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# Developmental delays and autism: Screening and surveillance

## ■ ABSTRACT

Screening and surveillance are crucial components to the early detection of developmental disorders in children, which enables early interventions that provide the best chances for improved outcomes. Identifying a developmental disorder is the initial step in evaluating the disorder. Surveillance is a flexible, continuous, longitudinal process aimed at identifying concerns, and it should be performed at every well-child visit. Screening involves administering a brief, standardized tool normalized for specific ages and stages of development to identify any developmental delays or specific concerns such as autism. Screening is recommended at every office visit and whenever a parent expresses a concern. Two general types of screening tests are available: problem-specific screening and broadband developmental screening. For each type, there are multiple different tests available that can be administered by a parent or a health care provider. Factors to consider in the test selection are the age range for which it is intended, time it takes to complete and score, cost, whether the test is paper-based or electronic, and the language availability.

**A**pproximately 1 in 6 children in the United States had a developmental disability or a chronic physical, behavioral, or emotional condition that placed them at risk for developmental disability in 2008.<sup>1</sup> These data also show that the prevalence of these disabilities increased by 17.1% from 1997 to 2008. The trend is even greater for autism. In a study of 8-year-old children in Atlanta, GA,<sup>2</sup> the estimated prevalence of autism spectrum disorder increased 269% from 1996

to 2010, an average increase of 9.3% each year.

Overall, the prevalence of any developmental disability was 13.9%. This includes the following prevalence percentages<sup>1</sup>:

- Learning disabilities, 7.7%
- Attention deficit hyperactivity disorder (ADHD), 6.7%
- Other developmental delay, 3.7%
- Autism spectrum disorder, 1.47%

Despite the high prevalence of these disabilities, many children are not appropriately diagnosed and treated. More than 30% of parents referred to professionals reported that help was not offered for their children's developmental disorders.<sup>3</sup>

## ■ IDENTIFICATION

Early identification through screening and surveillance is crucial because it enables early intervention, which improves outcomes for children with developmental disorders. Identifying a developmental disorder is the initial step in evaluating the disorder. It permits access to disease-specific intervention, and it helps parents understand their child's needs.

Identification also allows for reproductive counseling. For example, if a child has an autism spectrum disorder, the parents can be informed about their risk of having another child with the disorder. Siblings of these children have increased risks of a learning disorder. Finally, early identification allows access to free behavioral intervention through the Individuals with Disabilities Education Act, parts B (school-aged children) and C (36 months and younger).<sup>4</sup>

## ■ SURVEILLANCE

Ongoing surveillance is advised in addition to screening for developmental disabilities.<sup>5</sup> Surveillance is a flexible, continuous, longitudinal process performed at every well-child visit and aimed at identifying concerns. Screening involves administering a brief, standardized tool normalized for specific ages and stages of development to identify any concerns.

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### Screening vs surveillance

#### Screening

Involves administering a brief standardized tool for identifying concerns. Normed for specific ages/stages of development.

#### Surveillance

Is a flexible, continuous, longitudinal process performed at every well-child visit. Aimed at identifying concerns.

#### Surveillance components

The components of developmental surveillance include the following<sup>5</sup>:

- Eliciting and addressing parents' concerns
- Obtaining a developmental history by asking about developmental changes since the previous visit and requesting age-specific information (eg, whether the child is pointing or walking)
- Making accurate developmental and behavioral observations on fine and gross motor skills, speech and language, and social engagement
- Conducting a neurologic examination
- Identifying environmental, genetic, biologic, social, and demographic factors that present potential developmental risks or protection
- Maintaining an accurate record of documenting the process and findings.

The developmental history should note milestones and any delay, deviation, or regression from standard development expectations. Specific patient risk factors such as preterm birth, prenatal substance exposure, seizures, and growth abnormalities should be documented. Family risk factors including parental mental health, developmental disorders, or history of substance abuse should be recorded.

Developmental patterns should be assessed at each visit and classified as normal, delayed (normal sequence but slower rate of acquisition skills), dissociation (delay in one area of development but not others), deviance (achievement of milestones but not in the typical sequence, such as occurs with cerebral palsy), or regression (loss of previously acquired skills or a slowing or cessation of acquiring new skills).

Surveillance should note any abnormalities of body posture, patterns of movement, and muscle tone. Surveillance also should include looking for stereotypic movements like hand flapping, rocking, pacing, spinning, toe walking, and repetitive behaviors

(such as overly repetitive play). Eye contact should also be assessed. For example, does the child initiate eye contact, make only selective eye contact, or avoid eye contact?

Verbal and nonverbal communication should be assessed when observing how the child interacts with the physician and family members. Does the child use gestures such as pointing appropriately? Children with deficits in symbolic language, such as those with autism spectrum disorder (speech, gestures), may use hand-over-hand communication such as leading a parent by the hand or placing a parent's hand on what they want. Tantrums also can occur in children with developmental disabilities who lack more appropriate ways to communicate.

Behavioral observation includes scrutinizing engagement, impulsivity, and attention span. Tantrums, irritability, oppositionality, unusual fearfulness, and anxious, sad, or flat affect are warning signs of potential developmental or behavioral disorders. Facial expressions should be appropriate to the circumstance.

#### ■ SCREENING

All infants, toddlers, preschoolers, and early elementary-aged children should be screened at regular intervals. Older school-age children with developmental concerns or who are struggling in school may require testing by a psychologist.

The American Academy of Pediatrics (AAP) recommends routine developmental screenings for specific disorders at ages 9, 18, and 30 months (or at 24 months if a 30-month visit is not planned).<sup>5</sup> The screening at 9 months is intended to uncover potential vision and hearing problems, cerebral palsy, and other neuromotor disorders. At 18 months, screening can help identify cerebral palsy, autism spectrum disorders, global developmental delays, and specific language disorders. Screening for autism, global developmental delays, and specific language disorders should be repeated at the 24- or 30-month visits. In addition, AAP recommends an academic readiness assessment at age 4 to 5 years.

Development also should be screened whenever a parent expresses concern. Parental concerns about a child's speech, language, behavior, or other development have a sensitivity and specificity in detecting developmental deficits that approximates those of commonly used screening tools.<sup>3</sup> The message is to act immediately if a parent expresses a concern. If a parent is not concerned, continue with routine surveillance and scheduled screening.

**TABLE 1**  
Commonly used developmental screening tests, both autism-specific and broadband<sup>6,7</sup>

	Ages	Administration time	Cost	Sensitivity	Specificity
<b>Autism-specific screening tools</b>					
M-CHAT: Modified Checklist for Autism in Toddlers (www.mchatscreen.com)	16–30 mo	5 min	Free	85%–87% 95%–99%	93%–99% 95%–99%
PDDST-II: Pervasive Developmental Disorders Screening Test-II (www.pearsonclinical.com)	12–48 mo	< 15 min	Cost	92%	91%
<b>Broadband developmental-behavioral screening tests</b>					
ASQ: Ages and Stages Questionnaire, Third edition (www.agesandstages.com)	1–66 mo	10 min	Cost	82%–89% 50%–100% depending on age	78%–91% 39%–100% depending on age
ASQ: Social Emotional Test (www.agesandstages.com)	Varies	10 min	Cost	71%–85%	90%–98%
PEDS: Parents' Evaluation of Developmental Status Test (www.pedstest.com)	0–8 yr	2 min	Cost	86% (44%–78% primary care sample) 38%–79%	74% (63%–81%) 72%–85%
Brigance Early Childhood Screens III (www.curriculumassociates.com)	0–35 mo 3–5 yr 5–6 yr	10–15 min	Cost	73%–100% 74%–100%	72%–100% 85%–100% depending on age

## ■ SCREENING TOOLS

The two types of screening are problem-specific screening and broadband developmental-behavioral screening.

- Problem-specific screens are available for autism, speech delay, cognitive delay, or motor delay; they do not assess multiple different areas of development.
- Broadband developmental-behavioral screening tests are general and assess multiple areas of development, including autism.

Standardized tools with known reliability, sensitivity, specificity, and validity should be used. If the parents express no specific concerns, broadband developmental-behavioral and autism screening should be conducted at the AAP-recommended intervals. If a concern is noted on screening using a problem-specific tool, broadband screening is recommended because an abnormality in one domain may be a red flag for other developmental abnormalities.

Factors to consider in the choice of a test are the age range for which the test is intended, cost, length of

time it takes to complete and to score, whether the test is paper-based or electronic, and the language availability (many tests are available in several languages).

Screening tests may be administered by the primary care physician or trained office staff before the scheduled office visit and then interpreted by the physician. Alternatively, screening tests meant to be completed by parents, teachers, or daycare providers can be mailed to the home before a scheduled visit to be completed and then interpreted by the physician at the next office visit.

There are many resources for screening tools and algorithms, both broadband and autism-specific. Some commonly used tests are compared in **Table 1**.<sup>6,7</sup>

## ■ BILLING CODES

The CPT code 96110 (developmental testing; limited, with interpretation and report) is used for screenings completed by a parent (or other caregiver) and interpreted by the health care provider. The code can be used for each screening tool, if multiple tools are used per visit. Testing administered, scored, and

interpreted by the provider can be billed under CPT code 96111 (developmental testing; extended, with interpretation and report). The CPT code 96111 can be used only once per encounter, regardless of the number of tests administered.

### ■ DISCOVERING AN ABNORMALITY: REFERRALS, RESOURCES

Appropriate referral is indicated if a developmental concern has been uncovered during screening. If a concern is raised, either by parent report or identified by screening/surveillance, the child should be referred to the appropriate specialist for diagnostic testing (eg, developmental and behavioral pediatrics, neurology).

If the child is younger than 3 years, the Help Me Grow program ([www.Helpmegrow.org](http://www.Helpmegrow.org)) can provide additional screening and connect families to developmental services. It uses a network of community providers for support and maintenance during the referral process. Children 3 years and older are eligible for evaluation through the public school system.

Referral to physical therapy, occupational therapy, and speech and language evaluation may be appropriate. An audiology referral for a hearing evaluation is recommended whenever a concern is raised.

Neurology or physiology can be useful for evaluating abnormal gait and other motor disabilities typically seen with muscular dystrophy, cerebral palsy, and spina bifida. A genetics consult may identify causes of developmental delays and autism spectrum disorders. Neurology or genetics also may offer testing to assess for neurologic and metabolic causes of developmental delays. Developmental pediatricians can also evaluate for developmental disorders including autism.

Recognize that verbal children also can have autism spectrum disorders. In these children, the quality of communication is abnormal. When a concern about developmental delay is expressed or uncovered during screening, refer immediately for a diagnostic evaluation to avoid a delay in diagnosis and access to services. Early identification permits early intervention, which offers the best chance to improve outcomes.

### ■ SUMMARY

Screening for developmental delays and autism spectrum disorders in addition to ongoing developmental surveillance is recommended for all children at regular intervals, and is indicated whenever a parent expresses concern. Multiple screening tests are available. If a developmental concern is identified during screening, appropriate referral is indicated for further assessment.

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