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Promoting Early Identification of Autism in the Primary Care Setting: Bridging the Gap Between What We Know and What We Do

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Additional information is available at the end of the chapter

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1. Introduction

During the last decade, research on Autism Spectrum Disorder (ASD) has made tremendous progress with regard to early identification and diagnosis. These advances were made possible by a growing number of rigorous research studies with large sample sizes that utilized a combination of: (1) retrospective parent report and home video studies [1], (2) prospective studies of infant siblings of children with ASD [2], (3) population-wide studies of ASD screening tools [3], and (4) studies on the early stability of diagnostic classifications [4]. Advances in best practices related to early identification are reflected in a 2006 policy statement published by the American Academy of Pediatrics [5], and a corresponding set of clinical practice guidelines [6]. According to these guidelines, it is recommended that Primary Care Providers (PCPs; e.g., family physicians, pediatricians) administer formal screening tests during every well-child visit scheduled at 18 and 24 months, independent of known risk factors or reported concerns. Moreover, PCPs are urged to promptly refer children for Early Intervention¹ services as soon as ASD is seriously considered.

Even though the age of first diagnosis has gradually decreased during the last decade [7], population based studies reveal that most children with ASD continue to be diagnosed after three years of age [8]. Given that a reliable diagnosis of ASD is possible by 24 months, and that about 90% of parents whose children are later diagnosed with ASD express documented concerns before age 2 [9], the gap between best practice guidelines and community imple-

¹ Throughout this chapter, we use capital letters when referring to the publicly funded Early Intervention system

mentation is tangible. This chapter outlines a sequence of four connected activities aimed at improving early identification of ASD and promoting successful referrals for Early Intervention services. For each step in the sequence, this chapter (1) describes the barriers that autism advocates, families, and PCPs face, and (2) showcases novel educational approaches that aim to promote families' access to prompt and appropriate Early Intervention services.

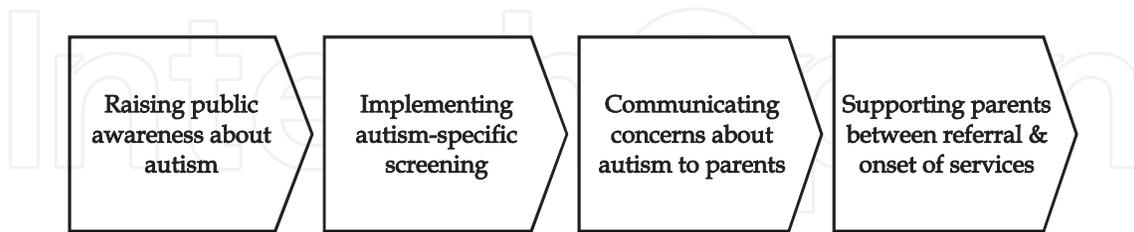


Figure 1. A sequence of four connected activities aimed at improving early identification of ASD and promoting successful referrals for Early Intervention services.

2. Raising Public Awareness about Autism

The prevalence of ASD in and of itself has heightened public awareness. What was once considered a rare condition is now reported to affect 1 in 88 children [7]. Recent data from a study that included population-wide screening procedures suggest that the true prevalence of ASD may be even higher [10]. In the case of ASD, awareness is essential because awareness promotes detection, and successful detection efforts result in earlier intervention, maximizing optimal outcomes for this population. Given that there is an average 13-month lag from initial evaluation to diagnosis, and that the average age of initial evaluation is 48 months with diagnosis occurring at 61 months [11], ASD awareness efforts are far from complete. Importantly, limited awareness of the behavioral characteristics of young children with ASD has been noted for both parents and healthcare professionals. For example, data collected in 2004 by Porter Novelli and the Centers for Disease Control and Prevention show that 63% of parents reported not knowing what behaviors most suggested ASD, and that 57% did not know the best time to get help for children with ASD [12]. These data also indicated that healthcare professionals need more information on developmental milestones and developmental disabilities in that 30% recommended that concerned parents should wait to see if their child's development progresses, and only 41% felt they had the necessary resources to educate parents. Further, awareness campaigns continue to document a considerable gap between best practice and the behaviors of healthcare professionals [13].

2.1. Barriers to public awareness about autism

Awareness efforts are critical to improve rates of detection, access to Early Intervention services, and promote optimal outcomes. It is clear that a lack of education and access to accurate information are key barriers to ASD awareness efforts. Before addressing issues related to dissemination of information, it is important to evaluate more emotionally-hinged barriers,

namely the predominance of negative and stigmatizing stories about ASD in the media and social stigma that may vary across cultures. It is unclear whether stigma and negative stereotypes interfere with people's ability to access accurate information, whether a lack of accurate information promotes stigma and stereotypes, or whether the two are reciprocally linked.

1. Portrayals of ASD in the media

In addition to being a key source of entertainment and news, mass media tends to perpetuate stereotypes and social beliefs in a way that defines and maintains an existing social order [14]. Portrayals of ASD in film (e.g., *Rainman*, *What's Eating Gilbert Grape?*), fiction (e.g., *The Curious Incident of the Dog in the Night-Time* [15]; *Daniel Isn't Talking* [16]), and non-fiction parent accounts of ASD (e.g., *Real Boy: A True Story of Autism, Early Intervention, and Recovery* [17]; *Let Me Hear Your Voice: A Family's Triumph Over Autism* [18]) provide an index of the general increase in ASD awareness. However, there is some disagreement as to whether these representations have a positive or negative impact on awareness efforts [19, 20]. Claims of 'miracle cures' for ASD that victimize vulnerable families and contribute to unrealistic perceptions of the treatability of ASD are clearly harmful [21]. Jones and Harwood provided a content analysis of 1,228 articles about ASD published from 2002 to 2005 in the Australian media [20]. This analysis revealed some interesting patterns, including a limited amount of factual information in media sources, and descriptions of people with ASD as either dangerous and uncontrollable or unloved and poorly treated. Overall there was a predominance of 'negative' stories about ASD including numerous references to the impact on families, difficulties with diagnosis, and criminal cases. The authors submit that the implication of this type of coverage is likely a reduction in people's willingness to engage with individuals with ASD, creating barriers for social and educational inclusion. Further research is needed to evaluate the impact of media stereotypes of ASD on screening and early identification efforts.

2. Cultural representations of ASD

Vast differences in attitudes and approaches to ASD have been reported for culturally and linguistically diverse groups. For example, it has been reported that families in Korea are hesitant to seek help for their children's developmental problems, including ASD, because they are seen as a mark of shame [22]. The effects of stigma have been evaluated for HIV/AIDS, mental illness, ASD, tuberculosis, leprosy, and cancer [23]. Social stigma relating to a condition or disorder can contribute to decreases in willingness to disclose disease status, health-seeking behavior, quality of care received, and social support [24]. Stigma may also be inadvertently perpetuated by healthcare professionals who maintain prejudice and negative stereotypes about ASD and mental health conditions [25, 26]. Cultural interpretations of disability can often be found in the context of religion. For example, a qualitative study indicated that Orthodox Jewish Israeli parents view their child with ASD as having a high spiritual status or important religious mission [27]. In contrast, almost half of the Irish families interviewed by Coulthard and Fitzgerald reported that having a child with ASD had prompted them to distance themselves from religion [28]. Cultural perspectives may also influence families' uptake of services. For example, a general lack of trust in service providers has been described as one factor related to African American's underutilization of mental health services [29].

3. Financial barriers to successful awareness campaigns

The most practical and often insurmountable barrier to effective awareness campaigns is that of financial restriction. Incredible expense is associated with communicating a message to the public, and campaigns with insufficient funding are often limited in their success. One study, for example, reported that reliance on public service announcements often leads to suboptimal time slots resulting in limitations in the delivery of the message to the intended audience [30]. Autism Speaks collaborated with the CDC and the Ad Council on the 'Learn the Signs. Act Early.' campaign, and initiated 'Light It Up Blue', a campaign to celebrate World Autism Awareness Day. In conducting these and other awareness efforts, Autism Speaks spends more than \$15,000,000 annually [31].

2.2. Novel approaches to raising public awareness about autism

Bertrand and colleagues define health awareness campaigns as programs designed to communicate educational messages to promote awareness and/or behavior change to a target population through large-audience channels such as the Internet (websites and social networking sites), television, radio, and print media (magazines, billboards, and posters) [32]. Support for the effectiveness of awareness campaigns are mixed with some associated with positive behavior change [33], and others having little to no effect [34]. Further, recent events demonstrate that negative awareness campaigns may be ineffective if they are perceived as disturbing or offensive. In December 2007, the New York University Child Study Center initiated an ASD awareness campaign in New York City that utilized advertisement notices resembling ransom notes indicating that 'We have your son. We will make sure he will no longer be able to care for himself or interact socially as long as he lives. Autism.' The ads were immediately met with significant backlash from the disability community as many families and individuals with ASD called and emailed the center to report that the ads were offensive and hurtful. It was suggested that ads such as this would contribute more to the spread of stigma and fear than to improve awareness efforts, and as a result of this outcry the Child Study Center cancelled the awareness campaign [35].

2.2.1. The 'Learn the signs. Act early.' campaign

In 2004 the CDC launched an ongoing public health campaign entitled "Learn the Signs. Act Early" (LSAE; [12]). The primary target audience for the campaign is parents of children aged 4 years or less, healthcare professionals (particularly pediatricians), and early educators, including childcare providers and preschool teachers. Campaign objectives are to increase awareness of developmental milestones and early warning signs, to increase knowledge about the benefits of early action, to increase dialogue between parents and providers, and to increase early action when developmental delay is suspected. Very effectively, this campaign incorporated several key features considered crucial for promoting behavior change [36].

1. *Using a theoretical framework to conceptualize and guide behavior change.* The Transtheoretical Model was used to plot where the target audiences were in terms of a) their awareness and monitoring of developmental milestones, and b) acting early when a delay is first

suspected [37]. This model assumes that the change of health-related behaviors is a multi-stage process where individuals move from precontemplation, to contemplation, to preparation, to action, and finally to maintenance. Results from surveys and focus groups revealed that, even though many parents were aware of ASD, they were not aware of relevant developmental milestones, and did not believe that ASD was particularly relevant to them (i.e., precontemplation stage). Healthcare professionals and early childhood educators showed more awareness of relevant developmental milestones, but reported that they did not routinely monitor these milestones or communicate concerns with parents [36].

2. *Influencing the information environment.* The LSAE campaign developed a comprehensive approach for providing parents of young children with accurate information. Campaign materials include factsheets on developmental milestones (in English and Spanish), a campaign website, print and web banner advertisements, television and radio public service announcements, and a 24/7 live call center (1-800-CDC-INFO). The campaign was launched with a satellite media tour with the CDC Director; the public service announcements aired in collaboration with various TV and radio networks; and the campaign materials were distributed in partnership with local grassroots organizations, private sector companies, and key advocacy organizations (e.g., Autism Society of America, Autism Speaks, and First Signs). Similarly, complex information environments were also created for healthcare professionals and early childhood educators.
3. *Creative message framing.* One of the biggest challenges for public health campaigns is to stand out in our society's very crowded information environment, so that the message of the campaign gets sufficient exposure [36]. To increase the likelihood that the campaign messages capture the target audiences' attention, LSAE used a creative approach for creating and delivering messages. For example, the resource kit for healthcare professionals featured a picture of a child with the background text, 'A 4-year-old child with autism was once a 3-year-old child with autism, was once...'. Similarly, the TV public service announcement was first aired in New York's Times Square, reaching more than 91 million people.
4. *Creating a supportive environment to assist individuals with behavior change.* To support the target audiences' transition from contemplation to action, LSAE developed several key tools. For example, the campaign used familiar images such as a growth chart, but modified it to encourage and support the tracking of emotional, cognitive, and social development. Materials for physicians included fact sheets with milestones and red flag warning signs by age as well as informational cards to encourage doctor-parent dialogue.
5. *Incorporating process analysis and exposure assessment.* The campaign organizers utilized surveys and focus groups to understand the target audience (e.g., their knowledge, beliefs, attitudes, and behaviors) and how best to reach them. In addition, focus groups were also used to develop, test, and refine potential campaign concepts and accompanying images. Results revealed that fear-based messages that focus on the severity of ASD quickly turned parents away. Thus, instead of focusing on 'ASD', messages targeted the parents' natural and strong desire to monitor their child's growth and development. Finally, outcome

surveys indicate 34% of parents reported some familiarity with the LSAE campaign. Significant changes in target parent behaviors were detected in that more parents knew of the behaviors likely to be associated with ASD, the best time to get help for ASD, and the developmental milestones their child should be reaching [38]. Similarly, substantially more healthcare professionals believe that they have the resources necessary to educate parents about monitoring child development, and fewer advocated a 'wait and see' approach, indicating that the marketing campaign was effective [39].

3. Implementing autism-specific screening

Both the Social Security Act [40] and the Individuals with Disabilities Education Improvement Act [41] reaffirm the mandate for PCPs to play a central role in the identification of developmental disabilities. Between birth and 2nd birthday, children are recommended to participate in a sequence of 11 preventive pediatric healthcare visits (i.e., well-child visits). In the context of these visits, healthcare professionals have a unique opportunity to develop a long-term, trusting relationship with the children and their families. Parents expect that healthcare professionals take an interest in their child's development and behavior, competently identify strengths and weaknesses, and are able to help them access available community resources, if necessary [6].

3.1. Limitations of developmental surveillance

Developmental surveillance is defined as a "flexible, longitudinal, continuous, and cumulative process whereby knowledgeable healthcare professionals identify children who may have developmental problems" ([5] p. 407). Surveillance includes eliciting and attending to the parents' concerns, maintaining a developmental history, making accurate and informed observations of the child, identifying the presence of risk and protective factors, and documenting the process and findings. According to the AAP recommendations on developmental surveillance and screening [5], healthcare professionals are recommended to implement developmental screening during all well-child visits. At the same time, this policy statement also asserts that developmental surveillance by itself is insufficient for detecting developmental concerns in a large number of children. Instead, the AAP recommends using a combination of developmental surveillance and formal screening tests. Research has shown that healthcare professionals who rely solely on clinical judgment are much less accurate in estimating developmental status than professionals who implement formal screening tests [42, 43]. That is, the clinical impressions of healthcare professionals tend to have excellent specificity (i.e., if children are identified, concerns tend to be valid). At the same time, their sensitivity in detection developmental delays is quite poor, leading to many un-identified children and revealing significant difficulties in detecting less obvious delays. For example, Hix-Small and colleagues [44] conducted a study where global developmental delays (at 12 and 24 months) were identified based on both, clinical impressions and a formal screening test (Ages and Stages Questionnaire, ASQ; [45, 46]). Results revealed that 48% of children with true developmental delays would have been missed if only clinical impressions were used. Similarly, in a

study that aimed to identify toddlers with ASD, Robins [47] screened a total of 4,797 children, identifying 21 children who were later diagnosed with ASD. Of those 21 children, only 4 were previously red-flagged by the child's pediatrician.

3.2. Recommended and implemented screening practices

The use of general developmental screening instruments has been recommended by the AAP since 2001 [48]. Current recommendations for identifying children with developmental disabilities (not specifically ASD) suggest population-wide screening at 9, 18, and 30 months [5]. Empirical information on the extent to which these recommendations have been implemented is limited. Two national surveys of AAP members completed in 2002 and 2009 indicate that implementation has been slow [49, 50]. When asked about their screening practices, only 23.0% (2002) and 47.7% (2009) of physicians reported that they 'always' or 'almost always' administer a formal screening tool. Since many healthcare professionals may administer standard screening tools in a non-standard manner (e.g., by asking some but not other items) or only administer these tools to patients considered 'high risk', these numbers likely overestimate true implementation [51]. Researchers who asked parents to report on the screening practices of their healthcare professionals found that less than 27% of parents of children between 10 to 35 months recalled completing a developmental screening questionnaire within the last 12 months [52]. Only two survey-based studies have evaluated the implementation of ASD-specific screening instruments. In a 2004 survey of 255 pediatricians licensed in Maryland and Delaware, dosReis and colleagues reported that only 8% of the respondents screened for ASD [53]. In a 2007 survey of 51 pediatricians licensed in Alabama and Mississippi, Gillis reported that 28% reported using ASD-specific screening instruments [54]. Importantly, only one pediatrician reported routine screening for ASD at 18- or 24-months, suggesting that many healthcare professionals administer ASD-specific screening tests only to children who are considered 'high risk'.

3.2.1. Barriers to successful screening in the primary care setting

Well-child visits are often the only routine, formalized, and longitudinal contact a child has with a healthcare professional and thus is an ideal place to implement population-wide screening. Given this widely acknowledged responsibility, it is striking that many practices do not implement developmental and ASD-specific screening measures as recommended by the AAP. In the following we will consider several key barriers that interfere with healthcare professionals' ability to implement effective screening practices.

1. Parental compliance with the preventive pediatric healthcare schedule

The Medical Expenditure Panel Survey provides nationally representative information on preventive care for children between 0 and 5 years of age [55]. Results indicate that the average compliance ratio is 71.3% ($SD = 1.4\%$), indicating that on average, parents attend about 3 out of 4 AAP recommended well-child visits. In addition, findings reveal large variation in well-child visit attendance based on the families' socioeconomic status, access to resources, and geography. That is, the compliance ratio was significantly below average if the child was

without health insurance ($M = 52.5\%$, $SD = 3.8$), lived below the poverty level ($M = 62.8\%$, $SD = 2.4$), lived with a single parent ($M = 65.5\%$, $SD = 2.7$), was Hispanic or Black ($M = 64.5\%$, $SD = 2.1$, or $M = 64.7\%$, $SD = 2.9$, respectively), or had parents without a high-school degree ($M = 60.8\%$, $SD = 3.1$). Moreover, in terms of geography, the compliance ratio ranged between 90.9% ($SD = 5.0$) in New England and 51.3% ($SD = 3.4$) in the West South Central Census division. To account for this variability in parental compliance with the preventive pediatric care schedule, practices may be able to screen about 30% more children by flexibly administering screening measures during sick-visits, when necessary [56].

2. Competing priorities, time, and reimbursement constraints

During the last decade, the AAP [5, 6, 57] has published three separate statements on the early detection of developmental-behavioral problems. Recommended screenings include: (1) screening for maternal postpartum depression (in the first year), (2) broad-band developmental screening (at 9, 18, and 24/30 months), (3) ASD-specific screening (at 18 and 24 months), (4) social-emotional screening (contingent upon abnormal developmental or ASD screeners), (5) kindergarten readiness screening (at 4 years), and (6) mental health/psychological function screening (age 5 years and thereafter). Implementing such a dense screening schedule in the context of short well-child visits filled with competing priorities (e.g., vaccinations, medical surveillance), and limited reimbursement options is often noted as a key challenge by health-care professionals [53].

3. Availability of high-quality screening instruments

Given that screening tools are being developed, revised, and evaluated on an ongoing basis, the AAP practice guidelines do not recommend any particular ASD-specific screening instrument [6]. Instead, the AAP guidelines include a review of several potential measures, leaving it up to the healthcare professional to select an instrument that fits the particular needs of their practice. To date, the ASD-specific screening measure that has been adopted most widely in primary care settings is the Modified Checklist for Autism in Toddlers (M-CHAT; [47, 58, 59]). The M-CHAT is a 23-item yes/no parent report screener for ASD. Screening positive (i.e., "failing") is defined as failing any three items, or any two of six critical items. Failed items are reviewed with a follow-up interview, typically administered by phone a few weeks after the screener is completed. Most of the research evaluating the efficacy of this measure has focused on the positive predictive value (PPV), defined as the number of true positive cases divided by number of cases that screened positive. Robins reported on the screening results of 4,797 toddlers (screened during their 15-, 18-, or 24-month well-child visits) [47]. The numbers of toddlers who failed the M-CHAT questionnaire, failed the M-CHAT follow-up interview, and were eventually diagnosed with ASD, were 466, 61, and 21, respectively. Thus, if the results of the follow-up interview were considered, the M-CHAT revealed a PPV of .57. However, without the follow-up interview, the PPV of the M-CHAT was as low as .06. These estimates are consistent with data reported by Kleinman and colleagues [59], who reported PPVs of .65 and .11, depending on whether the follow-up interview was or was not considered. Based on these findings, at least three conclusions seem warranted: (1) without administering the follow-up interview, the M-CHAT is likely to over-identify children by a factor of 17:1; (2) over-identifica-

tion can be dramatically reduced by administering the follow-up interview (3:1); (3) even though the sensitivity of the M-CHAT has not been evaluated, comparisons to prevalence estimates of ASD suggest that the M-CHAT is likely to miss a considerable number of children [7]. Assuming current prevalence estimates (1:88), the sample reported by Roberts [47] likely included about 55 children with ASD. Even after considering participant attrition as a factor (i.e., families who did not complete the follow-up interview or diagnostic evaluations), the number of children with ASD actually identified by the researchers ($n = 21$) is considerably lower than would be expected.

4. Limited parent literacy

The extent to which limited parent literacy interferes with the implementation of broad-band developmental and ASD-specific screening measures has not been investigated. However, data presented by Davis and colleagues suggest that limited parental literacy has the potential to pose significant obstacles, particularly in the context of practices that primarily serve indigent or immigrant communities [60, 61]. Based on a convenience sample of 396 parents from one large medical center (i.e., Louisiana State University Medical Center, Shreveport, LA), 11% and 16% of parents showed a reading level below 4th and 7th grade, respectively. Limited parental literacy may be an important factor in explaining missing data problems, reported across many population-based screening studies. For example, Hix-Small and colleagues reported that only about 54% of the administered screening questionnaires were completed and returned [44].

5. Need for practice-wide system change

The successful implementation of effective screening practices requires more than educational opportunities for individual staff members. Instead, what is needed is a context that supports organizational restructuring [51, 62]. That is, practices need to develop, evaluate, and refine office-wide implementation systems that divide responsibilities among staff members at multiple levels. For example, the screening instrument may be distributed by a member of the front desk staff, scored by a nurse, reviewed with the family by a provider, and possible referrals may be coordinated by a social worker. Developing such an office-wide implementation system requires an 'internal champion' to lead the charge, a process for collecting data to monitor progress, and a seamless integration with the clinics' electronic medical record system. In order to be sustainable, the implementation system also needs to be sufficiently robust to be workable in the context of busy periods (e.g., the onset of the winter viral season) and staff turnover.

3.2.2. Novel approaches to support autism-specific screening practices

Research suggests that traditional methods of education, including printed educational materials and didactic, lecture-based continuing medical education (CME) sessions, have little to no effect on the behavior of healthcare professionals [63, 64]. During recent years, several alternative approaches to the traditional CME format have been suggested. These approaches include specialized modules on ASD that are included as part of pediatric residency training programs (e.g., CDC Autism Case Training) [65, 66], and academic detailing where a focused

training session on early identification of ASD is presented to the entire office staff of individual practices [67]. In the following section, we will describe a third approach that has been used widely to improve the delivery of high-quality healthcare, although it has yet to be implemented with a focus on improving early detection of children with ASD.

The Breakthrough Series Collaborative Model

The Breakthrough Series Collaborative Model (BSCM) has been developed by the Institute of Healthcare Improvement (IHI, www.ihl.org) [68], and used successfully to improve the delivery of preventive services by pediatric practices [69], follow-up to newborn hearing screening [70], and child mental health service use [71]. In this model, several healthcare provider teams partner with external experts to overcome specific barriers that impede the delivery of high-quality care within their organization. Figure 2 presents the key elements of a Breakthrough Series model.

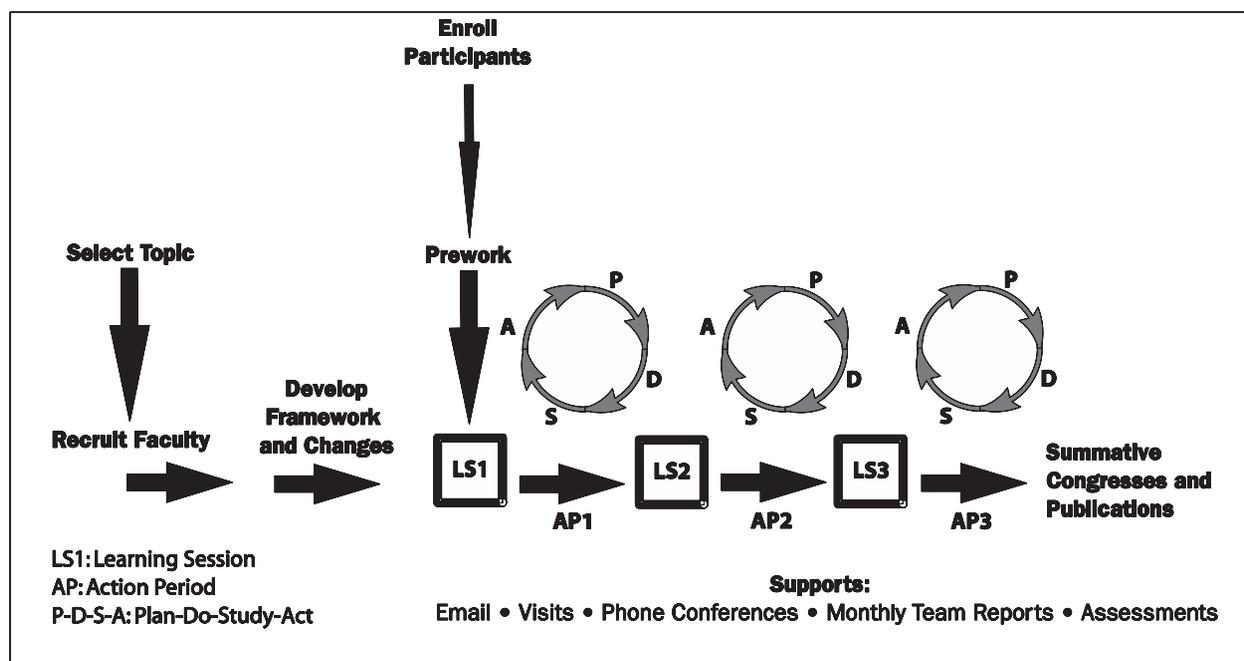


Figure 2. Breakthrough Series Model

The breakthrough series starts with the selection of a specific topic that is considered ripe for improvement. Even though data on the efficacy of learning collaboratives to increase early identification of ASD has not been published to date, we suggest that this would be a very appropriate topic, (1) because of the high prevalence rates of ASD, and (2) because the existing knowledge in this area is sound but not widely used. Once the topic is selected, a faculty team is assembled that combines expertise in the subject area as well as an improvement advisor who coaches teams on improvement methods. Organizations elect to join the collaborative through an application process, appointing multi-disciplinary teams within the organization (a champion's committee). The multi-disciplinary teams from all organizations are then brought together for Learning Sessions that combine the exchange of formal academic

knowledge with practical voices from peers. In between the Learning Sessions, teams engage in Action Periods during which they implement change in a cyclical fashion: a) teams develop a PLAN to implement change, b) they DO the work to implement the change, c) they STUDY their progress by measuring clinical behaviors, and d) they ACT upon the results by refining their approach (Plan-Do-Study-Act cycles of learning).

4. Communicating concerns about autism to parents

When multiple risk factors are present (e.g., the child has a family history of ASD, the child's parents or other family members are concerned about behaviors related to ASD, the child's pediatrician notes concerns about ASD, or the child fails an ASD-specific screener), the AAP clinical practice guidelines recommend that the child's PCP simultaneously (1) provides parental education on ASD, (2) refers the child for a comprehensive ASD evaluation, (3) refers the child for an audiology evaluation, (4) refers the child to Early Intervention or Early Childhood Education Services, and (5) schedules a targeted follow-up visit within one month [6]. Accomplishing all five actions simultaneously is considered crucial to avoid costly delays.

Little is currently known about how parents experience autism-specific screening, parent education, and referrals provided by the child's PCP in accordance with the AAP clinical practice guidelines. By definition, these interactions between PCP and parent precede a formal ASD diagnosis. Thus, PCPs typically communicate a certain level of uncertainty about the child's ASD diagnosis, emphasizing that the child is considered to be at 'high risk for ASD', and focusing on the need for a comprehensive evaluation to 'rule out ASD'. Even at this tentative level, communicating concerns about ASD requires initiating or engaging parents in a difficult conversation. For some parents, this conversation confirms suspicions that lay dormant for various amounts of time. For other parents, it comes out of nowhere and confronts them with concerns they had not previously contemplated. In either case, parents might not yet be emotionally ready to consider the possibility that their child has autism. Parents often feel responsible for their child's behavior or delays, feel guilty about not noticing or acting upon these concerns more promptly, and fear the stigma all too often associated with developmental disabilities.

When prompted to reflect upon the time when their child was first diagnosed, many parents of older individuals with ASD express significant levels of discontentment, in some cases resentment and anger [72, 73]. In part, these strong emotions stem from the fact that most families experience significant delays between the time when they first note concerns [73], the time when they choose to share these concerns with their child's physician [9, 74], the time when their child is first evaluated [11], and the time when the ASD diagnosis is first given [7, 11]. On average, parents report seeing four to five doctors before an ASD diagnosis is made, which occurs on average at age of four or five years [7, 11, 72, 73]. Parental perceptions of delay in diagnosis due to 'watchful waiting' are associated with (1) lower satisfaction with the diagnostic process, (2) lower satisfaction with the help physicians offer after the diagnosis, and (3) lower parental confidence in the physician's ability to help [72, 73, 75].

Parents also express dissatisfaction with the manner in which their child's pediatrician discussed developmental concerns and/or delivered the ASD diagnosis. For example, parents report dissatisfaction if a diagnosis is made but next steps and outcomes are not discussed [26]. Similarly, most parents of children with autism express a preference for receiving a clear ASD label rather than hearing about their child's autism "tendencies" or "trends" [73]. This preference for sincere, prompt, and honest information, even if this means that the physician has to admit a level of uncertainty, can also be found in other medical conditions. For example, cancer patients reported the highest levels of satisfaction and the lowest levels of anxiety when they felt that their healthcare professional prepared them adequately for the diagnosis, when they felt they were being told "everything", when the word "cancer" was used, and when their need to discuss life expectancy had been satisfied [76]. Importantly, high levels of trust in the physician has been linked to high levels of adherence to recommended behavior change [77].

4.1. Barriers to successful communication between healthcare provider and parents

The AAP clinical practice guidelines recommend that once ASD is seriously considered (i.e., due to a failed ASD-screener or multiple risk factors) the parent is promptly educated about ASD and referred for Early Intervention services. Research on the implementation of general developmental screening suggests that referral rates for children who fail such screeners vary tremendously across providers ($M = 61\%$; range: 27% to 100%; [51]). Similarly, two descriptive studies on early identification of ASD in the healthcare setting found that referral to a clinical specialist (e.g., a developmental pediatrician) is the most likely response when autism is first suspected [53, 54]. In the absence of a simultaneous referral to Early Intervention, referral to a clinical specialist can significantly delay children's access to services due to long waiting lists. In addition, the preference for referring families only to a clinical specialist reveals that, even in the presence of a failed ASD-screener, PCPs may often not feel ready to discuss autism with the child's parents. The reasons why PCPs use their own clinical judgment or uncertainty to override the results from a positive screening test are currently poorly understood [78]. This being said, considering a possible ASD-specific referral requires a delicate balancing act between the PCP's clinical judgment, tolerance for uncertainty, trust in screening tests, expectations about parental reactions, self-efficacy with regard to giving 'bad news' and confidence in the available service system. In the following we will describe select components of this tenuous balancing act, and discuss how each factor challenges the PCPs ability to effectively communicate with parents about autism.

1. Limited, outdated, or incorrect information on ASD and effective interventions

In a recent survey, PCPs reported feeling less competent providing care to children with ASD compared to children with other neurodevelopmental disorders and chronic conditions [79]. As described above, research on early identification and intervention in ASD has evolved rapidly during the last decade. Thus, PCPs may not always have access to the most current information. For example, they may be unaware of recent advances in early diagnosis, they may hold misconceptions about early red flags (e.g., they may erroneously assume that children with ASD never show affectionate behaviors), or they may not be familiar or feel passionate about the effectiveness of early intervention services [80].

2. Doubts about the accuracy of ASD-specific screening tests

Available ASD-specific screening tests are far from perfect. As discussed above, if the M-CHAT is administered without the follow-up interview, over-identification is likely to occur at a rate of 17:1 [47]. Several authors have emphasized the utility of second-stage autism-specific screeners in a referral setting to help prevent over-referral and effectively direct high-risk children toward comprehensive ASD evaluations [61, 81, 82]. Even though the M-CHAT follow-up interview has been developed to reduce the number of false positive screens, a feasible process for implementing this interview in the context of children's well-child visits has not been developed. In the absence of an effective second-stage screening process, PCP's may use their own clinical judgment to prevent over-referrals.

3. Expectations about parental reactions

Even though timely referrals for a comprehensive ASD evaluation and Early Intervention services are important first steps, not all parents choose to comply with their pediatricians' referrals and pursue further evaluations [51, 75, 83]. Importantly, parental compliance rates with ASD-specific referrals tend to be lower in younger, and higher in older children. For example, Pierce and colleagues showed that 40% of parents refused a comprehensive follow-up evaluation after failing the CSBS Infant Toddler Checklist at 12 months [3]. Similarly, Pandey and colleagues reported that 37% of parents of younger children (16 to 23 months) refused a referral for a comprehensive ASD evaluation after a failed M-CHAT follow-up interview [84]. In older children (24 to 30 months), the refusal rate was only 21%. In making decisions about a child's referrals, PCPs may gauge the likelihood of a parents' compliance, and thus be more reluctant to make ASD-specific referrals for younger than for older children.

4. Lack of experience in delivering 'bad news' in uncertain situations

Primary care providers may be reluctant to administer population-wide screening measures for ASD if they have had little or no training in sharing bad news with patients. A review of the relevant literature in cancer has revealed that delivering difficult news can be stressful and physicians may struggle with handling their own emotions of sorrow, guilt, and feelings of failure [85]. Unsurprisingly, physicians report a desire for more training in delivering bad news [85], and physicians who have received such training have expressed increased competence in having conversations where difficult information needs to be delivered [86-88].

4.2. Novel approaches to improve communication about autism with parents

How to communicate difficult news to patients has been widely studied, particularly related to cancer. For example, Eid and colleagues [87] tested a standardized intervention to improve communication skills in hematology-oncology fellows and nurses. The fellows and nurses were tested pre-intervention via mock clinical interviews where a "patient" had to be informed of bad news concerning their cancer care. The intervention consisted of one 45-minute interactive lecture that outlined specific methodology for delivering bad news and case scenarios to highlight proper strategies. Fellows and nurses also had the opportunity to watch and score the investigators displaying ideal as well as incorrect practices for deliver-

ing bad news. A week after the intervention, fellows and nurses participated in another mock clinical interview. Both interviews were then scored using a fidelity checklist to measure skills taught during the intervention. Results indicated that fellows and nurses scored higher on the post-intervention clinical interview when compared to the pre-intervention interview; qualitatively, they also reported that the intervention improved their communication skills while delivering bad news. Similar research has demonstrated that improvements in physician communication skills are associated with improved patient outcomes, including reductions in patient distress [88] and increases in patient satisfaction with the treating physician [89].

Multi-media training materials on communicating with parents about failed ASD-screeners

Given the short history of ASD-specific screening, little research is currently available on how to effectively communicate with parents about failed ASD-specific screening tests. In recent years, at least two groups have developed multi-media training materials that support PCPs in this area. As part of the “Learn the Signs. Act Early.” campaign, the CDC developed an in-class curriculum for current and future healthcare professionals, often presented in the context of hospital Grand Rounds (<http://www.cdc.gov/ncbddd/actearly/>) [65]. As part of this curriculum, learners watch and discuss video examples on how to communicate with parents about concerning screening results as well as various strategies for delivering difficult news. Importantly, learners are also provided with information about the stages of grief experienced by parents of children with disabilities. Similarly, as part of a webcast series on the medical home, the Waisman Center of the University of Wisconsin-Madison developed a 10-minute webcast on sharing screening results with families (<http://www.waisman.wisc.edu/connections>) [90]. The webcast covers topics such as the importance of developmental screening, understanding the difference between screening and diagnosing, and considering specific language to use when sharing concerns. It also discusses why sharing screening results can be difficult, and shares specific steps to follow when sharing screening results.

5. Supporting parents between referral and onset of services

Prompt access to Early Intervention can alter the developmental trajectory of individuals with ASD. A recent clinical trial tested the efficacy of a comprehensive developmental behavioral intervention program (Early Start Denver Model) in a sample of toddlers with ASD between 18 and 30 months [91]. Results from this study revealed significant treatment effects on children’s IQ, adaptive functioning, and autism symptoms. In many ways, this comprehensive treatment model for toddlers is consistent with the report of the National Research Council, which recommends that services should begin as soon as a child is suspected of having ASD and include a minimum of 25 hours a week, during which the child is actively engaged in systematically planned, and developmentally appropriate educational activity [92-94].

Comprehensive early intervention programs, consistent with the NRC recommendations or evidence based intervention practices [92-94] are currently not widely available to families of toddlers with ASD. Significant wait-times may delay children's prompt access to services [95]. In addition, programs are also not providing services at the recommended level of intensity. In a national survey of Early Intervention Coordinators, the vast majority of respondents indicated shortages of ASD-related personnel, including behavioral therapists (89%), speech-language pathologists (82%), and occupational therapists (79%). Further, Early Intervention Coordinators of almost half of the reporting states (44%) indicated that children with ASD receive 5 or fewer weekly service hours.

Families' ability to effectively utilize intervention services has also been linked to a range of demographic variables, including race and ethnicity [9, 96], immigrant status and cultural beliefs [97, 98], language [68, 99, 100], and SES [101]. Further, many families face geographic barriers in accessing ASD diagnoses and services. Children have been shown to receive diagnoses of ASD at older ages when the family lives in an area with few neurologists and psychiatrists [102]. Similarly, families in remote or rural areas often travel a great distance to reach services that are not available locally [103].

5.1. PCP behaviors that contribute to delays between referral and onset of services

The current chapter focuses on the gap between best practice and community implementation with regard to early identification of children with ASD. To fully support the needs of toddlers with ASD and their families, it is important to recognize that a similar gap between 'what we *know* and *do*' also exists with regard to early intervention practices. Thus, to ensure that children with ASD have access to appropriate services, PCPs should be mindful of several pitfalls that may contribute to delays between referral and onset of Early Intervention services.

1. Parents need to be reminded about the referrals

As described above, King and colleagues collaborated with 17 primary care practices to implement the AAP policy statement on developmental surveillance and screening [51]. Although a referral-tracking system is not specifically addressed in this policy statement, King and colleagues noted that more than half of the practices (9 out of 17) attempted to implement such a system. Because most practices include multiple healthcare professionals, a clinic-wide referral-tracking system is necessary to monitor which children had been referred and where they had been referred to. On the one hand, King reported that most clinics found referral-tracking to be a "time- and labor-intensive effort that was difficult to maintain over the long-term" (p. 357). On the other hand, clinics that were successful in implementing such a tracking system learned very quickly that many families didn't follow through with the recommended referrals, enabling them to develop strategies for providing additional reminders and supports. In addition, an effective referral-tracking system ena-

bled the physicians to develop better communication with local referral resources and receive more consistent feedback on the children they referred.

2. Parents need to be educated about ASD

An additional lesson learned by clinics implementing an effective referral-tracking system was that many families did not seem to understand the reason for their child's referral [51]. The parents' limited understanding is concerning, not only because it reduces the chances that the parent will follow through with the pediatrician's referral but also because a comprehensive ASD evaluation will progress more efficiently if parents are familiar with the behavioral characteristics of children with ASD and if they can report accurately about their child's behavioral red flags of ASD [6]. Finally, by educating the parents about ASD at the time when the referral is made, families have the opportunity to prepare themselves emotionally for the evaluation and the possibility that their child may have autism.

3. Early Intervention administrators need to be informed that ASD is suspected

In determining eligibility for Early Intervention services, evaluations may cover multiple areas of development, including (1) physical, including vision and hearing, (2) cognitive, (3) communication, (4) social or emotional, and/or (5) adaptive. The developmental profile of many toddlers with ASD is strikingly uneven with possible strengths in physical and cognitive development and specific delays in several social and communication milestones. Given that ASD symptoms may be observed in the absence of global developmental delays, it is important that the evaluation team is specifically charged with the task to 'rule out ASD'. If ASD symptoms are not specifically addressed during the evaluation, toddlers with ASD who also have strengths in global development may be missed and as a result may not be considered eligible for services.

5.2. Novel approaches to prevent delays between referral and onset of services

Several recent projects aiming to implement general developmental or autism-specific screening in the primary care setting found it necessary to create a dedicated staff position, a developmental or autism specialist, to provide second-stage screening services to prevent over-referral, and/or information, support, resources and referrals to families identified with developmental concerns [61, 104]. Other projects provided families with access to a developmental/autism specialist by creating a partnership with a local research group [3, 56]. Although this is a rather novel approach in the context of developmental and autism screening, the idea of a patient navigation program has been popular in other medical fields for several decades.

5.2.1. *The patient navigation program*

The American Cancer Society supported the nation's first patient navigation program in 1990 at the Harlem Hospital Center. Founded by Dr. Harold Freeman, patient navigation originally aimed to promote access to timely cancer diagnosis and treatment and to ensure coordinated

services by assisting patients and their families to navigate through the healthcare delivery system [105]. Ideally, patient navigators are familiar with the specific healthcare system through which the patient must navigate, culturally attuned to the patient, and connected to decision makers in the healthcare system. Patient navigation has the potential to improve the continuity of care [106], promote compliance with recommended referrals by fostering trust between patient and healthcare providers [107], and facilitate access to evaluations and services in underserved populations by connecting them to resources most appropriate for each patient's individual needs [107]. Although a successful patient navigation program bears significant promise for promoting early identification of ASD, such a program has not been implemented to date.

6. Conclusion

During the last decade, research on early identification, diagnosis and intervention for toddlers with ASD has made tremendous progress. Moreover, during recent years, the topic of community implementation of best practice strategies has risen to the forefront. In order to develop a sustainable service infrastructure for toddlers with ASD, systems for public awareness, early identification, and early intervention need to be scaled up in tandem with updated priorities in public policy and funding allocation. Eventually, efforts to increase early identification of children with ASD will only be successful if identified children have access to effective Early Intervention services.

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