A Training Model for the Diagnosis of Autism in Community Pediatric Practice

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ABSTRACT: ***Objective:*** **Early diagnosis of autism spectrum disorders (ASD) currently represents a critical public health and clinical practice issue. Waits for diagnostic services are quite lengthy and hinder the start of early intervention services thought to be crucial for optimizing functional developmental outcomes for children and their families. In this study, we present data from a newly developed training program (Screening Tools and Referral Training-Evaluation and Diagnosis training) designed to help pediatricians diagnose young children with ASD in the context of traditional community practice settings.** ***Methods:*** **A small, targeted group of community pediatricians participated in an intensive training, conducted specialized ASD evaluations within their own practices, and then referred a consecutive series of children to a medical center diagnostic clinic for an independent assessment of ASD.** ***Conclusion:*** **Results of this small pilot study indicate good agreement (71%) between pediatrician judgments and independent diagnostic ASD evaluations, but a significant trend toward overidentification when a diagnostic decision is forced. We discuss the implications of this study with regard to revisiting traditional service models of diagnostic assessment for young children with ASD.**

*(J Dev Behav Pediatr 30:*442–446, 2009) **Index terms:** autism spectrum disorders, diagnosis, screening.

With best estimate prevalence rates for autism spectrum disorders (ASD) estimated at 1 in 150,[1] the accurate diagnostic classification of young children with ASD is a public health issue of critical import. Although there is at present no single accepted intervention, treatment, or known cure for ASD, there is a growing consensus that early identification and intensive intervention can significantly improve short- and long-term outcomes for individuals and their families. A growing body of research indicates that children who receive autism-specialized intervention services at young ages show significant gains in cognitive and adaptive functioning and may be more likely to achieve fully integrated classroom placements at school age.[2–5] In addition, if linked with appropriate intensive autism-specific intervention, early diagnosis may reduce substantial and costly associated long-term service system demands.[6,7]

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There is a mounting evidence that caregivers of children with ASD are able to identify and report concerns about development to medical professionals by the age of 12 to 18 months.[8,9] Further, the diagnosis of ASD seems to become quite stable between 24 and 30 months.[10–12] However, currently the average age of diagnosis is not until around 4 years or older in underserved communities and subgroups of children with higher intelligence quotients.[13–15] This represents a serious, deleterious time lag from both (a) the age at which ASD can reliably be diagnosed and (b) retrospective reports of when parents first notice and disclose concerns to medical professionals. As pediatricians and family physicians are often the first point of entry, when there are potential developmental concerns they hold an important gate-keeper role in the early identification of ASD.[16]

To address the gap between concern and diagnosis and take advantage of the potential impact of early intervention, several consensus panels, across numerous professional groups, have issued practice parameters endorsing early ASD screening in clinical practice settings.[17–19] Most recently, the American Academy of Pediatrics endorsed formal screening for ASD at 18 and 24 months, as well as at any point when caregiver concerns are raised. Although several tools with fairly robust psychometric properties are available for surveillance and entry point screening, the path followed subsequent to positive screening is less clear as traditionally there are barriers to accessing diagnostic evaluations (i.e., long waits and lack of providers). Ideally, the definitive diagnosis of ASD in the first years of life should be accomplished by a team of developmental and behavioral pro-

fessionals with specialties related to ASD and other developmental disorders. The reality is that such diagnostic teams, or even individual professionals with appropriate specialization, are not available in many locations. Further, even when such professionals are available, the waitlists for diagnostic services are so long (e.g., 6–12 months in many locations) that children commonly identified and referred for evaluation at or before the age of 2 years may not be seen until after their third birthday.[20]

METHODS

In response to above reviewed deficiencies in the early identification of autism spectrum disorders (ASD), we developed and evaluated a pilot training program for physicians in assessing young children suspected of ASD within their own practices. Five community pediatricians were invited to participate in a program entitled, "Screening Tools and Referral Training-Evaluation and Diagnosis" (START-ED). These pediatricians were specifically targeted and personally invited as they had established practices in underserved geographic areas, had previously completed an office-based training program for introducing clinically validated screening tools into primary care settings, and were willing to fulfill the obligations related to the training program. The educational objectives of the START-ED were to provide pediatricians with a functional framework and assessment tools to accurately identify and diagnose ASD in young children based on developmentally sensitive DSM-IV criteria, with the explicit purpose of expediting fluid entry into the early intervention system. The training was designed with the end goal of assessing children between 2 and 3 years for ASD within a 1-hour time frame. The START-ED training itself comprised 3 phases. The first phase consisted of an intensive 2-day workshop that included a series of interactive training experiences as well as real-time evaluations of children under the proposed 1-hour framework. Specifically, this framework included reviewing the completed Modified Checklist for Autism in Toddlers,[21] administering the Screening Tool for Autism in Two-Year-Olds, and completing a DSM-IV-based diagnostic interview as well as a medical history interview. The Screening Tool for Autism in Two-Year-Olds is an empirically derived, interactive measure developed to screen for autism in children between 24 and 36 months. It consists of 12 activities in the areas of play, imitation, and communication (i.e., requesting and directing attention). It was chosen for inclusion as it can be administered and scored in 20 minutes and possesses strong psychometric properties (i.e., a sensitivity of 0.92, a specificity of 0.85, a positive predictive value of 0.86, and a negative predictive value of 0.92 compared with DSM-IV diagnoses in a clinic-based validation sample).[22] Although the training model described potential diagnostic interviewing techniques, ultimately no specific formal interview protocol was created, rather methods for following-up on concerns from the Modified Checklist for Autism in Toddlers and Screening Tool for Autism in Two-Year-Olds were presented. Information on making a differential diagnosis, explaining results to parents, and using proper coding for reimbursement was also included. With regards to billing and coding, pediatricians were provided with guidance and training in use of (a) appropriate consultation or new/established patient codes as well as (b) procedural coding and modifiers (i.e., developmental testing/evaluation—96111; neurobehavioral status examination—96116).

For the second phase, video cameras were installed within each practice, so that pediatricians' assessments could be recorded. A member of the university-based clinic (Z.W.) reviewed a series of practice tapes from each pediatrician and provided specific feedback. The practice administrations continued until the pediatricians felt comfortable with the assessment procedures. As this was a pilot training project, comfort level was subjective and set by each individual trainee with a range of 4 to 6 practice assessments across the group. During the final phase of the project, each pediatrician conducted the autism assessments independently and completed a diagnostic certainty checklist. This checklist forced the clinician to indicate whether they felt the child had ASD (i.e., "In your judgment, does this child fall somewhere on the autism spectrum? Yes/No") and to indicate their certainty of this diagnosis on a Likert scale (i.e., How certain are you of this diagnosis?' 1 = highly uncertain to 5 = highly certain). They were also asked to refer this consecutive series of families for independent evaluation through the university clinic. Families referred for evaluation through the autism diagnostic clinic received no cost evaluation conducted blind to the pediatrician's previous evaluation results. The independent evaluation process included completion of a clinical interview, direct evaluation of the child with the appropriate module of the Autism Diagnostic Observation Schedule, and additional testing where clinically indicated. Subsequent to the clinic evaluation the blinded primary diagnostician completed the same forced choice diagnostic form as the pediatricians.

RESULTS

Of the 5 community physicians attending the START-ED training, 4 referred patients for subsequent independent evaluation. One pediatrician experienced difficulty getting appropriate referrals in her community and was not able to perform sufficient assessments to begin independent evaluations under the program. Twenty-five children were referred, 20 with an initial autism spectrum disorder (ASD) classification and 5 who were nonspectrum. Twenty-one families participated in the independent evaluation process; this number included 19 of the children with an ASD diagnosis and 2 of the 5 with a nonspectrum classification. Children ranged in age from 22 to 37 months at the time of their evaluation (Table 1 for additional sample characteristics). The number of children referred by each pediatrician ranged

Table 1. Descriptive Statistics on Referral Sample Characteristics (n = 21)

Variables	M	SD	Min	Max
Age	30.48	3.74	22	37
ADOS: communication	4.23	2.66	0	8
ADOS: reciprocal social interaction	6.19	4.57	0	14
ADOS: total (communication + social)	10.52	6.91	1	20
Mullen ELC	83.25	17.87	68	106
Vineland ABC	79.00	8.83	66	91

ADOS, Autism Diagnostic Observation Scale (n = 21); Vineland ABC, Vineland Adaptive Behavior Composite Standard Score (n = 15); Mullen ELC, Mullen Scales of Early Learning—Early Learning Composite Standard Score (n = 4).

from 1 to 7. An ASD diagnosis was confirmed based on independent evaluation in 14 of the 19 children (74%). Of the 2 children classified as nonspectrum by their pediatric ASD consultation, 1 child received an independent diagnosis of ASD and 1 did not (50%). Overall, the independent diagnostic evaluation was in agreement with the initial pediatrician classification in 15 of 21 cases (71%). Agreement with the 4 referring pediatricians ranged from 57 to 100%.

In all 6 cases for which there were diagnostic disagreements, other clinically significant developmental concerns were clearly evident (i.e., global developmental delays or speech/language delays). Clinical diagnostic certainty ratings from the independent evaluation process were also significantly lower for children not receiving an ASD diagnosis (ASD mean = 4.27; non-ASD mean = 2.41; $t(19) = 3.72$, $p < .05$). Pediatrician diagnostic certainty ratings were not lower for children whose diagnostic status was not confirmed during independent evaluation nor were they lower for children not receiving a diagnosis at the initial pediatric evaluation.

DISCUSSION

In this study, we evaluated a unique training model developed for community pediatricians attempting to provide a time-efficient diagnostic evaluation structure for successful classification of young children suspected of autism spectrum disorders (ASD). The most promising finding of this project was that many young children with ASD could be accurately identified within the basic consultation model involving completion of a standard ASD screener (i.e., the Modified Checklist for Autism in Toddlers), a basic interactive screening tool (i.e., the Screening Tool for Autism in Two-Year-Olds), and simple diagnostic interviewing. In fact, a majority of the young children participating in this model were accurately identified within this 1-hour framework.

Although a majority of cases were identified correctly, current implementation of this model resulted in a misclassification and significant overidentification by the pediatricians. The potential negative impact of suggesting a child has ASD when they do not is hard to overstate. However, there are several important considerations in understanding this group of children (i.e., false positives) in the context of the current training program. Pediatricians and the independent evaluator at the university-based clinic were asked to make diagnostic classifications within a forced choice model with no provisions for ambiguous diagnostic status available. It is possible that if such an option were present that false-positive diagnoses would decrease. The lower independent evaluation diagnostic certainty ratings and presence of additional developmental diagnoses in the children initially misclassified suggests that further examination of the clinical and familial characteristics associated with all subgroups (i.e., those accurately diagnosed as well as those misdiagnosed) might also be a mechanism for improving accuracy of classification under such a model.

In addition to difficulties with overidentification of ASD, there are several significant methodological limitations of this study. The small number of pediatricians and children involved, the lack of baseline data concerning pediatrician skill and experience in ASD classification, the absence of a formal assessment of fidelity to the suggested pediatric consultation protocol and resulting inability to determine the additive value of the specific training model over other simpler screening procedures (i.e., Modified Checklist for Autism in Toddlers alone), the small number of nonspectrum children completing the independent evaluation process, and the lack of data about family experiences and satisfaction with this model are all factors that limit our ability to comment on the ultimate success of this training program. Although no formal data are available regarding actual reimbursement figures, qualitative feedback from the participating pediatricians indicated that reimbursement to cover associated costs was not a prohibitive barrier to implementation of the consultation model; however, in absence of definitive data the ultimate financial viability of this model has not yet been established. An ultimate assessment of this viability would also necessitate a more rigorous examination of the actual time necessary to complete all aspects of evaluation. An hour framework was recommended and qualitative feedback from clinicians suggested that this was possible for many children. However, in the context of this study, clinicians were often seeing children from within established patient networks, where specific medical considerations and rule outs may have often been previously addressed, and the participating pediatricians knew that all families would be receiving an expedited, comprehensive psychological evaluation rapidly following their own evaluation. Further, it is important to note that this pilot training also included a very select group of experienced pediatricians who likely had more comfort, interest, and experience working with children with ASD and other developmental concerns. As such, questions about how such a program would generalize remain.

Thus, although this study is the first to our knowledge to demonstrate successful implementation of a training

model for a brief diagnostic classification within community pediatric practice, given the above substantial methodological considerations the ultimate viability and impact of this training model would require significant further study. Specifically, any future expansion of such a model would need to more systematically assess characteristics of those being trained (i.e., years of experience, training, baseline comfort level with ASD), the clinical characteristics associated with accurate and inaccurate diagnosis within the model (i.e., clinical features of the child/family), the functional value of the instruments of assessment (i.e., the incremental value of Modified Checklist for Autism in Toddlers, Screening Tool for Autism in Two-Year-Olds and interview), as well as examine the actual impact of the program in terms of time to receiving appropriate services for children diagnosed.

Such training models aimed at briefer, more rapid diagnostic classification must also take into account the reality that significant revision and condensation of gold standard assessment methodologies will undoubtedly contribute to more errors in definitive classification. In this context, critical attention should be paid to the potential risks associated with the brief diagnostic models in terms of achieving the goal of expediting appropriate early intervention services for young children with developmental concerns. One specific risk to consider in this regard is how this brief model impacts families in their pursuit of appropriate services. The diagnostic assessment experience itself contributes to an array of reactions in caregivers and there is a considerable evidence in other areas of pediatric illness/disability, indicating that the way in which diagnostic information is conveyed has a long-term influence on parental attitudes, on families' levels of stress and acceptance, and on coping strategies in general.[23] Parents of young children with ASD are often asked to be primary agents of intervention, service coordinators, as well as advocates in a confusing context of unprecedented scientific, political, and media attention. As such, it is extremely important to examine whether briefer diagnostic models may present additional challenges and risks as they substantially limit the time clinicians can spend educating, guiding, and supporting parents in these challenging roles.

Another major concern is whether early definitive diagnosis of ASD is and should be the most clinically appropriate goal when assessing a young child with developmental concerns. The functional goal of diagnostic assessment often surrounds the clarification of child's unique neurobehavioral strengths and vulnerabilities to identify and implement appropriate intervention goals. In this regard, the ideas of "risk" and "prevention" may represent ideals of early screening and assessment, rather than definitive diagnosis of ASD. Specifically, affording pediatricians the ability to designate children "at risk for ASD" in situations where concerns are high or ambiguous would be useful in expediting services and minimizing confusion and associated distress.[20] Such a classification of risk status simultaneously stresses both the need for immediate services and the eventual clarification. As such, risk classification maintains a primary function of a definitive diagnosis (i.e., expediting appropriate clinical interventions), while at the same time minimizing potential negative impacts of false classification and sustaining transparency. At present, the current and powerful pragmatic challenge for such a risk classification system is in ensuring appropriate intervention services follow such a designation. Traditionally, state early intervention services and insurance systems often require specific diagnosis or other developmental status/criterion to receive services. In this regard, pragmatic revision of assessment, eligibility, and service models for at-risk children would likely be viewed by many as ideal, but this ideal is certainly not in place in many states at present.

In absence of the ability to provide children with developmental concerns with appropriate intervention services without a diagnosis of ASD and in the face of lengthy waits for traditional specialized diagnostic evaluations during the presumed critical window of neurobehavioral plasticity, the potential impact of ASD-specific diagnostic training programs is promising. Certainly, rigorous expansion and study of such models including refinement of the specific clinical, child, and family characteristics associated with successful diagnosis is clearly necessary. However, there seems to be a great potential for system level impact of highly trained and accessible community providers. Even a small number of community pediatricians performing similar diagnostic consultations on a small scale could dramatically shift lag times between identification of ASD risk and initiation of appropriate intervention services at a population level. For example, a group of 20 trained pediatricians performing on average one evaluation a week would be able to perform more than 1000 consultations a year for children between the ages of 2 and 3 years. At present, this number far exceeds the estimated prevalence rates for ASD (1 of 150) for the entire cohort of children born in 2007 in the state in which this program was implemented (~85,000).[24]

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Book Review

Developmental Parenting: A Guide for Early Childhood Practitioners

by Lori A. Roggman, Lisa K. Boyce, and Mark S. Innocenti. Baltimore, MD, Paul H. Brooks Publishing Company, 2008, 248 pp, Softcover, $26.95.

Developmental parenting is an excellent book for anyone who is involved in caregiving of children and can also be generalized to serve children of any age. The book focuses on 2 important central concepts. The first being developmental parenting, which refers to valuing, supporting, and adapting to a child's development and developmental needs. This is an important concept for not only parents but also to caregivers in child care centers, family child care homes, nursery schools, preschools, and those who supervise, train, and support nonparental caregivers. The second important concept is facilitating developmental parenting through a parenting-focused model. This model "emphasizes parents' support of their children's development. Using this model, the practitioner focuses neither directly on the child nor on the parent but rather on the parent–child interactions that support child development." This is in contrast to the traditional child-focused model where a practitioner works with a child directly on an activity and parents are expected to be an observer and learn through imitation of the practitioner. It is also different from the parent-focused model that focuses on helping the parents get basic needs met or informing the parents about child development and activities to do with their child to promote development.

I appreciate the abundance of evidence base the authors provide to support their viewpoints. They provide very helpful diagrams and informational charts throughout the book. There are often sample dialogues among therapist, child, and mother to illustrate important points. The book is very easy to read and the practical examples and real-life experiences are helpful.

I am impressed by the comprehensiveness of this book. It not only introduces a new concept to enhancing child development but also helps readers put developmental parenting into practice. The authors give advice about selecting an appropriate curriculum and activities, assess outcomes, managing and supervising a parenting program, and evaluating and improving such programs. As a reader, I feel lucky to gain such insightful knowledge and practical advice from authors with vast experiences in home-based early childhood interventions.

In our current times where home visitation programs and early intervention programs are provided for children with developmental delay or at risk for developmental delay, it is important we provide the highest quality services to children and families. This book teaches providers how to facilitate parents with the skills to enhance a lifetime of developmental parenting skills. I have no doubt it will make a positive impact on parent–child relationships and also on family relationships with therapists.

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