioners and others. “Pediatric primary care settings” was also defined in a similarly, broad fashion, in this study. “Pediatric primary care settings” includes, but is not limited to, pediatricians’ offices, family medicine practices, academic settings, health departments and others.

The literature review to follow will refer to provider’s self-efficacy. For the purposes of this study, “self-efficacy” refers to a provider’s perceived view of their competency and ability to adequately address various concerns related to ASD identification and management. Provider “attitudes and beliefs” refer to the provider’s self-perceived role and personal thoughts related to ASD identification and management. Provider “knowledge” refers to the provider’s self-reported knowledge regarding ASD. These terms are discussed together as the literature reveals them to be interrelated.

For the study to have met the criteria of discussing ASD screening related to pediatric primary care, the study needed to discuss ASD screening as recommended by the AAP. That is, the studies needed to explore topics related to screening children for ASD in a pediatric primary care setting at 18- and 24- months of age (Gupta et al., 2007).
There were two studies included in this review that were exempted from meeting this criteria. The first was Anand, Carroll and Downs’ 2012 study. Although this study did not explicitly describe an implementation to improve ASD screening at 18- and 24- month pediatric primary care well-visits, it discussed a system that focused on improving preventive care screening in pediatric primary care. This system initially contained ASD related screening questions, and a later study assessed the system in a more explicit fashion related to the ASD screening criteria required for this literature review. Therefore, this study was included because it provided context and rationale for other studies included in this literature review.

The second study that was exempt from the ASD screening criteria included the 2014 study by Crais and colleagues. This study was designed to gain insight into provider perspectives regarding ASD screening in pediatric primary care at the 12- and 18- month well-child visit. Although this is not the recommended screening age as advised by the AAP, this study was included for two reasons. The first was that the study did discuss screening children for ASD at 18-months which falls under the AAP’s screening recommendations. The second was that the study discussed providers’ moral and educational perspectives regarding ASD screening in general, and it is assumed that such perspectives may be generalized to screening children for ASD at 18- and 24-months.

Studies that discussed ASD screening in countries outside of the United States were excluded from this literature review. Although these studies are very important to the field of ASD screening and research, this literature review sought to explore screening children for ASD in pediatric primary care settings in the United States. This is primarily due to the fact that the AAP is an American organization, and their recommended guidelines to ASD screening may not be applicable or feasible in international healthcare settings. Studies that recommended strategies
to improve screening for ASD in pediatric primary care, but did not explicitly include methodology and experimental data to support their recommendations were also excluded from this literature review.

Analysis Plan

In reviewing current literature, various themes related to the barriers associated with ASD screening arose. The literature revealed that the barriers impeding the ASD screening process as recommended by the AAP could be seen as barriers related to the logistics and procedures of screening for ASD in pediatric primary care or as barriers related to pediatric primary care provider. The barriers associated with pediatric primary care providers include provider attitudes, education, and efficacy regarding ASD screening and management. The proposed implementations to these two themes of barriers fall under two themes as well: implementations towards improving the logistics and procedures of ASD screening in pediatric primary care and implementations to address providers’ education, attitude, and efficacy.

The studies included in this literature review have been sorted into the topic related to ASD that they explore, The discussion of this review synthesizes the various topics these studies explore and provides insight that seeks to answer the two following research questions:

1. What are some of the recognized barriers that prevent ASD screening as recommended by the AAP?
2. What are some of the proposed implementations to mediate these barriers?
Literature Review

The following literature review consists of 23 studies that seek to gain understanding of a topic related to routine screening for Autism Spectrum Disorder (ASD) in pediatric primary care as recommended by the American Academy of Pediatrics (AAP). Some of the studies discuss the screening tools for ASD and implementing them in pediatric primary care and others examine how primary care providers view screening for ASD in their practice. The following studies are grouped based on the topic they discuss. From these studies, themes regarding the barriers and improvements to routine ASD screening in pediatric primary care are synthesized.

Use of ASD Screening Tools in Pediatric Primary Care

Of the 23 studies reviewed in this literature review, two of the studies assessed the appropriateness of using the Modified Checklist for Autism in Toddlers (M-CHAT) to screen children for ASD in pediatric primary care.

M-CHAT-Study 1. Kleinman and colleagues (2008) conducted a two part study to assess the appropriateness of using the Modified Checklist for Autism in Toddlers (M-CHAT) in screening children for ASD in primary care. During the first part of the study, Kleinman and colleagues administered the M-CHAT to 1) children considered to be at low-risk for ASD and 2) children at high-risk for ASD. The second study was a follow-up study in which they collected ASD diagnostic data from the children who were previously screened with the M-CHAT.

The first stage of the study consisted of a sample of 3,793 children, 3,309 of which were considered to be low-risk for ASD and 484 considered to be high-risk for ASD. Children were classified as high-risk for ASD if they already had documented ASD concerns prior to the study. Low-risk children were screened at their pediatrician’s office (in either Connecticut, Massachusetts or Rhode Island) and high-risk children were screened after being referred to the
researchers by an ASD specialist or during their intake into an early intervention service (in either Connecticut or Massachusetts). The researchers conducted telephone follow-up interviews with any caregiver whose child screened positive on the M-CHAT. Children who continued to screen positive after follow-up, or if the child’s primary care provider indicated ASD-concerns even in the presence of a negative screen, were invited to receive a free diagnostic evaluation (Kleinman et al., 2008).

Of the low-risk children, 189 failed the initial screening with 20 of the children receiving an ASD diagnosis, resulting in a positive predictive value (PPV) of only 0.11, which is fairly low. The PPV increases significantly to 0.65 with the use of the M-CHAT follow-up interview. Of the low-risk children, 31 screened positive on both the M-CHAT and the follow-up interview. The PPV for the high-risk children who failed the initial screen was 0.60 and 0.76 when the child failed both the M-CHAT and the follow-up interview (Kleinman et al., 2008).

The second stage of the study consisted of re-screening the children from the first stage of the study who did not receive a positive score on their initial completion of the M-CHAT; which they received two years prior. If the child received positive scores on the re-screener and follow-up interview, they were invited to receive ASD diagnostic evaluation along with the children who received positive scores on both the initial M-CHAT screening and follow-up interview (Kleinman et al., 2008). The evaluations during the second study revealed a PPV of the M-CHAT of 0.38 without the follow-up interview and 0.59 with the follow-up interview. The evaluations during the second study revealed that seven children who were later diagnosed with ASD were not identified during the initial screen (Kleinman et al., 2008).

The two part study concluded that the M-CHAT is an appropriate measure to screen children for ASD in pediatric primary care when implemented with the two-step screening
process. The PPV of the M-CHAT significantly increases when administered with follow-up, specifically when administered in a low-risk population. Such is the population when children at pediatric primary care well-visits are screened. As such, this study reveals that effective screening for ASD in primary care with the M-CHAT requires the completion of the M-CHAT follow-up interview (Kleinman et al., 2008).

**M-CHAT-Study 2.** Chlebowski, Robins, Barton and Fein (2013) also assessed the appropriateness of using the M-CHAT to screen a low-risk population of children in primary care. During their study, 18,989 children were screened with the M-CHAT at primary care practices in proximity to the University of Connecticut or Georgia State University. Any caregiver whose child received a positive screen on the M-CHAT was contacted by research staff to complete the follow-up portion of the M-CHAT, often referred to as M-CHAT/F (Chlebowski, Robins, Barton & Fein, 2013). Of the 18,989 children screened with the M-CHAT, 1,737 screened positive on the initial screen. Of the 1,737 children screening positive, 1,023 caregivers completed the M-CHAT/F. After the completion of the M-CHAT/F, only 272 children continued to screen positive for ASD risk. Diagnostic evaluation was completed by 171 of the children that either continued to screen positive on the M-CHAT/F or were flagged by their provider to receive diagnostic evaluation even in the presence of a negative screen on the M-CHAT. Diagnostic evaluation resulted in an ASD diagnosis for 92 children and 75 were diagnosed as having some form of developmental concern (Chlebowski, Robins, Barton & Fein, 2013).

The study revealed that the PPV of the M-CHAT alone was only 0.06, but increased to 0.54 after administration of the M-CHAT/F. This suggests that the M-CHAT/F is necessary to efficiently screen a population of low-risk children for ASD and helps to facilitate the reduction of false-positive screens. The authors note that of the children screening positive on both the M-
CHAT and M-CHAT/F, but who did not receive a diagnosis of ASD, a majority presented with some form of developmental concern, indicating that even if the child may not have ASD, the false-positive resulting after a positive M-CHAT and M-CHAT/F screen may still help to identify children requiring some form of developmental intervention (Chlebowksi, Robins, Barton & Fein, 2013).

Language and Cultural Barriers to ASD Screening

Of the 23 studies included in this literature review, four studies discuss the cultural adaptability of screening for ASD in pediatric primary care with the use of formal ASD screening tools.

**Screening Latino Children for ASD.** In a 2013 study, Zuckerman et al. conducted a mail-based survey of 257 California primary care pediatricians (PCP) to assess their developmental screening practices, both general and ASD-specific, and to gather their perceptions in regards to screening and diagnosing Latino children for ASD. This study was the first to explore how primary care pediatricians view cultural disparities that may affect their ability to screen children for ASD. The survey posed PCPs with questions regarding four different topics. The first set of questions considered the developmental and autism screening practices of the participating PCPs. Of the 257 PCPs surveyed, 80.5% reported that they perform some form of developmental screening at some point in time, but only 30.4% of the PCPs conducted developmental screening as recommended by the AAP Bright Futures Periodicity Guidelines, which suggests routine developmental screening at 9, 18 and 24/30-months of age. Additionally, 42.9% of the PCPs reported that they perform ASD-specific screening at 18 and 24-months of age per AAP recommendations. Although these findings reveal that developmental and ASD-specific screenings are not being conducted in primary care settings in a
manner that aligns with AAP recommendations, the occurrence of developmental and ASD-specific screening in Spanish was even lower. Only 17.7% of PCPs reported that they provide developmental screening in Spanish and 28.7% offer ASD-specific screening in Spanish. These results reinforce the notion that primary care providers are not adhering to the AAP’s recommendations, but furthermore, that even greater barriers exist in screening Spanish-speaking children for ASD (Zuckerman et al. 2013).

The survey also assessed PCPs’ attitudes towards screening Latino children for ASD along with their perceived barriers to screening this population of children. PCPs’ attitudes towards screening Latino children for ASD primarily focused on the provider’s perception of parental ASD knowledge. A 4-part scale revealed that 73.9% of the PCPs reported that they felt that Spanish-speaking parents of Latino children were “not at all” or “not very” knowledgeable about ASD, as opposed to 20.4% stating the same for parents of Non-Latino White children. Provider efficacy for recognizing signs of ASD also varied with 60.4% of providers revealing that it was “somewhat” or “very difficult” recognize signs of ASD in Latino children as opposed to the 33.2% of PCPs expressing such difficulty in screening White children for ASD (Zuckerman et al. 2013).

**Latino Parents’ Perspectives of ASD Screening.** Zuckerman and colleagues (2014) continued their exploration of barriers affecting the ASD diagnosis of Latino children but this time focused on gathering such insight from the perspectives of the parents of Latino children diagnosed with an ASD, becoming the first study published to do such. Participants in the study were parents to Latino children aged 2-10 years of age and previously diagnosed with ASD. Thirty-three parents participated in the study with 25 of the 33 parents participating in five focus groups and seven participating in individual interviews. Participation in the individual
interviews was a result of scheduling conflicts that prevented the parents from participating in one of the focus groups. The topics discussed during the focus groups and individual interviews fell under three domains: “community perceptions and knowledge of ASD, barriers experienced before and during the ASD diagnostic process, and suggested ways to overcome barriers.” (Zuckerman et al., pp. 302, 2014). Three main themes regarding barriers to ASD diagnosis identified by the parents of Latino children arose from the study.

**Barriers to how ASD is viewed in Latino culture.** The first theme encompasses barriers resulting from how ASD is viewed by the Latino community (Zuckerman et al., 2014). Some of the parents reported that there is a lack of knowledge regarding ASD in the Latino community. One mother reported that she had not known what ASD was until her child was diagnosed, and a shared notion that conditions like ASD “do not exist in many Mexican Communities” (Zuckerman et al., pp. 304, 2014). Parents also described the culture of mental health and disability stigma in the Latino community that caused some parents to hide their concerns about their children’s behavior out of fear that their child would be looked down upon by the community. This stigmatization of the disabled is further compounded by traditional Latino views of masculinity, or Machismo. Some mothers in the study revealed that fathers “saw having a weak or disabled boy as a poor reflection on them as a man” (Zuckerman et al., pp. 304, 2014). These cultural barriers prevented some of the parents in the group from sharing their concerns regarding their child’s behavior, which is a factor that poses a challenge to primary care providers as they attempt to screen Latino child for ASD.

**Barriers related to Latino parents and family.** Parent and family factors comprised the second theme of barriers identified through the focus groups and individual interviews. Such factors include limited English proficiency, a lack of knowledge of available resources for their
child and a subsequent inability to advocate for the rights of their child, and poverty (Zuckerman et al., 2014). Although these factors were identified in regards to the entire diagnostic process of ASD, they are particularly pertinent barriers to the screening process of ASD. A lack of English proficiency may affect a parent’s ability to complete ASD-screening tools, and a deficit of knowledge regarding available resources may prevent parents from seeking out ASD screening in general.

**Barriers within healthcare system for Latino families.** The last theme of barriers identified by the parents participating in the study centered upon difficulties they faced with the healthcare system. Parents revealed that they felt that the concerns they expressed to their child’s primary care provider were dismissed due to the provider’s view that they had little knowledge regarding their child’s symptomatic behavior of ASD. In regards to the overall diagnosis of ASD, the parents in the study found the process too complex and inconvenient, as well as unpleasant for their child (Zuckerman et al., 2014).

**Summary findings of cultural barriers.** The researchers indicated various consequences as a result of the existence of these three thematic barriers to the ASD diagnosis of Latino children. Amongst these consequences include the normalization of parents’ ASD concerns, a sense of conflict and confusion about ASD and what it means for the parent’s child, denial in regards to their child’s ASD diagnosis, and lastly, a loss of trust in health care professionals and the health care system in general (Zuckerman et al., 2014). These studies reveal that cultural barriers may impede the ASD screening process, and as such, should be addressed in further research as a barrier to overcome in order to improve the ASD screening process in primary care.

**ASD Screening of Hispanic Children.** In a 2014 study to explore the feasibility and effectiveness of implementing general developmental and ASD-specific screening in a primary
care setting that predominantly serves Hispanic children, Widham and colleagues implemented a screening project in two primary care clinics in Santa Clara County, California. As part of the screening project, a bilingual (English and Spanish) clinical specialist administered the M-CHAT and the Ages and Stages Questionnaire (ASQ), a general developmental screener, to English or Spanish speaking parents of children who were between 16 and 30 months of age and were scheduled for well-child or follow-up appointments in one of the two clinics between January 2008 and July 2009. The tests were administered in the parent’s dominant language, and once completed, were scored by the clinical specialist and compiled into a summary form of the scores to be provided to the child’s physician. In its entirety, the study included 1,760 children who received developmental screening with the M-CHAT and ASQ. The analysis of the results of this study divided the children into four groups: “children who screened positive on both the M-CHAT and ASQ, screen-positives on the M-CHAT only, screen-positives on the ASQ only, and children who did not screen positive on either instrument” (Windham et al., pp. 1624, 2014).

The study found that Hispanic children were more likely to score positively on the M-CHAT than their non-Hispanic peers. Positive scores on the M-CHAT were also found to be more likely when the instrument was administered in Spanish than in English. This heightened likelihood of positive scores decreased with follow-up, but remained present. This finding is non-concurrent with previous studies that indicate a lower prevalence of Latino children with ASD than white children with ASD (Windham et al., 2014). The researchers attribute this finding to either a higher risk of ASD in the Hispanic population than was previously obtained, or that parents of Hispanic children interpreted the M-CHAT differently than non-Hispanic parents (Windham et al., 2014).
Cultural Applicability of M-CHAT. An analysis of each of the items on the M-CHAT was conducted and differences in response rates due to language or ethnicity were considered. Items on the M-CHAT that addressed whether the “child maintains eye contact, looks at something when someone points to it, and looks at something when the parent looks at it,” were shown to elicit different responses based on ethnicity (Windham et al., 2014, pp. 1628-1629).

This suggests that different cultural expectations and behavior might affect a parent’s response to certain items on the M-CHAT. Various items on the M-CHAT also were found to differ by the respondent’s language, which suggests that the Spanish translation of the item differs in meaning than that of the original English item (Windham et al., 2014). These findings suggest that a further analysis of the cultural applicability of ASD-screening tools like the M-CHAT is necessary.

Exploration of 2 Spanish Versions of M-CHAT Compared to English Version Fail Rates. In 2014, Kimple, Bartelt, Wysocki, and Steiner assessed the performance of Spanish versions of the M-CHAT. There are two Spanish translations of the M-CHAT including a Spanish-Spain version and a Spanish-Western Hemisphere version. In this study, Kimple and colleagues sought to explore the fail rates of the two Spanish versions of the M-CHAT and to see if there was a significant difference of fail rates between the two versions. The fail rate of each Spanish version of the test was also compared to the fail rates of the English version of the M-CHAT. In this study, fail rates refer to incidences in which the test was failed, indicating the child as high-risk for ASD. Kimple and colleagues analyzed 589 M-CHAT questionnaires administered to children at a university-based resident clinic for either their 18 or 24-month well-child visit. The combined fail rates for the Spanish versions of the M-CHAT was 23.6% while the fail rate for the English version of the M-CHAT was 11.3%. No significant difference
between the fail rates of the two different Spanish versions was noted (Kimple, Bartelt, & Wysocki, 2014).

This elevated fail rate attributed to Spanish versions of the M-CHAT is perplexing in considering the lower prevalence of Latino children with ASD than non-Latino white children. This brings into question how items on the M-CHAT change when translated into a language other than English as well has how cultural expectations may affect responses to the M-CHAT. As such, this study reinforces the need for research regarding the cultural adaptability of ASD screening tools as this the existence of such cultural barriers may impede the identification of children with ASD (Kimple, Bartelt, & Wysocki, 2014).

**Electronic Delivery of ASD Screening Tools**

Of the 23 studies included in this review, three studies explore electronic deliveries of common ASD screening tools in pediatric primary care.

**Utility of on-line M-CHAT in Urban Setting Serving Primarily African American Children.** Harrington, Bai and Perkins (2013) investigated the utility of the electronic version of the M-CHAT in screening children for ASD. They also sought to understand the effect that the electronic version of the M-CHAT has on false at-risk screen rates, delivery of the follow-up component of the M-CHAT, logistical barriers to screening (i.e. cost and time), and patient satisfaction with the electronic screening tool. The electronic online format of the M-CHAT presents the child’s caregiver with the same 23 questions presented in the original paper version of the M-CHAT. Upon completion of the 23 questions, the electronic version of the M-CHAT is automatically scored by the system. The M-CHAT follow-up interview questions are automatically presented by the online version if the score on the 23 item questionnaire was “positive” or “at-risk.” The interview follow-up questions are also automatically scored in the
electronic online format, and if the score indicates that the child is at-risk for ASD, then the system informs the caregiver and directs them to see the child’s pediatrician. The electric, online M-CHAT is also available for the child’s caregiver to complete outside of the clinic setting (i.e. at home, work, etc.)(Harrington, Bai & Perkins, 2013).

The researchers administered the electronic M-CHAT on an iPad at the General Academic Pediatrics outpatient practice in Norfolk, Virginia. As part of The Children’s Hospital of the King’s Daughters (CHKD), this pediatric primary care practice serves predominantly urban African American patients enrolled in Medicaid (Harrington, Bai & Perkins, 2013). During a two month period, the researchers used the electronic version of the M-CHAT to screen 176 children between 16 and 30 months at both sick and well-visits. After completing the electronic M-CHAT, the child’s caregiver was asked to complete a survey regarding their experience with the electronic, online format of the M-CHAT. Of the 176 individuals that completed the online M-CHAT, 92 of them had previously completed the paper version of the M-CHAT and of those 92, 72 of them expressed that they preferred the electronic version of the M-CHAT over the paper format. Of the 176 individuals competing the online version of the M-CHAT, 97% of them did not require help to do so, about 85% were able to complete the screen in three minutes or less, and 99% of them rated their experience with the electronic version as either excellent (78%) or good (21%) (Harrington, Bai & Perkins, 2013).

In an effort to compare the electronic version of the M-CHAT to the original paper version of the screener, the researchers retrospectively analyzed completed paper M-CHAT found in patient charts. Completed paper M-CHAT screeners from the charts of 197 patients seen at CHKD were pulled after being identified through their billing codes for developmental screening. Of the 197 M-CHATs, 33 of them were scored incorrectly, and of the 33, 11 affected
the final result of the screen. The incorrectly scored screens identified the children as low-risk for ASD when in actuality, they were at high-risk for ASD (Harrington, Bai & Perkins, 2013).

Through their comparison of the paper based and electronic version of the M-CHAT, the researchers found that the electronic version removed the risk of human error in M-CHAT scoring and resulted in greater completion and uniformity in the follow-up interview. This integration of the follow-up interview in the electronic version of the M-CHAT was suggested to decrease the number of false-at-risk screens as indicated by a reduction of at-risk score frequencies when compared to the paper version of the screener (3% vs. 10%, respectively) (Harrington, Bai & Perkins, 2013). The parent survey also suggests that the electronic version was fairly quick and easy to use and an overall pleasant experience for the user. This study suggests that electronic, online delivery of ASD screening tools with automatic scoring have the potential to improve the process of screening for ASD in pediatric primary care (Harrington, Bai & Perkins, 2013).

Utility of on-line M-CHAT Delivery. Sturner and colleagues (2016) sought to explore the utility of an electronic, web-based platform of the M-CHAT in increasing the feasibility and accuracy of completing the follow-up portion of the M-CHAT in pediatric primary care. The study consisted of 47 pediatricians from 22 primary care offices in Maryland and their patients. During the study period, 5,071 children were screened with ASD using an electronic version of the M-CHAT either at home or in their clinic’s waiting room using the Child Health and Development Interactive System (Sturner et al., 2016). The completed M-CHATs were automatically scored by the electronic medium it was delivered through. If the child screened positive on the M-CHAT, then the child’s primary care provider conducted the M-CHAT follow-up component using the Child Health Development System. This system helped to automate the
follow-up process by selecting the follow-up components for the provider to present to the child’s caregiver and automatically scoring the follow-up component as it was completed. The participating providers in this study received minimal training (about 10-minutes) on the use of the electronic follow-up system.

To test the validity of completing the follow-up in this manner, any child who screened positive on the M-CHAT was invited to the Kennedy Krieger Institute Center for Autism and Related Disorders (Autism Center [AC]) for diagnostic evaluation. Of the children who had positive screens on the M-CHAT, 99 of the children’s caregivers opted into the diagnostic services (Sturner et al., 2016). The researchers at the AC conducted in-person and telephone follow-up interviews and their results were compared to those obtained through the follow-up interviews conducted by the providers using the electronic decision support system. The comparison revealed that the findings on the follow-up conducted by the providers were the same as those obtained by the researchers at AC 86.6% of the time. The follow-ups conducted by the providers and researchers exhibited similar sensitivity, specificity, and positive predictive value (PPV). The researchers also found that the follow-up portion of the M-CHAT significantly improved its PPV (0.49 without and 0.68 with) and helped to reduce the rates of false-positive screens (Sturner et al., 2016).

Through this study, the researchers found that the performance of the electronic M-CHAT follow-up portion was essentially equivalent to the in-person and telephone follow-up interviews conducted by the trained researchers in the field of ASD. This holds true even in the consideration of the fact that the providers in this study received minimal training on how to use the system. As such, the study suggests that electronic decision support systems like the one used
to help providers to conduct M-CHAT follow-up in this study may be useful in implementing effective ASD-screening in pediatric primary care (Sturner et al., 2016).

**Utility of on-line M-CHAT-R in an Urban Clinic Serving Predominantly African-American Population.** In 2016, Brooks and colleagues assessed the feasibility and effectiveness of implementing the web-based version of the M-CHAT-R, a revised version of the Modified Checklist for Autism in Toddlers (M-CHAT) in primary care. See Appendix D to view the M-CHAT-R. Particularly, the researchers examined how the web-based revision of the M-CHAT-R affected the screening practices of providers serving a diverse population of patients in an urban clinic. Over a five year period, 2,557 toddlers were screened for ASD during their 18- or 24-month well-child visit at one of Children’s Healthcare of Atlanta-Hughes Spalding’s pediatric clinics. The sample consisted of toddlers with a mean age of 22.43 months and included predominantly African-American (87%) toddlers. The toddlers’ mothers were all fluent English speakers and their average level of education was 12.37 years; equivalent to a high school diploma/GED (Brooks et al., 2016).

Toddlers were screened with the paper-based version of the M-CHAT-R between June 2009 and February 2014 and with the web-based version from February 2014 and October 2014. A total of 2,042 toddlers were screened for ASD using the paper version of the M-CHAT-R and 515 were screened using the web-based version. The paper version of the M-CHAT-R was completed by the toddler’s caregiver in the waiting room before their child’s well-child visit and scored by study personnel. The study personnel reached out to the caregivers to complete the follow-up portion of the M-CHAT-R via telephone if the paper version had a score of 3 or more. If the follow-up was score was a 2 or greater, the toddler’s caregivers were offered free diagnostic services at Georgia State University.
The web-based version of the M-CHAT-R was completed by the child’s caregiver on a laptop in the waiting room while they waited for their child’s well-child visit. Upon completion, the web-based version of the M-CHAT-R was automatically scored. If the score was between a 2 and 7 on the web-based version, the follow-up portion was automatically presented to the caregivers. If the score on the follow-up was a 2 or more, or if the initial screening score was an 8 or higher, the child’s family was contacted by study personnel and offered free diagnostic services at Georgia State University. The web-based version of the M-CHAT-R was administered to a total of 515 toddlers (Brooks et al., 2016).

The researchers found that the mode through which the M-CHAT-R was delivered did not have a significant effect on the rate of screens that indicated the potential for an ASD diagnosis, nor did the modality of the test significantly affect the screen’s total score. The web-based method of delivery of the M-CHAT-R significantly affected M-CHAT-R follow-up completion and overall rates of screening (Brooks et al., 2016). During the study period, 35.1% of the paper screens that required follow-up were missing follow-up as opposed to the web-based version in which said instance only occurred 3.1% of the time. The utilization of the web-based version of the M-CHAT-R was associated with a 58.5% increase in screening frequency compared to the frequency of screening with the paper version. This study suggests that web-based screening tools have the potential to enhance the frequency of ASD screening while not jeopardizing the tool’s reliability and validity (Brooks et al., 2016).

**Automating Preventative and ASD Screening in Primary Care**

Of the 23 studies included in this review, three of the studies explore automating preventative screening in pediatric care with explicit implementations of automated ASD screening systems.
Child Health Improvement through Computer Automation (CHICA). In their 2012 study, Anand, Carroll and Downs describe how the various guidelines for recommended preventive services in pediatric primary care can become overwhelming for providers to be aware of, let alone implement. Coupled with the time constraints associated with primary care, it becomes increasingly challenging for providers to identify which preventative guidelines apply to their patients. In an effort to overcome this barrier to providing pediatric patients relevant and appropriate preventative services, such as ASD screening, the researchers created the Child Health Improvement through Computer Automation (CHICA), a computer decision support system designed to assist pediatric primary care providers in providing preventive services to their patients. The CHICA system was initially developed by the researchers in 2004 and introduced into a busy pediatric primary care practice that was part of a larger hospital system. It was then introduced into 3 additional community health centers in 2009. Each of the practices were located in Indianapolis, Indiana and serve predominantly underserved communities (Anand, Carroll & Downs, 2012).

CHICA is computer decision support system (CDSS) that assists providers in making clinical decisions by comparing patient specific information to computerized databases of clinical guidelines and recommendations. The CHICA system also has the capability to be integrated into an existing electronic medical record (EMR) which gives CHICA the ability to include the patient’s health records in its decision making. When a patient checks into one of the clinics with an integrated CHICA system, the clinic’s registration system prompts the CHICA system of the patient’s arrival and in turn the CHICA system gathers relevant information from the patient’s EMR (Anand, Carroll & Downs, 2012). Using the information from the patient’s EMR, produces a patient screening form that includes 20, age-appropriate and patient specific,
screening yes/no assessment questions. The questions are selected from a 198 question database and are available in both English and Spanish. The initial CHICA system contained questions related to ASD screening, but did not initially include a comprehensive ASD screening module (Anand, Carroll & Downs, 2012).

Upon completion of the PSF by the patient’s caregiver, or the patient, depending on their age, the PSF form is scanned into the CHICA system by the nursing staff prior to the patient seeing the primary care provider. The responses on the PSF are analyzed by the system, and a physician worksheet is generated. This worksheet contains pertinent alerts, reminders, and recommendations to the provider as determined through the CHICA’s decision making capability. Through these auto generated worksheets, providers are prompted to perform recommended preventative services regardless of their knowledge of various practice guidelines (Anand, Carroll & Downs, 2012).

In this particular study, the researchers sought to assess the rate at which the questions on the PSF sheet were being answered and to identify the most pressing risk factors present in the patients served at the clinics using the CHICA system. The researchers assessed the data collected through CHICA systems at these practices between June 2009 and June 2011. During this time frame, 408,601 patient screening questions were generated by the CHICA system, and of those questions, 362,363 were answered. This 89% response rate reflects the utility of automated screening systems in pediatric primary care, and indicates the potential of automated screening services to be integrated in ASD screening procedures (Anand, Carroll & Downs, 2012). The automation of ASD screening using the CHICA system was conducted in the following study.
Utility of ASD Screening Module Integrated within CHICA. In an effort to increase provider compliance with AAP ASD screening guidelines, Bauer, Sturm, Carroll and Downs (2013) evaluated the effectiveness of an ASD screening module integrated within CHICA. The module was automated to alert the provider of the need for ASD screening at the 18- and 24-month well-visit as suggested by the AAP. Upon patient check-in, the CHICA system with the ASD module printed a PSF that asked the child’s caregiver two questions: whether or not the child has a sibling diagnosed with ASD and if the caregiver has concerns regarding their child’s development. If the caregiver answered yes to both questions, the ASD module prompted the provider to skip formal screening and refer the child to intervention and specialist services. If the caregiver did not respond yes to both questions, the ASD module printed out the Modified Checklist for Autism in Toddlers (M-CHAT), which the child’s caregiver completed in the waiting room. The completed M-CHAT was then scanned into the CHICA system by nursing staff. The ASD module automatically scored the scanned M-CHAT and interpreted the results for the provider. The system also automatically printed portions of the M-CHAT follow-up for providers to discuss with the child’s caregiver (Bauer, Carroll, Sturm & Downs, 2013).

If the CHICA system finds the score on the M-CHAT to indicate ASD concerns, it provides the provider with a provider worksheet that asks them to indicate if they confirm the positive screen as well as indicate if they referred the child to audiology or an ASD specialist for further follow-up. To support providers in discussing the results of the positive screen with the child’s caregivers, the CHICA system prints supplemental counseling resources for the provider, referred to as “just in time, JIT” worksheets (Bauer, Carroll, Sturm & Downs, 2013). The JITs developed for the ASD module includes information about community resources for children with ASD, information about early intervention services and eligibility, and major discussion
points for providers when sharing the positive screen results with the child’s caregivers (Bauer, Carroll, Sturm & Downs, 2013).

To test the new ASD module’s effectiveness in promoting ASD-screening in primary care, the researchers randomly implemented the ASD module in two of the four clinics using the CHICA system. A baseline rate of ASD detection for the two clinics selected for the ASD module was obtained by analyzing the billing codes of 5,128 who were between the ages of 17 months and 5 years and seen at any of the clinics three times since the implementation of CHICA in the clinics. Of the 5,128 children, only 8 had a billing code for ASD, revealing a baseline rate of ASD detection of 0.2% amongst all four clinics (Bauer, Carroll, Sturm & Downs, 2013).

The ASD module was implemented in the two selected clinics in November 2010 with the study running until the end of July 2012. During this time frame, 857 children eligible for ASD-screening according to AAP guidelines were seen in the two clinics. Of the 857 eligible children, 567 (66%) of them were formally screened for ASD using the automated ASD module as indicated by the upload of a completed M-CHAT form into CHICA (Bauer, Carroll, Sturm & Downs, 2013). Amongst the 567 children screened, 171 had at-risk M-CHAT scores of which, physicians responded to only 73 (Bauer, Carroll, Sturm & Downs, 2013). Of the 73 M-CHAT scores addressed by the providers, 50 children were considered by the providers to not have ASD, 13 children were referred for further ASD evaluation, 2 children were referred to audiology and 8 children were suspected of having ASD but were not referred to any specialist or early intervention services. The study revealed that the ASD system helped to impact provider screening practices, however, a notable failure to address the system warnings was reported during the study (Bauer, Carroll, Sturm & Downs, 2013).
CHICA and Provider Knowledge of ASD. In 2015, Bauer, Carroll, Saha, and Downs investigated whether or not the automated ASD module integrated into CHICA contributed to provider knowledge regarding ASD or affected their perceived role in ASD management. Surveys were administered to both the clinics using the CHICA system without the ASD module and the clinics integrated with the ASD module. The former group was used as a control in the study and the providers working at clinics with the CHICA system integrated with the ASD module were labeled as the intervention group. The surveys gathered physician demographic information and asked 20 questions related to their knowledge of ASD and four questions regarding the provider’s perceived role in ASD management. Participating providers were also asked to report their use of formal screening tools to screen their patients for ASD (Bauer, Carroll, Saha & Downs, 2015).

The surveys were administered upon implementation of the ASD module, 12 months post implementation and 24 months post implementation with 45, 39, and 42 providers responding at each point, respectively. At baseline, 42% of responding providers reported using a formal screening tool to screen for ASD, with the intervention group reporting a similarly low rate of screening at 47% (Bauer, Carroll, Saha & Downs, 2015). While the control group reported fairly consistent screening rates in both the 12 and 24 month surveys (46% and 42% respectively), the intervention group saw an increase in screening rates with 79% of providers reporting formal screening 12 months after implementation of the ASD module and 88% reporting formal screening 24 months post-implementation. Regarding its influence on provider use of formal screening tools to screen for ASD in primary care, the CHICA system integrated with the ASD module had a notable impact on provider screening practices. However, the system did not do
much to increase provider knowledge regarding ASD nor their perceived role in ASD management (Bauer, Carroll, Saha & Downs, 2015).

Compared to baseline and the control group, ASD knowledge amongst the providers in the intervention group did not change significantly at any point in time during the study. Providers in both the control and intervention group also exhibited consistent perceptions regarding their role ASD management throughout the study. A majority of providers saw their role in supporting their patients with ASD through referrals to diagnostic and intervention services. Given this perceived role, it is surprising to find that the 12 and 24 month surveys revealed that 77% of providers in the intervention group and 66% in the control reported difficulty connecting their patients with community and specialty resources (Bauer, Carroll, Saha & Downs, 2015).

Provider Perspectives on ASD Screening in Primary Care

Of the 23 studies reviewed, two of the studies aimed to understand primary care providers’ attitudes and perceived barriers to screen for ASD in pediatric primary care.

Providers’ Perceived Barriers to Screening for ASD – Study 1. A 2014 study conducted by Crais et al. sought to explore the perspectives of various primary care providers in regards to their perceived barriers to screening for ASD in their practice and the implementations that may enable them to consistently and efficiently screen. The study utilized focus group methodology to engage primary care providers of various professional backgrounds in conversations regarding screening for ASD at 12 and 18 month well-child visits. Although the study focused on screening for ASD at the 12- and 18- month well-child visit, as opposed the 18- and 24- month visit as recommended by the AAP, the study still revealed valuable insight into providers’ perspectives on screening for ASD in general. The focus groups represented eight different primary care
practices. The practices exhibited diversity amongst the population they serve (rural, suburban, and urban populations) as well as structural diversity; private pediatrician and family practices along with public health clinics were included in the focus groups (Crais et al., 2014). The entire study included a sample of 66 primary care providers of varying professional roles. The 66 participants included public health physicians and nurses, family practice physicians and nurses, social workers, a physician’s assistant and a primary care resident. The focus group revealed that providers perceived barriers to ASD screening that fell under five unique categories: interpersonal issues, procedural processes, contextual issues, tool design, and ethical moral dilemmas (Crais et al., 2014).

**Interpersonal barriers.** The interpersonal barriers expressed by the providers revealed that they were often concerned with the way in which the child’s caregivers would react to their child being screened for ASD. Some of the providers expressed that they feared for their patient’s caregivers to have a stigmatized notion of ASD and demonstrated uncertainty in how to navigate such a situation. The providers also expressed that they have come across difficulties when the child’s caregiver disagrees with the provider’s clinical assessment of the child’s behavior. Cases in which the caregivers disagreed with the provider’s concerns of ASD and those in which the caregivers expressed ASD concerns that the providers did not share were seen as inhibitory to proper ASD screening by the providers. Interpersonal barriers also took the form of providers’ desires for clearer indicators of ASD and their trust in the current research regarding the effectiveness of early intervention for children 12-18 months old. The providers shared that they often have difficulty discriminating between typical behavior and behavior that may be indicative of ASD. The challenge posed by a lack of provider efficacy is potentially exacerbated by varying opinions regarding the need to screen child for ASD 12 and 18 months
and a perceived lack of concrete evidence showing the benefits of such screening (Crais et al., 2014).

**Procedural barriers.** The providers expressed various procedural barriers screening for ASD in their practice. Some of the providers shared that they routinely observe children for atypical behavior that may be indicative of ASD, and therefore, didn’t see the need to formally screen for ASD using a screening tool. Other providers expressed that they find the tools to be useful in guiding them to observe particular behaviors and symptoms. This reveals the varying importance that providers place on using formal screening procedures in their practice. When formal screening tools were used, the providers expressed difficulties in determining whose responsibility it was to administer the tools, score them, and share the results. Some providers also expressed difficulty adding paper screening tools to electronic medical charts. Additional procedural barriers expressed by the providers including challenges for the caregivers to adequately complete the tools, and clinical time constraints. The providers shared their desire for education and training on supporting their patients with ASD (Crais et al., 2014).

**Contextual barriers.** The contextual barriers noted by the providers were related to both factors regarding the child and their caregivers and those related to more system-based concerns. The providers shared that they found cultural and socioeconomic factors were influential during the screening process and presented challenges to accurately screen for ASD. Language and literacy issues were also noted as affecting a caregiver’s ability to complete ASD screening tools. The system-based concerns related to the availability of early intervention services as well as reimbursement from insurance and Medicaid (Crais et al., 2014).

**Tool design barriers.** The study revealed that very few of the participating providers were administering the M-CHAT and those that were using it where not knowledgeable of the
follow-up component of the screener. Even fewer providers participating providers demonstrated a desire for quick, short (five items or less), culturally sensitive screening tools with a low reading level. Providers also revealed a preference for screening questions with options beyond just “yes or no” (“sometimes”, agree,” etc.). The ease in which the screeners could be integrated into daily practice was prevalent in the providers’ conversations regarding ASD screening tools. Providers suggested that the tools should be electronically available, readily accessible and easy to score (Crais et al., 2014). There was an uncertainty amongst providers regarding who should complete the screener, and where and when this screening should take place (i.e. at home before the child’s visit, in the waiting room, during the visit, etc.) (Crais et al., 2014).

*Ethical and moral barriers.* The participating providers displayed varying ethical and moral barriers related to ASD screening. Providers noted that there is a risk-to-benefit analysis that they feel should occur when considering screening children for ASD. Some providers were concerned by the effect that falsely identifying children without ASD as having ASD, while others declared that they saw the benefit of early identification as more substantial than the risk of a false-positive screen (Crais et al., 2014).

*Summary of provider perceived barriers from study 1.* Through the use of provider focus groups, Crais and colleagues (2014) found that providers often find difficulties navigating the time constraints preventing ASD screening, limited knowledge of the tools used to screen for ASD, and inadequate training specific to ASD identification and management. An uncertainty in how to overcome challenges preventing referral and obtainment of early intervention services for their patients upon an “at-risk” ASD screen also contributed to their apprehension towards screening for ASD in pediatric primary care. Providers also desired greater research regarding
the effectiveness of early intervention and the appropriateness of screening for ASD in pediatric primary care (Crais et al., 2014).

**Providers’ Perceived Barriers to Screening for ASD – Study 2.** In an effort to gain insight on primary care providers’ attitudes towards ASD screening as recommended by the AAP and their perceived barriers to implementing such screening into their practice, Fenikilé and colleagues (2015) conducted focus groups and interviews with 15 family medicine physicians practicing in Kansas. The 15 participating family medicine providers served pediatric patients, were aged 34 to 60, had 5 to 27 years of experiences, and practiced in varying family medicine practices (academic settings, private/solo practices, and group practices). None of the participating physicians utilized ASD-specific screening tools and it was noted that only one of the 15 providers had knowledge of the M-CHAT.

The focus groups and interviews revealed participating providers’ views on ASD prevalence, routine ASD screening, major barriers to autism screening, ASD management and suggested improvements to screening for ASD by primary care providers. The physicians expressed concerns regarding whether or not the increase in ASD prevalence was a result of new diagnostic criteria for ASD. They also noted that the requirement for an ASD diagnosis to receive various intervention services may contribute to this rise in prevalence. In terms of their view on the routine screening of ASD as recommended by the AAP, the physicians shared the sentiment that they would rather only screen for ASD when the parent reports explicit concerns and in such a case and prefer the use of a general developmental screener as opposed to an ASD specific screener (Fenikilé et al., 2015). The consensus amongst the providers was that taking the time to administer ASD screening was not an efficient use of their limited time with their patients. Some of the physicians, however, found that the objective nature of screening tools
were useful in addressing ASD concerns with parents. Those that found utility in ASD screening tools suggested that integrating them into the patient’s electronic medical record (EMR) would better help to facilitate their use in practice (Fenikilé et al., 2015).

**Perceived barriers.** The major barriers to implementing ASD screening as perceived by the physicians included a lack of time to spend with patients and a lack of funding and reimbursement for ASD screening services. The physicians shared that a lack of knowledge and training was also a barrier to instilling ASD screening in their practice. Some of the physicians shared that although family medicine providers work with pediatric patients, their family medicine residencies didn’t place an emphasis on child development and as such, the providers experience resulting difficulties in addressing developmental concerns in their practice (Fenikilé et al., 2015). Related to this lack of knowledge in ASD screening, the physicians also shared that they are unaware of and have difficulty with connecting their patients with ASD services and interventions. It was a shared notion amongst the physicians that they were less likely to screen a child for ASD if they wouldn’t be able to take the next step and provide a child with a positive ASD screen with the necessary resources (Fenikilé et al., 2015).

**Recommendations for improvement.** When asked what they think would be effective in improving ASD screening in primary care, particularly family practice, the physicians desired systematic health-care reforms (i.e. incorporating care coordinators into family practice to help with referrals and more time with patients). They also desired access to evidence supporting routine ASD screening and more comprehensive physician training (Fenikilé et al., 2015).

**Provider Education and Efficacy in ASD Screening and Management**

Of the 23 articles reviewed, four studies sought to gather information regarding primary care providers’ education and perceived efficacy in ASD screening and management.
Assessment of Primary Care Providers Care for Children with ASD. Golnik, Ireland, and Borowsky (2009) developed a 27-item survey to assess primary care physicians’ views towards providing primary care for children with ASD. The survey asked 539 primary care physicians, who were predominantly pediatricians, to reflect upon their own competence in regards to the quality of care that they could personally provide to children with ASD.

They were also asked to identify barriers that would prevent them from providing such care. Survey responses revealed the participating primary care physicians had overall low levels of perceived ability in providing comprehensive primary care to children with ASD, lacked knowledge of resources to provide children with ASD and their families and felt that they were unable to satisfy and gain the trust of families with children with ASD. The physicians also reported that improvements needed to be made to primary care in order to improve the quality of care received by children with ASD. The physicians also expressed a desire to receive ASD training in order to contribute to such quality improvements (Golnik, Ireland, & Borowsky, 2009).

Replication of Previous Study with Nurse Practitioners. In 2013, Will, Barnfather, and Lesley utilized the same survey developed by Golnik and colleagues to assess the perceived self-efficacy of primary care nurse practitioners’ (NP) ability to identify and care for children with ASD. Will and colleagues administered the survey to 126 NPs at a 2011 national NP convention. Of the 126 NPs, 106 identified as family NPs. A master of science in nursing was reported as the highest level of education received by 85.7% of the participating NPs. The survey identified five main barriers faced by NPs in their efforts to provide primary care to children with ASD. These noted barriers include a lack of care coordination, concern from families regarding the safety of vaccines, limited resources such as a lack of time, limited provider education about
ASD, and a lack of practice guidelines for the primary care of children with ASD (Will, Barnfather, & Lesley, 2013).

Barriers such as limited provider education about ASD and a lack of time during office visits may affect the ability of NPs to identify children at risk for ASD. Through this survey, Will and colleagues point to the need for ASD specific education as an implementation to overcome the identified barriers facing primary care NPs. Recent literature has expanded to consider how such deficits in provider efficacy and education affect incidences of ASD screening (Will, Barnfather, & Lesley, 2013).

**Parent and Provider Perceptions of ASD Management in Primary Care.** Carbone and colleagues (2013) conducted parent and provider surveys to gain an understanding of perceived primary care provider efficacy in managing ASD from both the view of parents and practicing primary care providers. The surveys were used to ask parents to rate the ability of their child’s primary care provider to address specific needs of their child with ASD such as their provider’s “ability to address early behavioral or developmental concerns” and their “ability to make appropriate referrals for diagnostic evaluation” (Carbone et al., 2013, p. 967) In all, the surveys addressed a total of 17 ASD-specific needs. The primary care providers were asked to rate their own ability in the same areas asked of the parents.

A total of 144 parent surveys were completed by the parents of children receiving educational services at specialized ASD schools in Salt Lake City, Utah. The parents were predominantly college educated (59%) and privately insured (66%). A majority indicated that their child receives primary care services from a pediatrician (83%) (Carbone et al., 2013). A total of 114 pediatricians completed the survey. The pediatricians were all members of the Utah Chapter of the AAP and predominantly (77%) served in urban practices with 68% of the
providers having ten or more year of clinical experience. The provider survey also asked the
providers to indicate their ASD-screening practices and it was revealed that 55% of the providers
routinely screen for ASD during their patient’s 18-month well-child visit (Carbone et al., 2013).
Although the situation may have arisen, the providers and parents were not linked in the study.
The parents were asked to consider their child’s primary care provider, while the participating
provider were asked to consider their practice in general, not a specific patient. All of the
parental responses were analyzed and compared to all of the analyzed provider responses
(Carbone et al., 2013).

The surveys revealed that although the providers rated their ability to address ASD-
specific needs in primary care as “good” for 10 of the 17 addressed needs, parents rated their
child’s provider as “not good” in addressing 14 of the 17 addressed needs (Carbone et al., 2013).
In assessing their “ability to make the appropriate referrals for diagnostic evaluation,” 80% of
providers indicated their ability as “good,” with only 50% of parents reporting the same rating
(Carbone et al., 2013, p. 967).

In regards to connecting families and children with ASD to community support services,
39% of providers assessed their ability as “good” with 28% of parents doing the same. There was
also notable discrepancy in providers’ perceived “ability to provide advice and guidance to
families about treatment,” with 57% of providers assessing their ability as “good” compared to
only 37% of parents reporting their providers ability as such (Carbone et al., 2013, p. 967).
These low assessments of provider ability in meeting ASD-specific needs, and discrepancies
between parental and provide views towards provider efficacy led the researchers to suggest
educational interventions to improve provider ability in supporting children and families with
ASD (Carbone et al., 2013).
Compliance with AAP Recommendations. Self, Parham, and Rajagopalan (2015) administered surveys to 396 pediatricians and family physicians working in primary care settings across Kansas, Oklahoma, and Iowa to assess whether their ASD screening practices complied with AAP recommendations. The surveys asked participating providers questions regarding how they screen, diagnosis and refer patients for ASD, their knowledge of the recommendations set forth by the AAP and demographic information, which included information regarding their pre-professional education. The surveys revealed that only 17% of the providers participating in the study screened for ASD at the 18 and 24-month well-child visits as suggested by the AAP. There was a strong correlation between higher levels of provider efficacy as well as a correlation between ASD related pre-professional trainings and compliance with the AAP’s ASD screening protocol. This suggests that quality ASD education and increased self-efficacy may promote ASD screening for providers with such qualities and qualifications, but may act as barriers to screening for those that do not (Self, Parham, & Rajagopalan, 2015).

ASD Educational Programs for Primary Care Providers

Of the 23 studies reviewed, five of the studies assess the effectiveness of educational interventions to increase provider knowledge regarding ASD and influence primary care providers to take an active role in ASD screening and management.

Screening Tools and Referral Training-Evaluation and Diagnosis (START-ED). Warren, Stone and Humberd (2009) developed the Screening Tools and Referral Training-Evaluation and Diagnosis (START-ED) program. The researchers invited five community pediatricians to participate in the launch of the program. Each of the pediatricians worked with underserved populations and expressed desire and commitment to improve their ability to support their patients with ASD. The program aimed to empower community pediatricians to
screen, refer and diagnosis children with ASD with the goal that this knowledge would help providers to better connect their patients to early intervention services. In an effort to accomplish such a goal, the researchers developed the START-ED to contain three phases to build upon provider competencies (Warren, Stone & Humberd, 2009).

During the first phase of the program, providers participated in a 2-day workshop that allowed providers to gain experience in reviewing completed Modified Checklist for Autism in Toddlers (M-CHAT) and develop skills to help address developmental concerns revealed in the M-CHAT through a DSM-IV-based diagnostic interview. Participants were also trained on using the Screening Tool for Autism in Two-Year-Olds (STAT). The Screening Tool for Autism in Two-Year-Olds involves a greater hands-on-approach providers than the M-CHAT, and consists of 12 various activities that give the provider insight into the child’s play, imitation and communication habits. Topics concerning billing and reimbursement were also presented during the first phase of the program (Warren, Stone & Humberd, 2009).

The second phase of the program included observing the providers’ assessment practices by installing cameras in the providers’ practices. The videos were analyzed by one of the researchers and each provider received tailored feedback and suggestions on how to improve their assessment practice. The providers then transitioned into the third and final phase of the program in which they independently completed the ASD assessments. In an effort to assess the providers’ confidence in their diagnostic ability, the providers needed to decide between two diagnoses (whether the child was considered to be on the autism spectrum or not), and then indicate their level of confidence in the diagnosis of a scale of one to five with one being “highly uncertain” and five being “highly certain” (Warren, Stone & Humberd, 2009).
The providers were asked to refer children that they diagnosed as being on the autism spectrum to receive evaluation at an autism diagnostic clinic. The children were evaluated at the clinic by professionals unaware of the participating physicians diagnoses, and the diagnoses obtained by the autism clinic professionals were compared to those obtained by participating physicians.

During the first implementation of the program, the participating pediatricians referred a total of 25 patients to the autism clinic, of which, 21 children had caregivers that consented to the diagnostic evaluations at the autism clinic. Amongst the 21 children referred for evaluation, the providers diagnosed 19 of them as being on the autism spectrum, and 2 of them with a non-ASD developmental delay. The professionals at the autism clinic confirmed the ASD diagnosis in 14 of the 19 children diagnosed by the participating pediatricians and found that one of the two children classified as having non-ASD developmental concerns by the participating pediatricians was actually on the autism spectrum. Each of the 6 children that received diagnoses from the autism clinic professionals that disagreed with the participating providers exhibited developmental concerns (Warren, Stone & Humberd, 2009).

The authors express notable limitations to their study including the small sample of providers participating in the study, methodological issues (forcing the providers to decide between ASD or not seems to have contributed to the over diagnosis of ASD by the providers in this study) and lack of baseline data to compare physician knowledge growth. However, their study holds significance in that it demonstrates the potential to educate pediatric primary care providers on how to screen and diagnose children efficiently in their practice. Through educating providers on ASD management (screening, diagnosis, referral), providers may be able
to overcome perceived barriers to screening related to the steps of ASD management that follow ASD screening (Warren, Stone & Humberd, 2009).

**Utility of Intensive Training for Primary Care Providers.** Swanson and colleagues (2014) sought to address some of the limitations present in the Warren (2009) study and built upon the findings of the Warren (2009) study by utilizing a larger and more diverse population of pediatric primary care providers. Similar to the Warren (2009) study, Swanson and colleagues (2014) evaluated the effectiveness of an intensive training program in increasing a provider’s ability to screen and diagnosis ASD in their practice. During a 2-day workshop, participating providers received training on how to properly administer and score the M-CHAT and the STAT, how to gain insight on a child’s behavior through caregiver interviews, how to synthesize relevant information to make a DSM diagnosis of ASD, ways to discuss diagnosis with the child’s family, and logistical concerns related to screening and diagnosis (i.e. ASD billing and insurance reimbursement). After training, providers sent in videos of them completing the STAT for the researchers to evaluate (Swanson et al, 2014). Providers that were geographically located near the main training location referred their patients to receive ASD evaluation from trained ASD specialists. To assess practice change, the participating providers completed surveys regarding their ASD screening, referral and diagnosis practices before and after completing the training (Swanson et al, 2014).

The training program was completed by 27 pediatric providers representing an array of specialties (pediatricians, developmental and behavioral pediatricians, pediatric nurse practitioners and a pediatric neurologist) working in various primary care practices (large/small-group practices, academic medical centers, practices serving underserved populations, and military hospital practices). The providers in the study had an average of 17.6 years of
experience (ranging from 2-39 years). The post training surveys were completed by 26 of the 27 participants and were administered to the providers on average 1.54 years after completion of the training. The data analysis excluded the responses of the 3 behavioral and developmental pediatricians and 1 pediatric neurologist participating in the study, as the researchers wanted to specifically observe how the training contributed to the practices of pediatric primary care providers and these participants were seen as specialty providers (Swanson et al, 2014).

Prior to the training, 91% of the responding providers indicated that they used the M-CHAT to screen children for ASD, however, each of the providers noted that they did not complete the M-CHAT follow-up portion. After training, 95% of the responders stated that they used the M-CHAT to screen for ASD, and, they expressed a greater utilization and completion of the follow-up portion of the M-CHAT. After training, 68% of the responding providers continued to conduct ASD assessment in their clinics, and 64% (0% before training) continued to use the STAT to screen children for ASD (Swanson et al, 2014). During the study, the participating providers referred 14 children to receive ASD assessment at the ASD clinic, and of the 14, 12 of the children received diagnoses from the ASD specialists that agreed with the diagnoses given by the participating providers (86% diagnostic agreement). Providers attitudes towards their role in diagnosing children with ASD also increased as a result of the program (2.27 out of 5 before training and 3.91 out of 5 prior to training; with 1 being highly inappropriate for primary care providers to diagnosis for ASD, and 5 being highly appropriate for primary care providers to diagnosis for ASD) (Swanson et al, 2014).

Through the training, providers exhibited growth in screening for ASD in their practice as indicated through their adherence to the appropriate and complete use of formal ASD screening tools. Providers also demonstrated a transition in the view of their role in ASD identification as
indicated by the increase in providers conducting individual diagnostic ASD evaluations in their practice. The researchers point to the limitation that the providers participating in the study had fairly considerable years of experience and were personally eager to increase their knowledge of ASD screening and diagnosis. As such, it is unclear how effective the program may be for a provider who is reluctant to evaluate their role in ASD management. Nonetheless, the study indicated that equipping providers with knowledge concerning the screening, diagnostic, a referral process of ASD management, may help them develop greater confidence in their ability to take on an active role in identifying their patients with ASD. This study suggested that receiving training on the steps that follow ASD screening may give them the tools to help overcome the barriers to ASD screening related to availability of diagnostic and referral services (Swanson et al, 2014).

**Utility of Provider Training with Educating Practices in the Community (EPIC).** In 2012, Honigeld, Chandhok, and Spiegelman assessed the effectiveness of provider training provided through the Child Health and Development Institute of Connecticut (CHDI) sponsored Educating Practices in the Community (EPIC) program. EPIC is a form of academic detailing program, which are programs that seek to provide healthcare providers educational resources through in-clinic visits. Various modules are provided through EPIC including modules that address general developmental and ASD-specific screenings (Honigfeld, Chandhok, & Spiegelman, 2012). Honigeld and colleges specifically focused on the utility of the aforementioned programs. The EPIC Autism Spectrum Disorder (ASD) Screening module was presented at 43 primary care practices (both pediatric and family practices) over a period of almost two years. The EPIC ASD Screening module provided training on the Modified-Checklist for Autism in Toddlers (M-CHAT) ASD-specific training tool. The EPIC Developmental
Monitoring module, which focused on general developmental screening with the Ages & Stages Questionnaire (ASQ) and Parent’s Evaluation of Developmental Status (PEDS), was administered to 14 different pediatric primary care settings from January 2009 to August 2010 (Honigfeld, Chandhok, & Spiegelman, 2012).

Each of the modules provided information regarding developmental delays, the utilization of the screening tools specific to each module, how to bill for developmental screening to ensure reimbursement, and how to connect their patients with supportive community resources. After each session, attendees were asked to complete an evaluation of the program and indicate their function in their practice. Across all sessions, 318 evaluations were completed by a range of primary care professionals including pediatricians, nurses, and medical assistants. Of the 318 who completed the evaluation, 94% indicated that they planned to utilize the information they received during their EPIC programs, with 26% indicating that time might be the largest barrier preventing them from doing so. The evaluations also revealed that 95% of those completing the evaluations found the programs to be useful. Beyond the evaluations, the researchers also performed chart audits of five of the practices that received the EPIC ASD Screening module to reveal whether or not ASD-screening practices increased after involvement in the program. Charts of 18-month well-child visits from before the EPIC ASD Screening module and three months after the module were compared for information indicating that a ASD-specific screen was conducted at the 18 month visit. Across each of the five practices, statistically significant increases in ASD-screening practices were noted, indicating the possible utility of such academic detailing programs in implementing ASD-screening in primary care (Honigfeld, Chandhok, & Spiegelman, 2012).
Utility of the Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ). The Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ) is an organization that provides learning collaboratives (LC) that are meant to help provide primary care providers with the tools to improve their practice in a variety of domains (Carbone, Norlin, & Young, 2016). These investigators assessed the effectiveness of the “Early Autism Detection and Referral in the Medical Home,” a LC designed by the UPIQ with the intentions of supporting the implementation of ASD-specific screening at the 18- and 24-month well-child visits, inform primary care providers how to refer high-risk children specialists, and support providers in creating a family-centered care model for supporting their patients with ASD. Twenty-six primary care practices from Utah participated in this LC. Of the 26 practices participating, 20 were pediatric practices and six were family medicine practices. At least one physician, one office manager, one nurse or medical assistant, and one parent with a child diagnosed with ASD were represented at each of the practices (Carbone, Norlin, & Young, 2016).

The practices were divided into three different cohorts with 8 practices in the first, 12 in the second, and 6 in the third. The first and second cohorts consisted of practices in proximity to Salt Lake City, Utah, which Carbone and colleagues defined as urban practices. These two cohorts participated in similar LCs that lasted for six months. These LCs started with a workshop that included a presentation by a member or the AAP that discussed recommendations for ASD-screening, trainings on proper administration of the M-CHAT, suggestions for creating practice registries of children at-risk for ASD, and presentations from parents of children with ASD. A specialist in practice quality improvement from the UPIQ assisted practices in identifying their goals for improving care for their patients with ASD (Carbone, Norlin, & Young, 2016). One required goal set forth by the UPIQ specialist was the necessity for practices to create plans for
increasing their rates of ASD-specific screening at 18- and 24-month well-child visits. The specialist assisted the participants in creating a mode of execution for completing such goals, and over the six-month period of the LC, the participants within each practice met to assess their progress.

The participants also took part in monthly conference calls with research personnel that covered various topics relating to ASD screening and the health maintenance of children with ASD. During the six-month duration of the LC, the UPIQ specialist returned to the clinics on two different occasions to support the participants in overcoming barriers to achieving their identified goal. The clinics within the third cohort received a different mode of delivery for the LC. The initial in-clinic workshop received by the first two cohorts was made into a webinar for the third cohort in an effort to avoid travel to the remote clinics. The duration of the LC received by the third cohort was also shorter than that of the first two, lasting only three months rather than six, with the UPIQ specialist visiting the clinics once during this period. Despite these differences, the training content received in each LC was very similar (Carbone, Norlin, & Young, 2016).

In order to assess the effectiveness of the LCs in contributing to a rise in ASD-specific screening, chart audits were conducted to look for documentation of such screening at either 18 or 24-month well-child visits. The first chart audits were conducted following the initial workshop and were conducted monthly until the conclusion of the LC. Across the three cohorts, 1930 charts were audited during the duration of the LCs. Chart audits conducted after the initial workshop were compared to those obtained at the end of the LC. It was revealed that clinics in the first cohorts initially only screened for ASD at the 18 or 24 month well-child visit 29% of the time, but following the LCs, these practices were conducting such screening 95% of the time (Carbone, Norlin, & Young, 2016). An increase in the frequency of screening was also observed.
amongst the third cohort. Initially, ASD screening was only being conducted at these practices 5% of the time, but after participation in the LC, that number rose to 84%. The researchers also followed up with the practices involved in the study four years later. Of the 26 practices involved in the LC, 18 of them continued to implement ASD screening into their practice. The eight practices that did not continue ASD screening either decided to no longer conduct ASD screening, did not respond to the researchers’ request for follow up, or were no longer in business. Of the 18 practices that continued to screen children for ASD, 16 of the practices continued to screen over 80% of the children in their practice for ASD (Carbone, Norlin, & Young, 2016).

**Utility of Extension for Community Outcomes (ECHO).** The Extension for Community Outcomes (ECHO) model was developed at the University of New Mexico Health and Sciences Center with the intent to improve the care for underserved and minority populations in New Mexico infected with hepatitis C (Mazurek, Brown, Curran, & Sohl, 2016). The ECHO used video-conferencing to connect primary care providers with specialists to help inform their practice. The model’s success in increasing provider efficacy in treating patients with hepatitis C along with the improved health outcomes for the patients they serve has led to the exploration of its possible utilization in informing the primary care practice of other conditions. In 2017, Mazurek, Brown, Curran and Sohl assessed the effectiveness of implementing the ECHO model as an effort to improve the ASD screening process as well as medical and psychiatric care for children with ASD. In their pilot program, a 6-month ECHO Autism curriculum was created and taught during a 2-hour clinic that was conducted twice a month on a biweekly basis.

The curriculum was delivered via video-conferencing by an expert panel consisting of a clinical psychologist, a pediatrician with a specialization in ASD, a social worker, dietician, child
and adolescent psychiatrist and a parent of a child with ASD (Mazurek, Brown, Curran, & Sohl, 2016). With the videoconferencing, participating primary care providers were able to interact with the expert panel and their peers. During the session, instruction regarding ASD screening guidelines and practices was provided by the expert panel along with a collaborative discussion amongst the expert panel and participating primary care providers regarding some of the participating primary care providers’ ASD cases. Each of the sessions had an average of about 19 participants, however, data was only collected from 14 participants during the 6-month implementation period of the ECHO. These 14 providers, 10 of which were pediatricians, completed questionnaires prior to and following their involvement in the ECHO program.

The questionnaires were used to assess the provider’s efficacy towards screening children for ASD and health care management of children with ASD as well as their ASD screening practices. The self-efficacy questionnaire revealed greater levels of self-efficacy following involvement in one of the 2-hour clinics. Among the pediatricians participating in the study, AAP compliant ASD screening demonstrated a rise from 30% to 60% following involvement in one of the clinics (Mazurek, Brown, Curran, & Sohl, 2016).
Discussion

A review of current literature suggests that there are inhibitory factors that may prevent the implementation of routine Autism Spectrum Disorder (ASD) specific screening in a pediatric primary care setting. This research sought to explore the barriers to early screening in a pediatric primary care settings and the extent to which these barriers stand in the way of routine screening and adherence to the recommendations set forth by the American Academy of Pediatrics (AAP), which recommends the screening for ASD at the 18- and 24- month well-child visit. Along with barriers, this research sought to explore possible improvements to overcome such challenges.

Analysis of current literature revealed that the effective screening of ASD in pediatric primary care as recommended by the AAP may be impeded by two domains of barriers: those related to the logistical and procedural aspects of ASD screening and those related to the knowledge, attitudes and perceptions of pediatric primary care providers. As such, implementations must be made to address both domains of barriers to help integrate routine ASD screening into the practice of pediatric primary care. The following discussion synthesizes the barriers and implementations present in the current literature of 23 studies, describes the resulting implications to practice and makes recommendations for future research.

Logistical and Procedural Barriers of ASD-Screening

A review of current literature reveals that there exists practice-based and system-wide logistical and procedural barriers to screening for ASD in pediatric primary care. These practice-based logistical and procedural barriers include time constraints, deciding when in the patient visit ASD screening should take place, and who should administer the screening (Bauer, Carroll, Strum & Downs, 2013; Harrington, Bai & Perkins, 2013; Crais et al., 2014; Fenikilé et al., 2015) System-wide procedural barriers include difficulty being reimbursed by insurance companies for
conducting such screening, and difficulties in the referral and diagnostic aspects of ASD identification (Carbone et al., 2013; Crais et al., 2014; Fenikilé et al., 2015).

In regards to the barriers related to referrals and diagnostic services, literature has revealed that primary care providers may run into issues obtaining early intervention or diagnostic services for their patients. In this sense, providers may feel deterred to screen for ASD if they find that they are unable to connect their patients to resources in the presence of a positive ASD screen (Carbone et al., 2013; Crais et al., 2014; Fenikilé et al., 2015). Implementations to mediate the practice-based barriers include determining the best way to administer screening tools in practice with considerations to when, where, and how the screening tools should be conducted in primary care (Bauer, Carroll, Strum & Downs, 2013).

Provider education, which is addressed later in this discussion, seems to be one way to attempt to overcome system-wide barriers such as insurance reimbursement and how to bill for such services. Although greater effort and research needs to be made on how to improve access to early intervention and diagnostic services, educating providers on how to navigate this imperfect system may give them greater confidence in screening their patients for ASD (Warren, Stone & Humberd, 2009; Swanson et al., 2014).

Logistical Barriers of ASD-Screening Tools. The following are barriers to ASD screening that relate to the logistics of the screening tools used to screen 18- and 24- month olds in primary care, as recommended by the AAP. The literature reviewed in this study primarily focused on the Modified Checklist for Autism in Toddlers (M-CHAT) and its revision, the Modified Checklist for Autism in Toddlers Revised (M-CHAT/R), as the M-CHAT is the most widely used screener for ASD in primary care (Arunyanart et al., 2012). Therefore, the following barriers are specific to the M-CHAT.
Cultural Adaptability of ASD Screening Tools. Kimple, Bartelt, Wysochi and Steiner (2014) revealed the barriers associated with translating the M-CHAT into Spanish. They found that versions of the M-CHAT translated into Spanish were seen to have higher rates of positive screens compared to English versions of the M-CHAT. This puts into question the effects that translating the M-CHAT has on its validity and predictive power, as well as the cultural adaptability of such ASD-specific screeners (Kimple, Bartelt, Wysochi & Steiner, 2014).

Windham and colleagues (2014) also sought to examine the cultural adaptability of the M-CHAT. They found that particular items on the M-CHAT were likely to elicit different responses associated with ethnicity. Some of this variation was alleviated through the completion of follow-up, though the variation still remained (Windham et al., 2014). These studies reveal that further research regarding the cultural adaptability of ASD specific screening tools is essential to effective routine ASD screening for all children.

Two-Step Screening Tools. The M-CHAT is one of the most commonly used tools for screening for ASD in primary care (Arunyanart et al., 2012). Various studies have explored the appropriateness of utilizing the M-CHAT to screen large populations of children who are “low-risk” for ASD, such as the population that would constitute children visiting their primary care provider for a well-child visit (Kleinman et al., 2008; Chlebowski, Robins, Barton & Fein, 2013). These studies suggest that the M-CHAT is an appropriate tool to use in primary care on the condition that the follow-up portion (referred to as M-CHAT/F) is completed. In the absence of the follow-up portion of the M-CHAT, the M-CHAT has been shown to lead to high incidences of false-positive screens and low predictive power (Kleinman et al., 2008; Chlebowski, Robins, Barton & Fein, 2013).
The follow-up component of the M-CHAT has also been shown to assist in mediating some of the issues regarding the cultural appropriateness of the M-CHAT (Windham et al., 2016). Rather than only answering yes/no questions with limited context, the follow-up interview allows providers to have structured conversations with caregivers regarding their child’s behavior and any concerns that they might have. Although the M-CHAT becomes a useful tool for screening for ASD when administered with follow-up, the completion of follow-up creates another barrier to the completion of ASD screening in primary care. Time constraints have been cited as a major barrier to screening for ASD in primary care and completing two stage screening tools may become difficult given the already limited amount of time that primary care providers have with their patients (Crais et al., 2014; Fenikilé et al., 2015). If time constraints are preventing providers from administering the first step of the M-CHAT (the parent questionnaire), then it becomes unlikely that the provider will be able to find time to complete the follow-up interview of the screener. Such circumstances were revealed by Swanson and colleagues (2014) in which the participating providers were actively administering the M-CHAT, but none of them completed follow-up for positive screens.

*Traditional Delivery of M-CHAT.* The M-CHAT was originally designed to be administered in a paper format. Such an administration introduces additional barriers to administering ASD screeners in pediatric primary care. The first of these barriers is integrating paper screening tools into the technologically advancing field of pediatric primary care. Various studies have revealed that providers find it difficult to add paper screening tools to their patient’s electronic medical records (EMR) (Crais et al. 2014; Fenikilé, Ellerbeck, Filippi & Daley, 2015). This may result in difficulty storing screening results and maintaining an up-to-date patient record of ASD screening information.
The second barrier arises from the scoring of ASD screening tools delivered in a paper format. Literature has revealed that providers may have difficulty scoring the M-CHAT, which can result in inappropriate screening scores, both false-positives and negatives (Chlebowski et al. 2013). This potential for human-error in scoring screening tools presents a barrier that impedes upon the effectiveness of ASD screening in pediatric primary care.

A final barrier that arises from the paper delivery of the M-CHAT is the additional steps required of providers to obtain the M-CHAT follow-up information and determine which portions of the M-CHAT follow-up to administer (Harrington, Bai & Perkins, 2013; Bauer, Carroll, Sturm & Downs, 2013; Sturner et. al, 2016). Implementations to address these barriers should help to integrate the M-CHAT into electronic medical records, remove human-error in scoring, and assist providers in more efficiently administer the follow-up portions of the M-CHAT and M-CHAT follow-up.

**Recommendations for Implementations to Mediate Procedural and Logistical Barriers**

The following recommendations arise in the literature as potential implementations to mediate the logistical and procedural barriers associated with screening for ASD in pediatric primary care. These implementations aim to efficiently integrate formal ASD screening tools into the practice of primary care.

**Electronic Delivery of ASD Screening Tools.** Various studies have demonstrated that the electronic delivery of ASD screening tools may assist in streamlining the process of ASD screening in pediatric primary care and have noted the enhanced utility method (Harrington, Bai & Perkins, 2013; Sturner et al., 2016; Brooks et al., 2016). The delivery of the M-CHAT and its revised edition, M-CHAT/R, through electronic means has been shown to be a useful improvement to screening for ASD in primary care without affecting the validity of the screening
tools themselves (Brooks et al., 2016). The barrier of human error in scoring screening tools is eliminated through the use of electronic systems that have the capability to automatically score the screeners. In addition to the scoring capabilities of electronic based screening tools, these systems are able to automatically administer the appropriate follow-up portion of the M-CHAT immediately following a positive screen. This mediates time constraints and logistical barriers facing providers and helps to facilitate more consistent completion of the M-CHAT follow-up (Harrington, Bai & Perkins, 2013).

The electronic delivery of screening tools may help to better integrate the process of ASD screening into the practice’s electronic medical records system, contributing to more up-to-date record keeping (Bauer, Carroll, Sturm & Downs, 2013). Lastly, the electronic delivery of ASD screening tools may address the procedural barrier of deciding when and where to administer the screens during the well-child visit. The literature reveals the possibility of delivering ASD screening tools on an iPad or another electronic device in the practice’s waiting room, and the potential time benefits to having caregivers complete an electronic web-based version of the screening tool prior to arriving at the practice for their child’s well-visit appointment (Harrington, Bai & Perkins, 2013; Sturner et al., 2016; Brooks et al., 2016). Such electronic delivery methods of popular ASD screening tools may provide primary care clinics with various options on how, when, and where to screen for ASD that can be selected based on the practice’s particular logistical needs (integration with EMR, follow-up administration, time, etc.) and the needs of the families they serve (considerations regarding computer access at home, etc.).

**Automating the Screening Process.** The Child Health Improvement through Automation (CHICA) system described in three of the studies included in this literature review depict the possibility to automate ASD screening in pediatric primary care (Anand, Carroll &
In a sense, the automation of the ASD screening process modeled through the CHICA with an integrated ASD module address many of the logistical and procedural barrier impeding the ASD screening process in pediatric primary care. In addressing concerns regarding when and where to screen children for ASD during well-child visits, the CHICA system uses a strategic model in which pre-screening questions are automatically printed upon the child’s arrival to the clinic, and if appropriate, the M-CHAT is then automatically printed to be completed in the waiting room.

Although the screens are administered in a paper format, they are designed to easily be scanned into the CHICA system and uploaded into the patient’s electronic medical record (Bauer, Carroll, Sturm & Downs, 2013). The screens are automatically scored and the results are interpreted for the provider, preventing human error found in scoring. If necessary, the CHICA system prints appropriate follow-up components for the child’s caregiver to complete, which reduces the burden of the provider to have to identify which follow-up portions to administer. The system mediates some time constraints associated with ASD screening through streamlining the scoring and follow-up procedures (Bauer, Carroll, Sturm & Downs, 2013).

The CHICA system also supports primary care providers through alerts reminding to ensure that ASD screening occurred, and assisting them in discussing the results of the screening with the child’s caregiver through the creation of tailored educational worksheets (Bauer, Carroll, Sturm & Downs, 2013). In the case of a positive screen, the system directs the provider through the steps that should follow. Systematic procedural barriers to screening such as access to referral and diagnostic services is mediated as the system alerts the provider of appropriate community and diagnostic resources and how to refer to them. The CHICA system also helps providers through the billing process to ensure proper reimbursement for ASD screening (Bauer, Carroll, Sturm & Downs, 2013).
Carroll, Sturm & Downs, 2013). Such a system that mediates the logistical and procedural barriers to ASD screening should support screening in primary care, and this was demonstrated through the significant increase in screening practices noted in the providers at practices using the CHICA system with the ASD module. This increase in screening practices is promising, but a troubling occurrence and finding indicates barriers beyond the logistics and procedural components of the ASD screening process that prevent compliance to the AAP’s recommended screening guidelines (Bauer, Carroll, Sturm & Downs, 2013).

Upon initial implementation of the ASD module in the practices using the CHICA system, the clinic’s providers decided to not administer the M-CHAT to their patients at the 18-month well-visit because they were already screening with a general developmental screening during this visit (Bauer, Carroll, Sturm & Downs, 2013). Although the providers were aware of the AAP’s recommendation that both a general developmental screener and an ASD-specific screener should be administered at the 18-month well-child visit, they felt that administering both screeners would overwhelm the child’s caregiver with paperwork (Bauer, Carroll, Sturm & Downs, 2013). This can be potentially viewed as logistical barrier to the AAP’s guidelines (administering two tools in one visit may burden caregivers), placed in the context of the other studies reviewed in this literature, the providers’ decision to not administer the ASD screening at the 18-month visit may be indicative of primary providers’ attitudes and perceptions of screening for ASD in primary care. In this particular instance, the providers remained non-compliant with the AAP guidelines in favor of having the child’s caregiver complete less paperwork.

Bauer, Carroll, Saha and Downs (2015) found that although the CHICA system with the integrated ASD module contributed to higher rates of ASD screening, the system had no role in increasing provider knowledge regarding to ASD nor did it cause them to think critically about
their role in ASD management. This begs to question the sustainability of only implementing interventions that address logistical and procedural barriers related to ASD to the ASD screening process. If providers don't find ASD screening as recommended by the AAP to be appropriate, will their screening practices sustain when they are faced with logistical barriers to screening for ASD? This question presents another set of barriers preventing ASD screening in primary care; those resulting from provider attitudes, education and perceptions related to ASD screening and management.

**Provider-Based Barriers to ASD Screening in Primary Care**

Various studies presented in this literature review sought to understand screening for ASD from a primary care provider’s point of view. Surveys, interviews and focus groups have revealed the following barriers perceived by providers as inhibitory to screening for ASD in their practice.

**Perceived Logistical Barriers.** Providers cite various logistical barriers to screening for ASD in their practice including time constraints, integrating screening tools into practice, and other barriers described in relation to the logistics of screening for ASD (Crais et al., 2014; Fenikilé et al, 2015). These various barriers have been addressed through some of the implementations to improve the delivery of ASD screening tools and integrate them more seamlessly into existing practice entities (electronic medical records, etc.).

It is important to consider that practices vary drastically from one another, especially considering the diverse settings in which pediatric primary care is delivered (private/public practices, rural/urban practices, pediatrician offices, family medicine settings, etc.) (Crais et al., 2014). As such, the challenge of improving logistical barriers to screening for ASD in primary
care must be considered in the context of a provider’s specific practice and the needs of their patients.

**Perceived System-Wide Procedural Barriers** Difficulty identifying and connecting children with appropriate and effective early intervention, diagnostic and community resources following a positive screen was commonly stated by providers as a barrier to screening for ASD (Carbone et al., 2013; Crais et al., 2014; Fenikilé et al, 2015). Uncertainty in navigating complex and overpopulated early intervention services led some providers to avoid screening for ASD as they felt that even if they were able to identify children that may be at risk for ASD, they wouldn’t be able to help them gain access to supportive measures. Such an occurrence indicates a need for an evaluation of specialty and intervention services for children with ASD and the process that must occur for primary care providers to help their patients obtain such services.

**Provider Education and Efficacy**

Literature has revealed that pediatric primary care providers may not receive the education regarding child development that they desire (Golnik, Ireland & Borowsky, 2009; Carbone et al., 2013; Will, Barnfather & Lesley, 2013; Self, Parham, Rajagopalan, 2015). The field of pediatric primary care encompasses an array of specialties including pediatricians, family medicine providers, nurse practitioners, physician assistants and others. As such, the educational and formal training backgrounds of pediatric primary care providers is extremely diverse. With this expressed desire for more extensive education regarding ASD and the screening and management of this disorder, it is not surprising that providers often report low self-efficacy in their ability to properly support their patients with ASD concerns. The self-efficacy of providers to provide ASD services to culturally diverse populations is reported to be even lower (Zuckerman et al., 2013). The fact that caregivers of children with ASD appear to share this
notion of low provider efficacy in addressing the needs of their children with ASD presents a particularly troublesome issue to pediatric primary care which must be addressed to ensure comprehensive and inclusive pediatric primary care (Carbone et al., 2013). Provider education also seems to play a role in shaping provider attitudes towards ASD screening in pediatric primary care.

**Provider Cultural Competency and ASD Screening**

Zuckerman and colleagues (2013) gained insight into pediatric primary care providers’ perspectives regarding screening Latino children for ASD. Providers reported lower self-efficacy in supporting Latino children with ASD compared to their White, non-Latino peers. The providers also reported that they perceived Latino caregivers as less knowledgeable and competent in regards to ASD. This finding is in itself troubling, but becomes even more concerning when considering the cultural barriers of ASD screening.

In 2014, Zuckerman and colleagues utilized interviews with Latino caregivers to discover the stigmatization and lack of knowledge of developmental disabilities within the Latino community. The presence of such stigmatization may inhibit caregivers from recognizing ASD indicative behavior in their child, and if they do, may prevent them from reporting their concerns to their child’s primary care providers.

This lack of provider efficacy compounded with cultural barriers to screening Latino children for ASD may prevent Latino children from obtaining the best preventative care possible. Educational interventions for providers and community outreach and advocacy regarding ASD should be explored as possible implementations to mediate these cultural barriers to ASD screening.
Provider Attitudes

Provider education also seems to influence provider attitudes towards ASD screening and management in their practice. Provider attitudes concerning the necessity of universal screening for ASD vary dramatically (Crais et al., 2014; Fenikilé et al, 2015). Some providers found universal screening to be an appropriate method to identifying children with ASD while others stated that they would rather wait until the parent addresses developmental concerns to administer such screening. Providers also stated varying views regarding the use of ASD-specific screening tools, with some providers stating that they would rather use general developmental screening tools (Crais et al., 2014; Fenikilé et al, 2015). There also appears to be a notion amongst providers that they are not the main professionals to be providing services to children with ASD. Instead they see themselves as more of advocates to connect children with ASD with diagnostic and community resources. This attitude regarding their perceived role may make providers question their role in using screening tools to identify children with ASD (Crais et al., 2014; Fenikilé et al, 2015).

Educational Interventions

Literature reveals that providers often have low efficacy in their abilities to support children with ASD and families (Golnik, Ireland & Borowsky, 2009; Carbone et al., 2013; Will, Barnfather & Lesley, 2013; Self, Parham, Rajagopalan, 2015). A theme consisted throughout various studies indicates that providers see their role in supporting their patients with ASD as more of an advocacy position in which they are responsible for connecting their patients to specialists who can better meet their specific needs. As such, it becomes noteworthy to consider the fact that providers often exhibit difficulty in referring patients to specialists as well as explaining what they might expect to when they have access to such services. Therefore,
educational interventions that focus on promoting provider education have potential to increase screening efforts amongst primary care providers. The various educational interventions reviewed in this literature tend to holistically educate providers on ASD (Warren, Stone & Humberd, 2009; Honigfeld, Chandhok, & Spiegelman, 2012; Swanson et al, 2014; Carbone, Norlin, & Young, 2016; Mazurek, Brown, Curran, & Sohl, 2016).

Such programs equip providers with diagnostic skills for ASD beyond training on ASD screening. Even if the provider decides to not diagnose for ASD in their practice, this knowledge may help them to be able to better explain the process to the child's family as well as potentially mediate the perceived procedural barriers to ASD screening as expressed by primary care providers. The premise of these educational programs is that increased provider knowledge will result in greater provider self-efficacy and subsequently change provider attitudes regarding screening for ASD in primary care (Warren, Stone & Humberd, 2009; Honigfeld, Chandhok, & Spiegelman, 2012; Swanson et al, 2014; Carbone, Norlin, & Young, 2016; Mazurek, Brown, Curran, & Sohl, 2016).

**Implications to Practice**

This study reveals that screening for ASD in pediatric primary care as recommended by the American Academy of Pediatrics is feasible, but only if implementations are utilized to address both the logistical/procedural barriers as well as the provider-based barriers related to screening for ASD. Although logistical and procedural implementations have been shown to be useful in improving ASD screening practices, these changes are the most sustainable way to improve the management of ASD in pediatric primary care. The logistics of primary care practices are consistently changing and vary from practice to practice. As technology advances and primary care evolves, something that may currently act as a mechanism to improve
screening for ASD in primary care may eventually become a barrier to screening. Procedural barriers to ASD screening, such as access to diagnostic and early intervention services, must be addressed, but they too are very dynamic and may very well change in the future.

Therefore, the sustained method for improved screening for ASD in pediatric primary care comes through education of pediatric primary care providers. Provider knowledge and attitudes towards their role in ASD screening and management must empower primary care providers to seek active roles in the identification and support of children with ASD. A sense of responsibility to screen children for ASD born out of the knowledge that the early identification results in better outcomes for children with ASD is of the utmost importance. This study adds to the field of ASD management through the identification of two intertwined themes of barriers inhibiting ASD screening in pediatric primary care. Recommending agencies such as the American Academy of Pediatrics should seek to understand such barriers to better predict how their guidelines may be implemented into practice.

**Necessity of provider education on ASD screening and management.** As this study reveals, pediatric primary care providers have noted deficits in knowledge regarding how to appropriately identify children “at-risk” for ASD and supporting children who have already been diagnosed as ASD. As such, the training of pediatric primary care providers should be analyzed and structured to include more explicit training regarding typical and atypical childhood development. As previously mentioned, the field may benefit immensely from this structured education as ASD competent provider will be equipped with the tools and knowledge to overcome the logistical and procedural barriers to screening for ASD in pediatric primary care.

**Access to diagnostic and early intervention services.** The literature presents that providers have often experienced difficulties in accessing diagnostic and early intervention
services for their patients with ASD. This may be due to both system-wide barriers preventing access to such resources and barriers related to provider awareness and knowledge regarding such services. The field of pediatric primary care may benefit from more concrete methods through which partnerships between primary care practices and community and statewide intervention services may be established.

**Future Research**

The field of ASD screening and management in pediatric primary care may benefit from future research aimed towards the medical school curricula and training of pediatric primary care providers and the cultural appropriateness of existing ASD screening tools.

**Medical School Curricula** Considering the barrier that provider education creates in the process of screening children for ASD in pediatric primary care, it becomes apparent to recognize and understand the reasons and origins of such deficits in ASD knowledge. Future research should seek to understand the formal education received by prospective pediatric primary care providers and the emphasis it places on cultivating healthy childhood development and the identification of atypical development. In a field of diverse provider specialties, research regarding particularly residency training programs and their identified competencies may act as a beneficial contribution to the field of pediatric primary care.

**Cultural Discrepancies in ASD Identification** Although various studies in this review identified challenges related to the cultural adaptability of the ASD screening process and formal ASD screening tools, there was a deficit of studies that offered possible solutions to ensure culturally appropriate screening. Future studies addressing the general cultural competency of pediatric primary care providers and particularly how this affects the ASD screening process is essential. In addition to these provider-based barriers related to screening for ASD, the cultural
adaptability of the tools used to screen for ASD in pediatric primary care requires further research.

Future research should also seek to understand an array of cultural barriers to ASD screening. The studies present in this literature review only reveal barriers to screening Hispanic and Latino children for ASD. The field will benefit from knowledge regarding how various cultures view ASD and the ways in which providers may be able to empathetically work with families with views that may inhibit the ASD screening process.

Limitations

There are various limitations related this review that should be considered when assessing the information presented in it. First, the studies in this review were limited to those published after 2007. Studies produced prior to 2007 may help to inform the field through historical means and may help to see how historical context may influence ASD management and primary care practice. Another barrier present in this review arises from its exploratory nature. In an effort to understand the various barriers preventing the integration of ASD screening into pediatric primary care as recommended by the AAP, this utilized a limited number of studies to uncover themes related to the particular issue at hand. As such, future research may benefit from extensive research into one specific topic related to ASD identification and management in pediatric primary care. For example, a review of literature explicitly studying the use of electronic delivery of screening tools may provide greater detail and information related to the topic of electronic delivery than this review was able to.

Conclusion

Non-compliance to the American Academy of Pediatrics’ guidelines on Autism Spectrum Disorder (ASD) screening in pediatric primary care may be explained by two themes of barriers.
Logistical and procedural aspects of ASD screening in primary care such as time constraints and screening tool distribution prevent the integration of ASD screening in busy primary care practices. Provider-based barriers to ASD screening include provider knowledge, efficacy, and attitudes. As such, implementations to logistical/procedural barrier such as automation of the ASD screening process as well as educational interventions to contribute to providers’ ASD knowledge must be concurrently employed to contribute to feasible adherence to the AAP’s ASD screening recommendations.
References


Appendix A: The M-CHAT

Instructions and Permissions for Use of the M-CHAT

The Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999) is available for free download for clinical, research, and educational purposes. There are two authorized websites: the M-CHAT and supplemental materials can be downloaded from www.firstsigns.org or from Dr. Robins’ website, at http://www.mchatscreen.com

Users should be aware that the M-CHAT continues to be studied, and may be revised in the future. Any revisions will be posted to the two websites noted above.

Furthermore, the M-CHAT is a copyrighted instrument, and use of the M-CHAT must follow these guidelines:

1. Reprints/reproductions of the M-CHAT must include the copyright at the bottom (© 1999 Robins, Fein, & Barton). No modifications can be made to items, instructions, or item order without permission from the authors.

2. The M-CHAT must be used in its entirety. There is no evidence that using a subset of items will be valid.

3. Parties interested in reproducing the M-CHAT in print (e.g., a book or journal article) or electronically for use by others (e.g., as part of digital medical record or other software packages) must contact Diana Robins to request permission (mchatscreen2009@gmail.com).

4. If you are part of a medical practice, and you want to incorporate the M-CHAT into your own practice’s electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact Diana Robins to request permission.

Instructions for Use

The M-CHAT is validated for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). The M-CHAT can be administered and scored as part of a well-child check-up, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT was to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk for ASD will be diagnosed with ASD. To address this, we have developed a structured follow-up interview for use in conjunction with the M-CHAT; it is available at the two websites listed above. Users should be aware that even with the follow-up questions, a significant number of the children who fail the M-CHAT will not be diagnosed with an ASD; however, these children are at risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who fails the screening.

The M-CHAT can be scored in less than two minutes. Scoring instructions can be downloaded from http://www.mchatscreen.com or www.firstsigns.org. We also have developed a scoring template, which is available on these websites; when printed on an overhead transparency and laid over the completed M-CHAT, it facilitates scoring. Please note that minor differences in printers may cause your scoring template not to line up exactly with the printed M-CHAT.

Children who fail 3 or more items total or 2 or more critical items (particularly if these scores remain elevated after the M-CHAT Follow-up Interview) should be referred for diagnostic evaluation by a specialist trained to evaluate ASD in very young children. In addition, children for whom there are physician, parent, or other professional’s concerns about ASD should be referred for evaluation, given that it is unlikely for any screening instrument to have 100% sensitivity.

M-CHAT

Please fill out the following about your child’s usual behavior, and try to answer every question. If the behavior is rare (you’ve only seen it once or twice), please answer as if your child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?  
   - Yes  
   - No

2. Does your child take an interest in other children?  
   - Yes  
   - No

3. Does your child like climbing on things, such as up stairs?  
   - Yes  
   - No

4. Does your child enjoy playing peek-a-boo/hide-and-seek?  
   - Yes  
   - No

5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?  
   - Yes  
   - No

6. Does your child ever use his/her index finger to point, to ask for something?  
   - Yes  
   - No

7. Does your child ever use his/her index finger to point, to indicate interest in something?  
   - Yes  
   - No

8. Can your child play properly with small toys (e.g., cars or blocks) without just mouthing, fiddling, or dropping them?  
   - Yes  
   - No

9. Does your child ever bring objects over to you (parent) to show you something?  
   - Yes  
   - No

10. Does your child look you in the eye for more than a second or two?  
    - Yes  
    - No

11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)  
    - Yes  
    - No

12. Does your child smile in response to your face or your smile?  
    - Yes  
    - No

13. Does your child imitate you? (e.g., you make a face-will your child imitate it?)  
    - Yes  
    - No

14. Does your child respond to his/her name when you call?  
    - Yes  
    - No

15. If you point at a toy across the room, does your child look at it?  
    - Yes  
    - No

16. Does your child walk?  
    - Yes  
    - No

17. Does your child look at things you are looking at?  
    - Yes  
    - No

18. Does your child make unusual finger movements near his/her face?  
    - Yes  
    - No

19. Does your child try to attract your attention to his/her own activity?  
    - Yes  
    - No

20. Have you ever wondered if your child is deaf?  
    - Yes  
    - No

21. Does your child understand what people say?  
    - Yes  
    - No

22. Does your child sometimes stare at nothing or wander with no purpose?  
    - Yes  
    - No

23. Does your child look at your face to check your reaction when faced with something unfamiliar?  
    - Yes  
    - No

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Appendix B: M-CHAT Scoring

M-CHAT

Please score the interview items on this page. Critical items are marked in BOLD and reverse score items, meaning those for which a score of “Yes” indicates risk for autism (11, 18, 20, 22) are noted by the word REVERSE.

1. Does your child enjoy being swung, bounced on your knee, etc.? Yes No
2. Does your child take an interest in other children? Yes No
3. Does your child like climbing on things, such as up stairs? Yes No
4. Does your child enjoy playing peek-a-boo/hide-and-seek? Yes No
5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things? Yes No
6. Does your child ever use his/her index finger to point, to ask for something? Yes No
7. Does your child ever use his/her index finger to point, to indicate interest in something? Yes No
8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them? Yes No
9. Does your child ever bring objects over to you (parent) to show you something? Yes No
10. Does your child look you in the eye for more than a second or two? Yes No
11. Does your child ever seem oversensitive to noise? (e.g., plugging ears) (REVERSE) Yes No
12. Does your child smile in response to your face or your smile? Yes No
13. Does your child imitate you? (e.g., you make a face—will your child imitate it?) Yes No
14. Does your child respond to his/her name when you call? Yes No
15. If you point at a toy across the room, does your child look at it? Yes No
16. Does your child walk? Yes No
17. Does your child look at things you are looking at? Yes No
18. Does your child make unusual finger movements near his/her face? (REVERSE) Yes No
19. Does your child try to attract your attention to his/her own activity? Yes No
20. Have you ever wondered if your child is deaf? (REVERSE) Yes No
21. Does your child understand what people say? Yes No
22. Does your child sometimes stare at nothing or wander with no purpose? (REVERSE) Yes No
23. Does your child look at your face to check your reaction when faced with something unfamiliar? Yes No

Critical Score: 
Total Score: 

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Appendix C: Example of M-CHAT Follow-Up Interview

10. You reported that __________ does not look you in the eye for more than a second or two?

- No — Is this still true?
  - Yes — Then your child does look you in the eyes for more than a second or two?
    - Yes — Does s/he look you in the eyes when s/he needs something? ___
      - Yes only to one
        - Does your child look you in the eyes every day? ___
          - Yes — PASS
          - No — FAIL
    - No — Yes to two or more
      - On a day when you are together all day, does he/she look you in the eyes at least 5 times?
        - Yes — PASS
        - No — FAIL
  - No — No to all

Appendix D: The M-CHAT-R

Permissions for Use of the M-CHAT-R/F™


The M-CHAT-R/F is a copyrighted instrument, and use of the M-CHAT-R/F must follow these guidelines:

1. Reprints/reproductions of the M-CHAT-R must include the copyright at the bottom (© 2009 Robins, Fein, & Barton). No modifications can be made to items, instructions, or item order without permission from the authors.
2. The M-CHAT-R must be used in its entirety. Evidence indicates that any subsets of items do not demonstrate adequate psychometric properties.
3. Parties interested in reproducing the M-CHAT-R/F in print (e.g., a book or journal article) or electronically for use by others (e.g., as part of digital medical record or other software packages) must contact Diana Robins to request permission (mchatscreen2009@gmail.com).
4. If you are part of a medical practice, and you want to incorporate the first stage M-CHAT-R questions into your own practice’s electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact Diana Robins to request a licensing agreement.

Instructions for Use

The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from http://www.mchatscreen.com. Associated documents will be available for download as well.

Scoring Algorithm

For all items except 2, 5, and 12, the response “NO” indicates ASD risk; for items 2, 5, and 12, “YES” indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

**LOW-RISK:** Total Score is 0-2; if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.

**MEDIUM-RISK:** Total Score is 3-7; Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.

**HIGH-RISK:** Total Score is 8-20; It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer no. Please circle yes or no for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)

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<th>Yes</th>
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2. Have you ever wondered if your child might be deaf?

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3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)

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4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)

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5. Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)

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<th>No</th>
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6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)

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7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)

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8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)

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9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)

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<th>Yes</th>
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10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)

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</table>

11. When you smile at your child, does he or she smile back at you?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

13. Does your child walk?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

16. If you turn your head to look at something, does your child look around to see what you are looking at?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say “look” or “watch me”?)

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”?)

<table>
<thead>
<tr>
<th>Yes</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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### Appendix E: M-CHAT-R Scoring

**M-CHAT-R Follow-Up™ Scoring Sheet**

Please note: Yes/No has been replaced with Pass/Fail

<table>
<thead>
<tr>
<th>Question</th>
<th>Pass</th>
<th>Fail</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Have you ever wondered if your child might be deaf?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Does your child show things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)</td>
<td></td>
<td></td>
</tr>
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Total Score: ________

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Appendix F: Example of M-CHAT-R Follow-Up Interview

14. Does _______ look you in the eye when you are talking to him/her, playing with him/her, or changing him/her?

**Yes**

Please give me an example of when he/she looks you in the eye. (If parent does not give a PASS example below, ask each individually.)

**Yes**

**No**

**PASS**

**Does he/she look you in the eye...**

- When he/she needs something?
- When you are playing with him/her?
- During feeding?
- During diaper changes?
- When you are reading him/her a story?
- When you are talking to him/her?

**Yes**

**No**

**PASS**

**Yes only to one**

**No to all**

Does your child look you in the eye every day?

**Yes**

**No**

FAIL

On a day when you are together all day, does he/she look you in the eye at least 5 times?

**Yes**

**No**

FAIL

PASS

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