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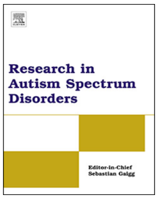

Decision factors for community providers when referring very young children for autism evaluation

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ABSTRACT

Background: Early intervention in autism spectrum disorder (ASD) improves outcomes, but treatment access depends on early identification. Despite reliability of most autism diagnoses by age 24 months, the majority of children with autism do not receive comprehensive evaluations until after age 36 months. Although many possible reasons exist for delayed evaluations, the referral decision process itself is not clearly defined nor understood. In particular, little is known about how perceptions of early childhood symptoms of ASD interact with decision criteria to ultimately refer a child for comprehensive diagnostic assessment.
Method: To better understand pre-referral perceptions and decision factors involved, we provided multiple video clips from early comprehensive autism evaluations as prompts, then asked early childhood clinicians and educators (n = 346) to make decisions about autism referral, then to identify factors considered when making decisions.
Results: Decision factors cited most often were play, social interactions/engagement, and verbal behaviors, but none were cited by a clear majority. Some important early signs were infrequently mentioned: absence of joint attention, social reciprocity and gestures. Accuracy of referral decisions was similar across disciplines, indicating a broad range of professionals capable of identifying early signs of autism.
Conclusions: Autism training across early childhood professional disciplines should emphasize importance of early signs involving significant absences of behaviors, such as low joint attention, gestures, and social reciprocity in addition to odd social, verbal, and play behaviors. Such targeted training may encourage earlier referrals when autism is suspected in young children.

1. Introduction

Researchers agree that early identification of autism spectrum disorder (ASD) and subsequent treatment can ultimately lead to better outcomes and quality of life (Granpeesheh, Tarbox, & Dixon, 2009; Johnson, Myers, & Council on Children with Disabilities, 2007; Vismara & Rogers, 2010; Warren et al., 2011; Zwaigenbaum, Bauman, Choueiri, Fein, & Karr, 2015; Zwaigenbaum, Bryson, & Garon, 2013). Although awareness of early signs of autism may be increasing along with the prevalence of ASD (e.g., 85% of children with ASD had developmental concerns noted in their educational and/or health records prior to age 3), currently as few as 42% of children with autism at age 8 received their first comprehensive evaluation before their third birthdays, with median age of diagnosis at 40–53 months (Baio, 2014; Baio et al., 2018; Christensen et al., 2016). To facilitate timely linkage to targeted interventions and

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supports, the US Interagency Autism Coordinating Committee has declared two major objectives: (a) reducing disparities in early access to detection and services and (b) improving models for detecting ASD (IACC, 2017).

Reasons for the late median age of diagnosis are not well researched. Beyond parent and family factors (e.g., socioeconomic status, cultural and language diversity), community resources and policies may play a role (Baio et al., 2018; Daniels & Mandell, 2014). In order to identify and remove barriers to earlier diagnosis, we first need to understand what happens when a child comes into contact with an early childhood health or education provider (e.g., early intervention or community health care) who may have a gatekeeping role. More specifically, what factors are considered as professionals decide whether or not to refer a child for a comprehensive autism evaluation?

Given that delays and differences (including speech and language delays) are typically noticed by parents within their child's first two years of life (Chawarska et al., 2007), early childhood clinicians and educators are likely to be the parents' first point of contact. Another pathway to early identification may be through universal screening for autism in healthcare and other settings. However, this type of screening is not consistently implemented and has generated some controversy (Al-Qabandi, Gorter, & Rosenbaum, 2011; Dawson, 2016; Mandell & Mandy, 2015; Siu & USPSTF, 2016). Both of these pathways lead to a point of decision (by the clinician or educator) about making a referral for comprehensive evaluation, then a parental decision to pursue or not pursue additional assessment. All of these decisions affect the timing of formal diagnosis. One study of parent-reported barriers to early identification indicated a need for better provider education along with more timely connection of families to ASD resources. Parents also commonly reported that providers did not listen to or validate parent concerns, but rather recommended a wait-and-see approach (Elder, Brasher, & Alexander, 2016). To facilitate access to care, a call has been made for interventions to enhance parents' and health care providers' recognition of ASD characteristics (Bonis, 2016). Not enough is known, however, about how early childhood professionals across disciplines make referral decisions that set the formal identification process in motion. Although we have some information about groups of children who have been consistently identified later than other groups (Baio, 2014; Baio et al., 2018; Christensen et al., 2016; Daniels & Mandell, 2014; Mandell, Novak & Zubritsky, 2005) actual barriers to early identification as a referral decision-making process have not been extensively explored. In addition to efforts to increase capacity in autism expertise and awareness of early signs, we believe that information about decision-making processes may improve early identification for all children.

Extensive research has explored ethical decision making (Schwartz, 2016) and shared decision making (Légaré et al., 2008). Research has also focused on which factors are likely to increase utilization of clinical guidelines (Ouimet, Landry, Amara, & Belkhodja, 2006). However, there is, to date, no published research on how individuals make decisions about actions to be taken when risk for autism is identified, with risk defined as the presence of early signs of ASD indicated by positive screening results, (e.g., Modified Checklist for Autism in Toddlers, Revised with Follow Up [M-CHAT-R/F: Robins et al., 2014], Infant Toddler Checklist from the Communication and Symbolic Behavior Scales-Developmental Profile [CSBS-DP: Wetherby & Prizant, 2002]), provider or parent concern.

Early signs of autism have been well-promoted throughout the various Learn the Signs, Act Early campaigns (CDC, 2018). Although early ASD presentations are heterogeneous, early signs such as differences in language and cognitive abilities, reduced levels of social (joint) attention and communication and increased repetitive behaviors with objects have emerged in the research literature as common indicators of ASD within the first two years of life (Zwaigenbaum et al., 2015). Ideally, pediatricians and other early childhood professionals who routinely see very young children are well trained in screening and detection of signs and symptoms of autism and are familiar with developmental, educational, and community resources as well as medical subspecialty clinics (Filipek et al., 2000; Johnson et al., 2007; Nadel & Poss, 2007). There is, however, no existing research regarding how early childhood professionals weigh evidence from parent concerns, observations, and screening when making referral decisions. Because they are in prime position to observe symptoms and make decisions about initial referrals, we believe that referral decision-making processes of early childhood professionals are an important area for research.

Although parent and provider early identification actions are complicated by the heterogeneity of autism symptom presentation, the importance of decision factors and processes of early childhood clinicians and educators regarding referrals deserves greater scrutiny. A comprehensive search of the literature identified a significant gap in our understanding of what factors early childhood professionals consider when making decisions about whether to refer a child for a comprehensive autism evaluation. In order to better understand current practice in decision making about autism referrals, we asked early childhood professionals across disciplines to make judgments about autism risk based on video observations, then asked which factors they considered when deciding whether or not a child exhibited early signs of autism and needed a referral for additional assessment. Videos were of children with and without autism undergoing evaluations with targeted opportunities for observation of social communication and restricted, repetitive behaviors.

2. Methods

2.1. Setting

The study was approved by the university's Institutional Review Board as conforming to the Declaration of Helsinki, 2000. Participants (professionals described below) gave informed consent and voluntarily submitted their discipline and decision information to researchers. Written, informed consent was also received from parents of children in videos used in the study (children also described below). Data were collected from urban, suburban, and rural areas in the western United States over the course of seven, day-long professional development workshops repeated in six regional locales (the largest urban/suburban locale held two workshops). Sponsorship of the workshop was shared by several groups, including a large autism parent advocacy organization, the

Table 1
Participants by profession or discipline.

Professions	*N* (%)
Health care professionals	82 (23.7)
Early intervention professionals	75 (21.7)
Education professionals	73 (21.1)
Speech, language and hearing professionals	63 (18.2)
Family service professionals	35 (10.1)
Mental-health professionals	18 (5.2)
Total	346 (100)

See Table A1 for details on self-reported professions and assignment to the above groups.

regional Leadership Education in Neurodevelopment Disabilities (LEND) program, a large private health care network, the state-funded developmental assessment center, state early intervention agency, state office of education, local chapters of Help Me Grow, and four major public and private universities. Recruitment for workshop participation was through each of these sponsoring entities who notified their memberships and employees.

Continuing education credits were offered across multiple disciplines (i.e., Continuing Medical Education (CME), Continuing Nursing Education, American Speech-Language and Hearing Association (ASHA), Psychology Continuing Education, and Professional Development hours for educators). Workshop registration was free, but nominal fees were charged for some CE credits (i.e., CME, ASHA). The workshop topics were focused on early identification, referral, and intervention strategies for very young children with autism.

2.2. Participants

Participants were drawn from the pool of over 500 workshop attendees. Information was gathered from 346 professionals who chose to participate in the study (69.2%). All participants were eligible. Our sample included pediatric health care professionals, child mental-health professionals, speech, language and hearing professionals, early intervention professionals, early childhood education professionals, and family services professionals who routinely serve children under 5 years old (see Table 1), including children with and without disabilities. Participants from each workshop location throughout the state were represented in the sample.

2.3. Procedures

Our research question was not related to the level of knowledge about early autism symptoms, so we wished to remove any bias related to prior knowledge levels. We were more precisely looking at how professionals made *decisions* about autism risk and what observations rose to the level of being “deciding” factors. To reduce potential bias due to differences in experience or education of participants, all were given approximately two hours of group instruction as a review of very early signs of autism, including video examples of typical and atypical early communication behaviors (i.e., toddlers with and without autism undergoing evaluation using the CSBS-DP; Wetherby & Prizant, 2002), including discussion about early gestures as communication strategies. Other behaviors, including restricted interests and repetitive behaviors were also noted in these video examples and discussed. This was intended to give participants a common level of background knowledge of early signs so that decision factors could be explored. Early signs related to social communication, vocalizations, play and social responding were all discussed, accompanied by video examples of very young children. Differences in rates of communication (i.e., reduced), and repertoire of communication means (i.e., reduced gestures, eye gaze, joint attention and facial expressions) in ASD compared to other delays were discussed through video examples.

Instruction also included operationalized definitions for early childhood behaviors, with typical and atypical examples given (see Table 2). Behaviors and operational definitions were derived from the Systematic Observation of Red Flags (Dow, Guthrie, Stronach, & Wetherby, 2017) the DSM-5 diagnostic criteria for autism spectrum disorder (APA, 2013) and the Autism Diagnostic Observation

Table 2
Operationalized definitions for behavioral coding by participants.

	Typical	Atypical
Social communication	Eye contact, accepting toys, playing games, following directions, directing facial expressions, sharing attention or enjoyment, requests, initiating a turn	Absence of social interaction, responses or initiations, no sharing, no requesting, odd social interactions
Play and sounds	Typical play with objects or body parts Typical prosody, or sound of vocalizations	Unusual examination or repetitive use of toys Repetitive sounds or prosody
Response to name	Responds within about 3 s (orienting or vocalizing)	Does not respond within about 3 s (no orientation, eye contact, or verbalization)

Schedule (ADOS) scoring algorithms (Lord, Rutter, DiLavore, & Risi, 1999). Examples of each behavior were described and categorized for participants with a focus on social communication, play, vocalizations, and the discrete behavior of responding to name.

Participants were then shown short video clips of children (ages 14–31 months) undergoing targeted evaluations for autism. The nature of the video clips was to show frequent naturalistic presses for social communication to give participants a focused sample of the child's abilities and deficits. Children were observed as they participated in social behavioral probes of the ADOS and in some cases, a standardized developmental evaluation, the Mullen Scales of Early Learning (Mullen, 1995). Video samples were chosen using a randomized process from within groups of children with and without autism. Children included those with early signs of ASD (screened positive for ASD or at-risk per parent or provider concern) and typically developing children (screened negative for ASD with no concerns). Children in the videos were part of a larger autism screening study that included screening with M-CHAT and Infant Toddler Checklist and comprehensive evaluations for autism. Designations of autism, language delay, or typical development diagnostic groups were made following administration of ADOS, Vineland-II (Sparrow, Balla, & Cicchetti, 2005), and Mullen by a research reliable clinician, with diagnosis confirmed at follow-up after age 3 by similar evaluation with the addition of the Autism Diagnostic Interview-Revised (LeCouteur, Lord, & Rutter, 2003; Miller et al., 2011).

One video from each group, chosen at random for each workshop date, was viewed by participants (random assignment was within each diagnostic group, not across diagnostic groups). Participants were not told which group each child was from prior to data collection, but they were told the age of the child for appropriate developmental reference. Although time constraints in some locales precluded viewing of a third video (child with language delay but not autism), 200 decisions and decision factor data regarding children with language delay were still collected.

As videos were introduced, participants were asked to focus on specific behaviors mentioned earlier in the day by making quick decisions based on their observations. The video of a typically developing child was presented first to calibrate typical behaviors observed within three behavioral categories: Social Communication, Play and Sounds, and Response to Name (see Table 2 for operationalized definitions). The second and third videos were of children with early signs of autism or language delay (but not autism). Participants were not informed of the child's diagnostic category prior to viewing any video clips or making decisions about referral. Video clips averaged 3 minutes' total running time, separated into 10-second clips. Counterbalancing of the order of video presentations was not performed specifically to allow for the calibration video of a typically developing child to be viewed first. Subsequent referral decision accuracy was therefore likely to be biased, and is reported here only for relative analysis rather than absolute interpretation.

A pencil-and-paper protocol was used by each participant to record judgments on whether a child was exhibiting behavior that was typical (T) or atypical (A) within the three broad behavioral categories (Social Communication, Play and Sounds, and Response to Name) in each 10-second video clip. These codes were not analyzed, but provided a way for participants to make decisions about the atypicality or typicality of specific behaviors in multiple small observations, then accumulate these results to form an impression. The purpose of this quick decision activity was to focus participants on specific behavioral observations rather than extraneous factors related to each video.

Participants were asked to focus on the video, then make decisions about the child's behavior (typical or atypical) after each 10-second video segment. As each child's video concluded, participants were asked (via written question), "Based on this observation alone, would you refer this child for an ASD evaluation? [Yes/No]." A follow-up question then asked, "What factors did you consider when making your referral decision?" [Open response]. A final question asked, "What factors would you like more information about when making your referral decision?" [Open response]. This last question was asked to capture decision factors that are part of a participant's internal checklist or schema for autism symptoms, even if those behaviors were not observed on the video or mentioned earlier in the day. The decision factor questions were open ended so as not to promote or exclude any particular decision factor or introduce bias as to what factors might be considered relevant. Participants were allowed to list as many factors as they wished, and they did not have to prioritize factors. Thus, it was possible to have any factor (e.g., eye contact) listed by 100% of participants.

After decisions were completed and overall referral decisions and decision factors were recorded and collected, participants were given feedback about each child's ultimate diagnosis (autism, language delay, or typical development) to facilitate discussion during the remainder of the training session, including any subsequent videos.

2.4. Measures and analysis

Open response questions (decision factors) described above were analyzed using consensual qualitative research (CQR) methods to code responses by themes (Hill et al., 2005). The authors performed the process of interpreting and establishing initial themes or categories independently within a sub-sample of the responses ($n = 30$) drawn at random from the entire sample. Categories were finalized after a further sub-sample ($n = 100$) were considered and consensus was reached. See Table A1 for final coding categories and examples of responses within categories.

Although decision factors were the main focus of the study, we also examined the accuracy of decisions regarding autism referral. Responses of either "Yes" or "No" were converted into either "Correct" or "Incorrect" codes based on the diagnostic group (i.e., "Yes" is a "Correct" response for a child in the autism group, but an "Incorrect" response for a child in the other groups). These decision results (referral decision accuracy) were then analyzed according to the participants' disciplines. These quantitative data were entered and analyzed in Microsoft Excel (2013) and IBM® SPSS® (Version 23, 2015). Percentages of decision accuracy by discipline were calculated and compared across groups using chi-square.

Two graduate and one advanced undergraduate psychology research assistants entered quantitative data. Every 5th participant form (20%) was double entered and checked for reliability. Exact agreement for quantitative data (i.e., Typical/Atypical ratings and

Yes or No referral decisions) was 100%. Consensus coding of the qualitative data was determined to be 90% reliable across two raters by exact agreement. All disagreements were then reconciled by a third rater who had also participated in the determination of themes.

3. Results

3.1. Decision factors

Participants were asked what factors they considered in their decision-making process regarding referrals for autism evaluation. Answers to both questions (i.e., “What factors did you consider…?” and “What factors would you like more information on…?”) were pooled together for analysis to avoid bias that might arise from the content of the randomly chosen video samples.

No clearly consistent factor was identified by a majority of participants. Rather, a variety of factors were reported by large subsets of the sample. Many participants reported several factors within one sentence that was teased apart by our researchers. For example, one participant stated when referring to a child, “He plays with objects correctly, watches speaker and does directions as asked.” This answer would be coded into themes of appropriate play, eye contact and social reciprocity, and tallied under each theme for purposes of determining frequency of mention. Another participant commented, “He demonstrated few to no gestures and no communicative intent. He had super limited verbalizations.” This answer would be coded as gestures, social interactions and engagement, and verbal behaviors, tallied under each theme, and reported as part of the frequency data.

After all responses were coded, we found that among the 794 opportunities to report decision factors across children, the most commonly reported decision factors were categorized as appropriate play (mentioned in 50.6% of 794 responses) and social interactions/engagement (mentioned in 45.97% of responses). For the appropriate play category, responses included examples such as “not playing with toys functionally,” “repetitive behaviors” and “odd play habits” to name a few. Social interactions/engagement included a pediatrician's response of “frequent use of appropriate social communication.” This category would also include responses similar to this school psychologist's, “He responded to questions and answered everything correctly.”

The next most prevalent decision factor found was the use and understanding of verbal behaviors (41.44% of responses). These answers would include responses similar to the SLP who wrote, “vocalizations are present, but behind.” Other participants simply reported the use of “atypical sounds,” or that the participant was “not talking.” Eye contact (35.77% of responses) was also a commonly cited factor among our participants. One mental health coordinator reported, “At 18 months, he has enough eye contact and awareness to not be referred for autism.”

Participants also cited factors of social reciprocity (21.41% of responses), which included responses such as “He responded to directions,” and “He wasn’t aware of others;” joint attention (10.20%), which included, “joint reference,” and “good use of joint attention;” and response to name (8.19%), which included, “turned toward name,” and “no response to name,” and gestures (6.6%), which included responses such as, “He made great gestures.” See Fig. 1. Table A1 indicates examples of specific responses included in each of the decision factor categories

A number of participants from our study did not report any decision factors (13.9%). These participants simply left that section of their observation sheet blank. This may be evidence that sometimes providers may not have clear reasons for referring or not referring a child for an autism evaluation, as participants had ample time to write their thoughts about autism risk (no other activity was occurring). This may also indicate a lack of confidence about decision factors, perhaps related to professional roles (e.g., administrative role vs. clinician or educator).

Regarding joint attention as a cited decision factor, references to gestures of any kind were considered and 51% of these were coded as “joint attention.” Mention of “shared attention” or any approximation of the typical three-point gaze that is considered to be joint attention in the literature (Lord et al., 2012) were also coded as “joint attention.” If a participant indicated only “pointing” (5% of all responses) but did not describe or specify the purpose of the point (e.g., “shared attention”), the consensus was to not include

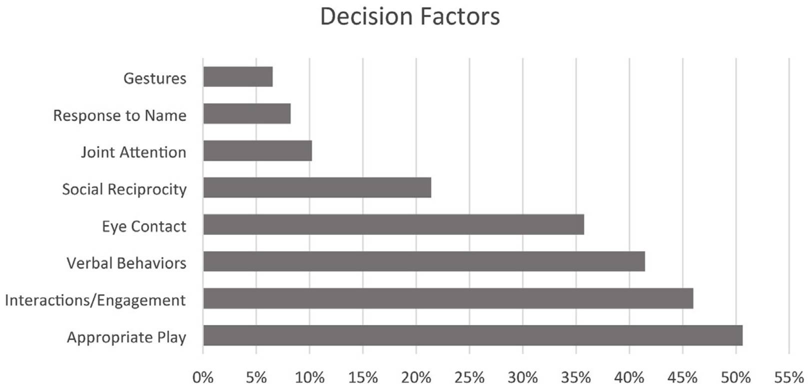

Fig. 1. Factors cited by professionals (across disciplines) as considerations when making decisions about referrals (percentages based on frequency counts, from 794 opportunities). Some participants (13.9%) gave no answer to the questions about decision factors.

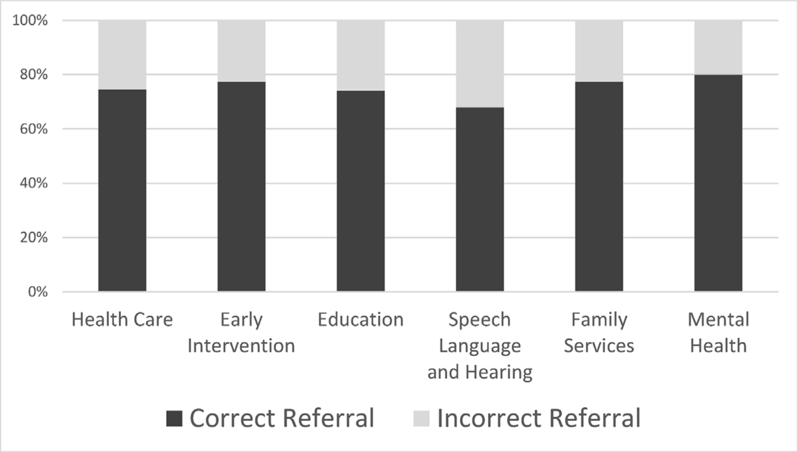

Fig. 2. Accuracy of autism group referral decisions made following brief, focused observations, by discipline, averaging 74%. Accuracy rates in the language delay group averaged 50% and in the typical development group, 87% of decisions were accurate.

these comments as “joint attention,” but as “gestures.” Another 2.8% of all comments referred to “communicative gestures,” which were not included as joint attention. These ambiguous responses were relatively infrequent, so the potential for understating joint attention as a decision factor due to semantics or word choice was relatively small. If the gestures theme is combined with joint attention to be conservative, the frequency of mention is still low at 17%.

3.2. Referral decisions

Statistics regarding referral decision accuracy are provided for relative reference only, as the setting of the workshop and prior instruction were likely to bias results in favor of referral. Referral decisions were analyzed. For example, if the referral decision was “Yes” for children in the autism group the decision was classified as accurate. If a “Yes” decision was given for children in the language delay group, or the typically developing group, the decision was classified as not accurate. For children in the autism group, referral decisions were accurate 74% of the time. See Fig. 2 for a depiction of these data. We were also interested in the relative rates of referral decision accuracy across disciplines. An analysis of all participant disciplines and referral decision accuracy showed no significant differences ($\chi^2 = 0.290$, $p > .05$, NS) across 20 self-reported discipline categories, so we further collapsed the data by grouping similar professions together. Disciplines were grouped into six categories including pediatric health care professionals, child mental-health professionals (i.e., school psychologists and child psychologists), speech-language and hearing professionals, early intervention professionals, early childhood education professionals, and family service professionals (See Table A2). A chi-square test on this collapsed grouping also showed no significant effect of discipline on accuracy of referral decisions ($\chi^2 = 0.719, p > .05$, NS). Decision factors cited by those who correctly referred children in the autism group (true positives) and those who did not (false negatives) were compared. Frequencies for all decision factors were low (2%–22% of responses), but there appeared to be slightly more attention to gestures and repetitive behaviors/appropriate play in the true positive group.

4. Discussion

Analysis of factors in making referral decisions found that participants in our sample listed a broad range of decision factors with no clear consensus on which were the most salient early signs to consider. Factors identified were generally in line with the Centers for Disease Control and Prevention public autism awareness campaign, “Learn the Signs, Act Early,” which places emphasis on several key identifiers for autism (CDC, 2018). Many professionals were focused on appropriate play (including restricted interests and repetitive behaviors) and social interactions/engagement, followed by use and understanding of verbal behaviors. Eye contact was cited about a third of the time as factors considered in referral decisions. Social reciprocity, gestures, joint attention, and response to name were seldom listed as decision factors.

Although it is not common for symptoms to be ranked in importance for any diagnostic criteria, it is interesting that participants did not arrive at any factors in common as a clear majority, suggesting that early childhood professionals may be using different decision factors as they notice early signs of autism. We were very interested to see that some early signs that are mentioned prominently in the research literature were seldom mentioned by participants as decision factors. For example, joint attention was recorded as a decision factor 10.2% of the time by participants. As with response to name, participants were allowed to list factors that they did not have the opportunity to observe, so participants could name joint attention as a decision factor regardless of whether or not they had seen opportunities for the behavior in the videos. This result was surprising, as low joint attention is frequently cited as one of the more significant early signs of ASD in toddlers (Charman, 2003; Chawarska, Klin, & Volkmar, 2003; Dawson et al., 2002; Johnson et al., 2007; Klin, Saulnier, Tsatsanis, & Volkmar, 2005; Leekam & Ramsden, 2006; Mundy, Gwaltney, & Henderson, 2010; Paparella, Goods, Freeman, & Kasari, 2011; Shumway & Wetherby, 2009; Wetherby, Watt, Morgan, & Shumway, 2007). The Infant

Brain Imaging Study (IBIS), a multisite study to help identify high-risk children (siblings of a child with ASD) in infancy has used brain imaging and developmental evaluations to identify earliest signs of ASD as it develops. The study has shown, among other findings, how brain systems underlie the important early social behavior of joint attention (Eggebrecht et al., 2017).

In practice, joint attention as an early symptom may be more difficult to notice, or *catalog* internally, as it is significant by its absence rather than as an unusual behavior that stands out as odd or socially isolating. Joint attention was mentioned in some of the earlier instructional videos prior to data collection in our study, so priming effects were expected, but not observed. The same may be said for use of gestures, which were mentioned only 6.6% of the time by participants. Although social engagement and interaction was frequently mentioned, the back-and-forth quality of social reciprocity was mentioned only 21% of the time as a decision factor. It may be that social reciprocity and social engagement seemed semantically similar, but level of engagement in joint activities is only one element of social behavior and might not reflect social reciprocity. Fine distinctions between social engagement and social reciprocity may be one area to target in future training.

With such important predictors of autism risk, more training in actively looking for typical and atypical rates of social reciprocity, joint attention and gestures are examples of early signs that can be emphasized to improve early autism identification. Another improvement may be better training in how to provide an environment and interaction to elicit spontaneous joint attention and gestures.

Although our analysis of referral decision accuracy was limited by several factors, it is interesting that the accuracy of the referral decisions in this situation was similar across disciplines. This is encouraging because it tells us that a broad range of disciplines represented in "frontline" early childhood personnel may be able to detect early signs of autism and refer for further evaluation equally, suggesting that training in screening and early identification of ASD need not be limited to any single discipline or setting.

Within this limited sample, children with autism were given "Yes" referral decisions 74% of the time, which is much higher than the actual rate of children receiving evaluations before 36 months, particularly for the region in which the study was conducted. This may be attributed to the priming within the study context (early identification workshop), or it may suggest that the parent and community factors in evaluation delays deserve exploration as well. There are no data available to determine rates of compliance with autism referrals, but wait times for obtaining a comprehensive evaluation have been reported in recent years to average 14 months in the US (Austin et al., 2016) and 3.5 years in the United Kingdom (Crane, Chester, Goddard, Henry, & Hill, 2016).

Among the referral decisions given in the study, children with language delay were sometimes identified as needing an autism referral and some typically developing children were given referral decisions as well. While these rates are likely to be biased in favor of referral within the study setting, and may not reflect actual rates of referral in practice, concern for over-referral may be a factor in decision-making. Some of the controversy surrounding universal screening has included this concern (Al-Qabandi et al., 2011; Dawson, 2016; Mandell & Mandy, 2015; Siu & USPSTF, 2016). Large screening studies have consistently shown that the about half of children referred for comprehensive evaluation following positive autism screens had another developmental delay, with the other half having ASD (Miller et al., 2011; Robins et al., 2014), which suggests a possible benefit (evaluation and diagnosis of other developmental delays) to referral even when autism is not the outcome.

4.1. Limitations

The use of video clips and the brevity of observations was not as naturalistic as the extended and repeated observations likely to occur for some early childhood professionals in the course of everyday practice. The nature of the videos (i.e., ADOS or Mullen tasks) did not allow for observation of all possible autism symptoms, so the open response question was incorporated to allow for expression of any decision factors or symptoms not observable in the videos. Variability in symptomatic presentation across children in the videos, or presentation order of the videos limits interpretation of accuracy of referral decisions, but that was not the prime focus of the study. The research question was to look into factors professionals consider when making referral decisions for comprehensive autism evaluation referral, which is not likely to have been affected by any of these limitations. While it is possible that participants may have improved in their accuracy of referral decisions with each subsequent video because of the feedback that was given, accuracy could also have been influenced by other factors, so the data were not analyzed except in aggregate, separated only by discipline.

Instruction on early signs of ASD given earlier in the day, although intended to reduce bias from varying levels of education about early signs of ASD, had the potential to appear in our results as decision factors. Analysis of decision factors was designed to include frequencies of mention for individual factors. Because only one of the behaviors from the instruction period was mentioned barely more than 50% of the time (appropriate play), with all other behaviors mentioned less frequently, we are satisfied that the instruction given earlier in the day may have informed, but did not overwhelm our decision factor results.

We acknowledge that simply looking at decision factors based on observation alone may not fully capture the complex process of deciding to talk to a family about autism risk. In the context of everyday contact with very young children, priming for autism symptoms (such as was done in the workshop) is missing in general practice, and the majority of typical behaviors observed in focused observations may overwhelm or have the effect of minimizing atypical behaviors that occur infrequently (Gabrielsen et al., 2015).

A very important element of judging autism risk is parent report of symptoms or worries, which was not included in the video samples. Children were not observed in the presence of any same-age peers to gather more information about social interactions, which is also true in most clinical settings. Educational settings, however, often provide the luxury of observing young children with peers. Because the question about decision factors considered was open ended, and included factors that were not observed, it was possible for participants to list additional factors (some wanted to know more about standardized testing results, and 14% wished to know more about screening results, for example), but parent report and peer interactions were not explicitly listed by any participants as decision factors.

4.2. Directions for further study

Future studies may consider reasons unrelated to referral decision-making for late or delayed referrals and evaluations, such as parent-cited factors. On a positive note, recent and current studies in clinics are investigating innovative strategies to address lengthy wait list issues, particularly reducing the wait period that contributes to delayed evaluation, diagnosis, and intervention for very young children (Austin et al., 2016; Gordon-Lipkin, Foster, & Peacock, 2017; Harrison, Jones, Sharif, & DiGuglielmo, 2017; McKenzie et al., 2015; Rotholz, Kinsman, Lacy, & Charles, 2017). These investigations, along with the current study, may provide more precise targets for training and practice to improve early identification of children with autism, resulting in earlier evaluations, intervention and subsequently improved outcomes for young children with autism.

4.3. Clinical implications

Identifying very young children with autism is a complicated issue. Surveillance, screening, parent concerns, heterogeneity of symptomatic presentation, availability of appointments and decision-making processes of early childhood professionals all play an important part in early identification. This exploratory study suggests the possibility that even when clinicians and educators know what early signs of autism are, they may not fully consider the importance of specific behaviors (or the *absence* of typical behaviors) and social interactions that warrant a referral for autism assessment, and thus may miss making some referrals in a timely manner. Even for seasoned clinicians and educators, continuing education and frequent reviews of autism research literature may improve accuracy of referral decisions. For disciplines in which formal training in early signs of ASD has not been included in pre-service education, seeking out in-service training on ASD is recommended.

We view it as very encouraging that clinicians across disciplines and settings were able to accurately identify children who needed autism evaluation referrals 74% of the time with only brief exposures. While this result may not be widely generalizable, it still represents a much higher *potential* for early referral and assessment than is currently reported in prevalence studies (Baio et al., 2018). Other barriers to early comprehensive assessment exist, and are beginning to be addressed by autism specialty clinics (Ahlers et al., 2018; Austin et al., 2016; Gordon-Lipkin et al., 2017; Rotholz et al., 2017). Parent decision factors, particularly shared decision making regarding assessment are an additional area of focus for in-service training (Golnik, Maccabee-Ryaboy, Scal, Wey, Gaillard, 2012; Levy et al., 2016).

In the absence of an established literature base on decision-making factors regarding autism risk, this study is a first look at the possible internal “checklists” of early autism symptoms, or how professionals use the information they have about autism early signs when making decisions. Information about what professionals in practice are using to help them identify autism in very young children may inform future training curricula and in-service programs across disciplines to help professionals think about the relative weights of some signs or parent reports or the accumulation of symptoms as opposed to the isolated, specific symptoms or typical behaviors reported or observed. This may, in turn, improve the timeliness of referrals for comprehensive autism evaluations and ultimately, outcomes for individuals.

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Conflicts of interest

The authors declare that they have no conflicts of interest.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.rasd.2018.09.009.

References

Ahlers, K., Gabrielsen, T., Ellzey, A., Brady, A., Litchford, A., Fox, J., ... Carbone, P. (2018). A pilot project utilizing pediatricians as initial diagnosticians in multidisciplinary autism evaluations for young children. *Journal of Developmental & Behavioral Pediatrics*.

Al-Qabandi, M., Gorter, J. W., & Rosenbaum, P. (2011). Early autism detection: Are we ready for routine screening? *Pediatrics, 128*(1), e211–e217. https://doi.org/10.1542/peds.2010-1881.

APA (2013). *Diagnostic and statistical manual, of mental disorders* (5th ed.). Washington, DC: Author.

Austin, J., Manning-Courtney, P., Johnson, M., Weber, R., Johnson, H., Murray, D., ... Murray, M. (2016). Improving access to care at autism treatment centers: A system analysis approach. *Pediatrics, 137*(Supplement 2), S149–S157.

Baio, J. (2014). Prevalence of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *Surveillance Summaries, MMWR, 63*(2), 1–21. https://doi.org/10.15585/mmwr.ss6706a1.

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., ... Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged

8 years – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *Surveillance Summaries, MMWR, 67*(No. SS-6), 1–23. https://doi.org/10.15585/mmwr.ss6706a1.

Bonis, S. (2016). Stress and parents of children with autism: A review of literature. *Issues in Mental Health Nursing, 37*(3), 153–163. https://doi.org/10.3109/01612840.2015.1116030.

Centers for Disease Control and Prevention (CDC: 2018). *Learn the signs. Act early*. Retrieved from https://www.cdc.gov/ncbddd/actearly/index.html.

Charman, T. (2003). Why is joint attention a pivotal skill in autism? *Philosophical Transactions of the Royal Society B: Biological Sciences, 358*(1430), 315–324. https://doi.org/10.1098/rstb.2002.1199.

Chawarska, K., Klin, A., & Volkmar, F. (2003). Automatic attention cueing through eye movement in 2-year-old children with autism. *Child Development, 74*(4), 1108–1122. https://doi.org/10.1111/1467-8624.00595.

Chawarska, K., Paul, R., Klin, A., Hannigen, S., Dichtel, L., & Volkmar, F. (2007). Parental recognition of developmental problems in toddlers with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 37*(1), 62–72. https://doi.org/10.1007/s10803-006-0330-8.

Christensen, D., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., Constantino, J., ... Yeargin-Allsop, M. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *MMWR Surveillance Summaries, 65*(No. SS 3), 1–23.

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20*(2), 153–162. https://doi.org/10.1177/1362361315573636.

Daniels, A. M., & Mandell, D. S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism, 18*(5), 583–597. https://doi.org/10.1177/1362361313480277.

Dawson, G. (2016). Why it's important to continue universal autism screening while research fully examines its impact. *JAMA Pediatrics*. https://doi.org/10.1001/jamapediatrics.2016.0163.

Dawson, G., Munson, J., Estes, A., Osterling, J., McPartland, J., Toth, K., ... Abbott, R. (2002). Neurocognitive function and joint attention ability in young children with autism spectrum disorder versus developmental delay. *Child Development, 73*(2), 345–358. https://doi.org/10.1111/1467-8624.00411.

Dow, D., Guthrie, W., Stronach, S. T., & Wetherby, A. M. (2017). Psychometric analysis of the Systematic Observation of Red Flags for autism spectrum disorder in toddlers. *Autism, 21*(3), 301–309. https://doi.org/10.1177/1362361316636760.

Eggebrecht, A. T., Elison, J. T., Feczko, E., Todorov, A., Wolff, J. J., Kandala, S., ... Pruett, John R., Jr. (2017). Joint attention and brain functional connectivity in infants and toddlers. *Cerebral Cortex, 27*(3), 1709–1720. https://doi.org/10.1093/cercor/bhw403.

Elder, J., Brasher, S., & Alexander, B. (2016). Identifying the barriers to early diagnosis and treatment in underserved individuals with autism spectrum disorders (ASD) and their families: A qualitative study. *Issues in Mental Health Nursing, 37*(6), 412–420. https://doi.org/10.3109/01612840.2016.1153174.

Filipek, P., Accardo, P., Ashwal, S., Baranek, G., Cook, E., Dawson, G., ... Volkmar, F. (2000). Practice parameter: Screening and diagnosis of autism: Report of the quality standards subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology, 55*(4), 468–479.

Gabrielsen, T. P., Farley, M., Speer, L., Villalobos, M., Baker, C. N., & Miller, J. (2015). Identifying autism in a brief observation. *Pediatrics, 135*(2), e330–e338. https://doi.org/10.1542/peds.2014-1428.

Golnik, A., Maccabee-Ryaboy, N., Scal, P., Wey, A., & Gaillard, P. (2012). Shared decision making: Improving care for children with autism. *Intellectual and Developmental Disabilities, 50*(4), 322–331.

Gordon-Lipkin, E., Foster, J., & Peacock, G. (2017). Whittling down the wait time: Exploring models to minimize the delay from initial concern to diagnosis and treatment of autism spectrum disorder. *Pediatric Clinics of North America, 63*(5), https://doi.org/10.1016/j.pcl.2016.06.007.

Granpeesheh, D., Tarbox, J., & Dixon, D. R. (2009). Applied behavior analytic interventions for children with autism: A description and review of treatment research. *Annals of Clinical Psychiatry, 21*(3), 162–173.

Harrison, M., Jones, P., Sharif, I., & DiGuglielmo, M. (2017). General pediatrician-staffed behavioral/developmental access clinic decreases time to evaluation of early childhood developmental disorders. *Journal of Developmental & Behavioral Pediatrics, 38*(6), 353–357. https://doi.org/10.1097/DBP.0000000000000448.

Hill, C. E., Knox, S., Thompson, B. J., Williams, E. N., Hess, S. A., & Ladany, N. (2005). Consensual qualitative research: An update. *Journal of Counseling Psychology, 52*(2), 196–205.

IACC. (2017). *2016–2017 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder*. Retrieved from https://iacc.hhs.gov/publications/strategic-plan/2017/.

Johnson, C., Myers, S., & Council on Children with Disabilities (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics, 120*(5), 1183–1215. https://doi.org/10.1542/peds.2007-2361.

Klin, A., Saulnier, C., Tsatsanis, K., & Volkmar, F. R. (2005). Clinical evaluation in autism spectrum disorders: Psychological assessment within a transdisciplinary framework. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.). *Handbook of autism and pervasive developmental disorders: Assessment, interventions, and policy* (pp. 772–798). (3rd ed.). Hoboken, NJ, US: John Wiley & Sons Inc.

LeCouteur, A., Lord, C., & Rutter, M. (2003). *The autism diagnostic interview-revised.* Los Angeles: Western Psychological Services.

Leekam, S. R., & Ramsden, C. H. (2006). Dyadic orienting and joint attention in preschool children with autism. *Journal of Autism and Developmental Disorders, 36*(2), 185–197. https://doi.org/10.1007/s10803-005-0054-1.

Légaré, F., Stacey, D., Graham, I. D., Elwyn, G., Pluye, P., Gagnon, M.-P., ... Desroches, S. (2008). Advancing theories, models and measurement for an interprofessional approach to shared decision making in primary care: A study protocol. *BMC Health Services Research, 8*(2), https://doi.org/10.1186/1472-6963-8-2.

Levy, S., Frasso, R., Colantonio, S., Reed, H., Stein, G., Barg, F. K., ... Fiks, A. G. (2016). Shared decision making and treatment decisions for young children with autism spectrum disorder. *Academic Pediatrics, 16*(6), 571–578.

Lord, C., Rutter, M., DiLavore, P., & Risi, S. (1999). *Autism diagnostic observation schedule (ADOS).* Los Angeles: Western Psychological Services.

Lord, C., Rutter, M., DiLavore, P., Risi, S., Gotham, K., & Bishop, S. (2012). *Autism Diagnostic Observation Schedule* (Second Edition). Los Angeles: Western Psychological Services.

Mandell, D., & Mandy, W. (2015). Should all children be screened for autism spectrum disorder? *Autism, 19*(8), 895–896. https://doi.org/10.1177/1362361315608323.

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116*(6), 1480–1486. https://doi.org/10.1542/peds.2005-0185.

McKenzie, K., Forsyth, K., O'Hare, A., McClure, I., Rutherford, M., Murray, A., ... Irvine, L. (2015). Factors influencing waiting times for diagnosis of autism spectrum disorder in children and adults. *Research in Developmental Disabilities, 45–46*(2015), 300–306. https://doi.org/10.1016/j.ridd.2015.07.033.

Miller, J., Gabrielsen, T., Villalobos, M., Alleman, R., Wahmhoff, N., Carbone, P., ... Segura, B. (2011). The Each Child Study: Systematic screening for autism spectrum disorders in a pediatric setting. *Pediatrics, 127*, 866–871. https://doi.org/10.1542/peds.2010-0136.

Mullen, E. (1995). *Mullen scales of early learning.* Bloomington, MN: Pearson, Inc.

Mundy, P., Gwaltney, M., & Henderson, H. (2010). Self-referenced processing, neurodevelopment and joint attention in autism. *Autism, 14*(5), 408–429. https://doi.org/10.1177/1362361310366315.

Nadel, S., & Poss, J. (2007). Early detection of autism spectrum disorders: Screening between 12 and 24 months of age. *Journal of American Academy of Nurse Practitioners, 19*, 408–417. https://doi.org/10.1111/j.1745-7599.2007.00244.x.

Ouimet, M., Landry, R., Amara, N., & Belkhodja, O. (2006). What factors induce health care decision-makers to use clinical guidelines? Evidence from provincial health ministries, regional health authorities and hospitals in Canada. *Social Science & Medicine, 62*(4), 964–976. https://doi.org/10.1016/j.socscimed.2005.06.040.

Paparella, T., Goods, K. S., Freeman, S., & Kasari, C. (2011). The emergence of nonverbal joint attention and requesting skills in young children with autism. *Journal of Communication Disorders, 44*(6), 569–583. https://doi.org/10.1016/j.jcomdis.2011.08.002.

Robins, D. L., Casagrande, K., Barton, M., Chen, C.-M. A., Dumont-Mathieu, T., & Fein, D. (2014). Validation of the Modified Checklist for Autism in Toddlers, Revised With Follow-up (M-CHAT-R/F). *Pediatrics, 133*(1), 37–45. https://doi.org/10.1542/peds.2013-1813.

Rotholz, D., Kinsman, A., Lacy, K., & Charles, J. (2017). Improving early identification and intervention for children at risk for autism spectrum disorder. *Pediatrics,* *139*(2), e20161061. https://doi.org/10.1542/peds.2016-1061.

Schwartz, M. (2016). Ethical decision-making theory: An integrated approach. *Journal of Business Ethics, 139*, 755–776. https://doi.org/10.1007/s10551-015-2886-8.

Shumway, S., & Wetherby, A. M. (2009). Communicative acts of children with autism spectrum disorders in the second year of life. *Journal of Speech, Language, and Hearing Research, 52*(5), 1139–1156. https://doi.org/10.1044/1092-4388(2009/07-0280.

Siu, A. L., & USPSTF (2016). Screening for autism spectrum disorder in young children: US Preventive Services Task Force recommendation statement. *JAMA, 315*(7), 691–696. https://doi.org/10.1001/jama.2016.0018.

Sparrow, S., Balla, D., & Cicchetti, D. (2005). *Vineland adaptive behavior scales, Second edition, Survey interview.* Minneapolis, MN: Pearson Inc.

Vismara, L., & Rogers, S. (2010). Behavioral treatments in autism spectrum disorder: What do we know? *Annual Review of Clinical Psychology, 6*, 447–448. https://doi.org/10.1146/annurev.clinpsy.121208.131151.

Warren, Z., McPheeters, M., Sathe, N., Foss-Feig, J., Glasser, A., & Veenstra-Vanderweele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics, 127*(5), e1303–e1311. https://doi.org/10.1542/peds.2011-0426.

Wetherby, A., & Prizant, B. (2002). *Communication and symbolic behavior scales developmental profile—First normed edition.* Baltimore: Brookes.

Wetherby, A. M., Watt, N., Morgan, L., & Shumway, S. (2007). Social communication profiles of children with autism spectrum disorders late in the second year of life. *Journal of Autism and Developmental Disorders, 37*(5), 960–975. https://doi.org/10.1007/s10803-006-0237-4.

Zwaigenbaum, L., Bauman, M., Choueiri, C., Fein, D., & Karr, S. (2015). Early identification and interventions for autism spectrum disorder: Executive summary. *Pediatrics, 136*(S1), S1–S9. https://doi.org/10.1542/peds.2014-3667B.

Zwaigenbaum, L., Bryson, S., & Garon, N. (2013). Early identification of autism spectrum disorders. *Behavioral Brain Research, 251*, 133–146. https://doi.org/10.1016/j.bbr.2013.04.004.