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**IMPROVING
DEVELOPMENTAL
SCREENING AND
FOLLOW-UP**

Change Package

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Tool to Assist with Quality Improvement Process



Model for Improvement

Question 1: What are we trying to accomplish?

AIM:

A specific, measurable, time-sensitive statement of expected results of an improvement process (a statement of a specific, intended goal)

A strong, clear aim gives necessary direction to improvement efforts, and is characterized as

- Intentional, deliberate, planned
- Unambiguous, specific, concrete
- Measurable with a numeric goal, preferably one that provides a “stretch” to motivate significant improvement
- Aligned with other organizational goals or strategic initiatives
- Agreed upon and supported by those involved in the improvement and leaders

Make your Aim actionable and useful. Include the following:

- A general description of what you hope to accomplish
- Specific patient population who will be the focus
- Some guidance for carrying out the activities to achieve Aim

Sample Aim Statement

By [insert date], Happy Valley Pediatrics will improve the provision of preventive and developmental services to patients younger than 5 years by implementing the Bright Futures framework in our practice. Our office will focus on adopting strength-based counseling strategies and tools, the routine use of structured developmental assessments, forming links with resources in our community, and instituting a recall and reminder system.

We will achieve this Aim by using the Bright Futures Implementation and Training tools and materials so that

- One hundred percent of charts for children younger than 5 years have preventive services documented on a preventive services prompting sheet.
- Ninety percent of children younger than 5 years have structured developmental assessments documented in their charts.
- More than 90% of families with children younger than 5 years have parental strengths and needs assessed at well-child visits.

Question 2: How will we know that a change is an improvement?

MEASURES:

Measures are indicators of change. To answer this key question (“How will we know that a change is an improvement?”), several measures usually are required. These measures also can be used to monitor a system’s performance over time. In PDSA cycles, measurement used immediately after an idea or change has been tested helps determine its effect.

In improvement, key measures and measurement should

- Clarify and be directly linked to aims or goals.
- Seek usefulness over perfection.
- Be integrated into daily work whenever possible.
- Be graphically and visibly displayed.
- For PDSA cycle measurement, be simple and feasible enough to accomplish in close time proximity to tests of change.

Question 3: What changes can we make that will result in an improvement?

IDEAS:

Ideas for change or **change principles** to be tested in PDSA cycles can be derived from the following:

- Evidence—results of research/science
- Critical thinking or observation of the current system
- Creative thinking
- Theories, questions, hunches
- Extrapolations from other situations

When selecting ideas to test, consider the following:

- Direct link to the Aim
- Likely impact of the change (avoid low-impact changes)
- Potential for learning
- Feasibility
- Logical sequencing
- Series of tests that will build on one another
- Scale of the test (3 patients NOT 30)
- Shortness of the cycle (1 week NOT 1 month)



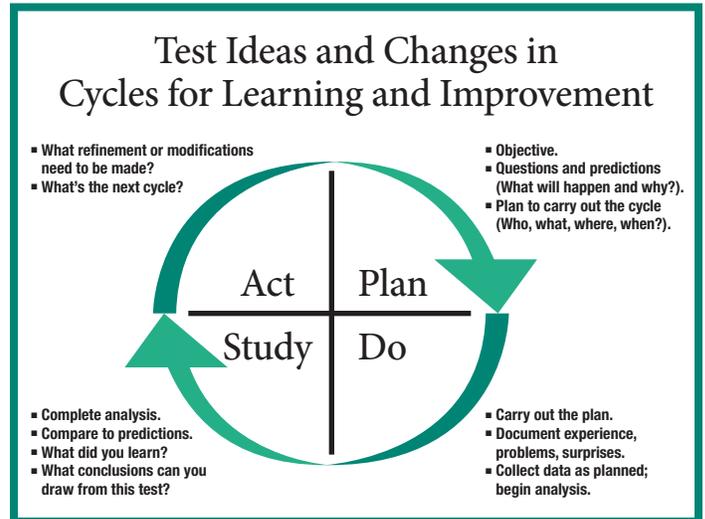
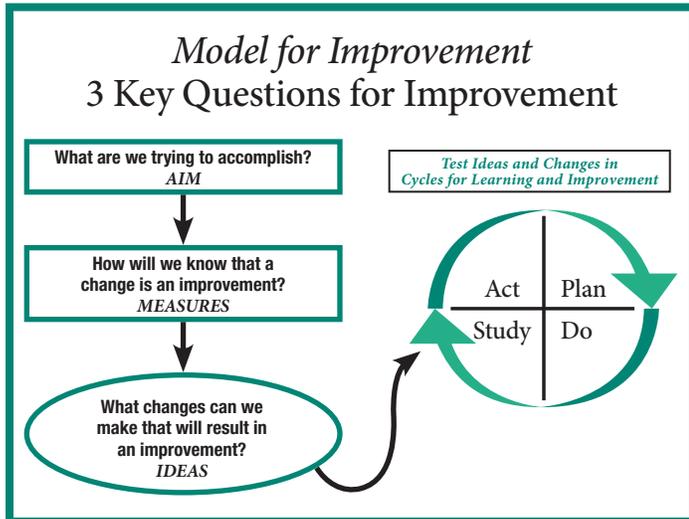
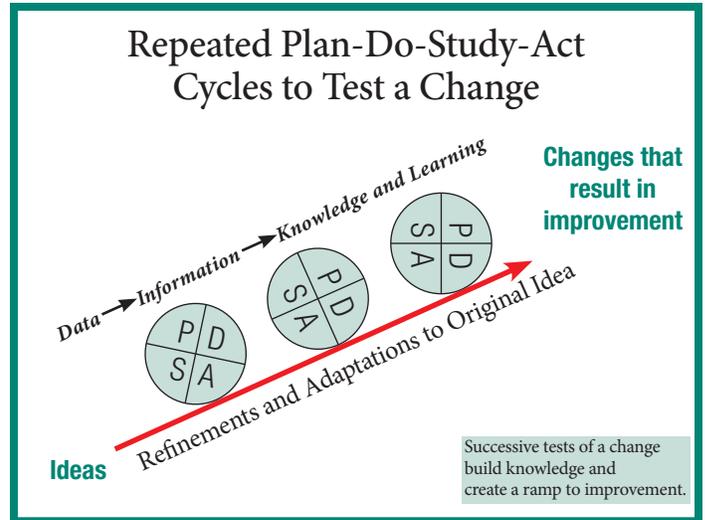
Model for Improvement Key Points

Why a Model? What Purpose?

- Provide organizing structure to guide thinking.
- Ensure discipline and thoughtfulness.
- Support improvement principles.
- Facilitate improvement.
- Foster common language.

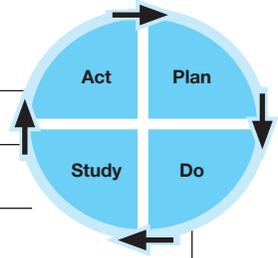
Improvement Principles

- Listen to customers.
- Tap knowledge of the system and people in it.
- Understand processes and interactions in the system.
- Use disciplined method in successive cycles to test changes.
- Test on small scale; move rapidly to improve.
- Measure to learn and to understand variation.



Tips to make the most of PDSA cycles and tests of change

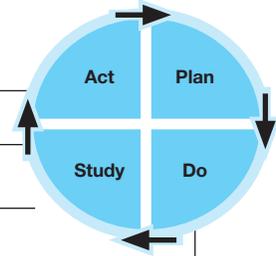
- ✓ Think a couple of cycles ahead.
- ✓ Plan multiple cycles to test and adapt change.
- ✓ Scale down size of test (number of patients, location)...A "cycle of 1."
- ✓ Do more cycles, at a smaller scale and faster pace instead of fewer, bigger, slower.
- ✓ Test with volunteers first.
- ✓ Do not seek buy-in or consensus for the test—particularly early on.
- ✓ Be innovative and flexible to make test feasible.
- ✓ Collect useful (*and only just enough*) data during each test.
- ✓ Test over a wide range of conditions.
- ✓ Learn from failures as well as successes.
- ✓ Communicate what you have learned.
- ✓ Engage leadership support.



<p style="text-align: center;">Model for Improvement PSDA Planning Worksheet</p>	<p>Team Name: _____</p> <p>Cycle: _____ Date: _____</p>
<p>PLAN</p> <p>Objective for this cycle:</p> <p>Questions:</p> <p>Predictions:</p> <p>Plan for change or test: (Who, What, When, Where?):</p> <p>Plan for collection of data: (Who, What, When, Where?):</p>	
<p>DO: Carry out the change or test. Collect data and begin analysis. Describe observations, problems encountered, and special circumstances.</p>	
<p>STUDY: Complete analysis of data; summarize what was learned.</p>	
<p>ACT: Are we ready to make a change? Plan for the next cycle.</p>	



Example



<p>Model for Improvement PSDA Planning Worksheet</p>	<p>Team Name: Happy Valley Pediatrics</p> <p>Cycle: <u>1</u> Date: _____</p>
<p>PLAN: Establish a reminder/recall system identifying and following up on patients needing preventive care. Objective for this cycle: Take a proactive approach by identifying patients who need preventive care and calling them to schedule appointments. Questions: How can patients who need preventive care be identified? How many patients are there who need well-child checks? Do we have time available on the schedules to see them? Who has time to do the scheduling? What information should be kept to track the effectiveness of the scheduling efforts? Predictions: Calling patients to schedule appointments should improve our goals for patient care. Plan for change or test: (Who, What, When, Where?): I will try to identify the patients who need well-child checks and assign calls to the office staff. Plan for collection of data: (Who, What, When, Where?): They will indicate the outcome of each call. If scheduled, they will indicate the date of the appointment so I can track whether the patient kept their appointment. I have assigned a report to more easily identify patients who need well-child checks, but, until it is programmed, I will use a report I currently have by entering dates of service and the procedure codes for health checks.</p>	
<p>DO: Carry out the change or test. Collect data and begin analysis. Describe observations, problems encountered, and special circumstances. The first run of the report produced 392 pages. This had to be broken down to be manageable. Ran the report again for only 0- to 1-year olds. This run produced 10 pages—229 patients. Using the report, we scheduled 121 patients, there were 47 scheduled before the project, 33 are pending and 28 were lost to follow-up.</p>	
<p>STUDY: Complete analysis of data. Summarize what was learned. This is a worthwhile effort. We will continue to take a proactive approach to scheduling well-child checks. The front office staff will routinely make calls. Calls will be assigned evenly among the office staff as part of their job duties. If we make appointments and patients do not keep their appointments, a warning letter may be sent defining our agency policy. If another appointment is missed, patients may be eligible for discharge. There is a system in place to identify patients who need warning or discharge letters but they are easier to identify if they miss their appointment. Getting all patients scheduled provides a means for follow-up on medical care as well as patient compliance.</p>	
<p>ACT: Are we ready to make a change? Plan for the next cycle. We made a second round of calls to this group of patients and there are still 33 pending, but we did schedule 121 through this effort. We will continue this effort with patients aged 1 to 2 years. Then, we will call 2- to 3-year-olds and go back and pick up the 2-month checkups for the 0- to 1-year-olds and so on. Continue to work with information services on the new report, which lists patients' date of birth and a table of the periodicity schedule with the date the well-child check is due based on the birth date and the periodicity schedule. Idea: This table/schedule would be helpful for parents. Can we make magnets for their refrigerators with the schedule for each of their children?</p>	

From the Bright Futures Training Intervention Project. For additional information, visit <http://brightfutures.aap.org>.



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Tools to Make Change and Implement Developmental Surveillance and Screening



STEPS TO USING SCREENING AND SURVEILLANCE IN YOUR OFFICE

Careful preparation will increase the likelihood you will successfully implement and sustain new systems for using screening and surveillance in your practice.

Elicit explicit support from practice leaders to use new structured screening tools

- Practice leader support is important when introducing new tools and strategies. Discuss with practice leaders the evidence that supports the use of developmental screening tools. Obtaining staff support for implementing new procedures will help persuade them to participate. Encourage leaders to discuss at staff meetings how soliciting parental concerns will improve patient care.

Assign responsibility for coordinating the use of developmental screening tools

- Identify a staff member to lead and coordinate efforts to incorporate screening into your practice. Consider creating a team of people to undertake this responsibility. It may be helpful to involve representatives of the physician, nursing, and administrative staff because they may all need to participate in implementation.

Communicate with staff about new procedures for screening

- Seeking ideas and input from staff will help you develop the right system for incorporating screening into your practice.
 - Inform staff of the available tools and resources.
 - Share information about how using these tools will improve patient care.
 - Describe how materials will be organized so that staff can easily access materials and information as needed.
 - Train everyone in the practice to provide consistent information to parents about the purpose of the screening and assessment, and how the information benefits their child's care.

Select screening instruments

- Several instruments are available for use in clinic settings. Consider:
 - Who will ensure that copies of the screening are available? Some tools are protected by copyright and must be ordered from the publisher. Other tools are in the public domain and can be reproduced. Assign someone to monitor the inventory and replenish supplies as needed.
 - Determine the interval for patients to receive the screening.
 - After you have determined the intervals for screening, be sure to think carefully about how you will identify the patients who are supposed to be screened (e.g., flagging charts, incorporating a reminder system into patient appointments).

Determine when the parent will receive the screening

- There are several options for distributing screening tools to parents.
 - Mail or email the screening to families prior to the appointment. Doing so allows the parent more time to complete the information. This option also allows input from daycare providers or others close to the child. Be certain to establish a procedure to follow if parents forget to bring the completed screening to the visit.
 - Give the tool to the parent during the office visit. Some parents may not read well. In this situation, it can be helpful to use a simple form and to offer parents the opportunity to get assistance when completing the tool. Ask parents, "Would you like to complete this on your own or have someone go through it with you?"
 - Determine how you will introduce the screening to parents. Consider explaining to parents that the screening is very important because it helps the physician understand their child's needs

better. Let parents know who they can ask for help if they need assistance. Remind them that all the information is confidential.

Who will distribute and score the screening?

- Office staff can play a key role in performing different screening tasks. Distribute the work across several staff. For instance, a receptionist can be in charge of making sure parents complete the screening while a nursing assistant, nurse, or developmental specialist can score the screening and highlight areas for the clinician to follow-up.

Test out ideas before implementing changes throughout the practice

- Before attempting practice-wide implementation of a new structured screening tool, try it out with five families and review what you learned from those encounters. Ask yourself: "Did this tool uncover important parental concerns I might have missed in the past?; How did the parents react to providing this information?; Do I need more information or training to make this a better interaction?; and How could we improve the flow of getting the parent the tool?" You may find it helpful to repeat such tests several times before you decide which new materials or strategies should be implemented practice-wide. It is important that the team testing new strategies keep track of its efforts to help determine which approaches are successful.

Prepare for the human side of change

- Changes—even those that a practice agrees to make—can be difficult. People react differently to changes. Some staff may resist changes because they are unfamiliar. Some changes may create additional work until everyone is more accustomed to the new routines (e.g., asking added questions during a visit, using a new tool). To already busy clinicians and staff, a change that is perceived as creating more work is likely to be avoided unless the benefit of the change is clear. Describing the benefits, acknowledging that such changes may require extra time, and recognizing everyone's efforts to improve care can increase the likelihood that providers and staff will use new tools and approaches.

Train clinicians and staff

- As you introduce the structured screening tools into your practice you may find using such tools is new to some or all of your clinicians and staff.
 - Consider holding informal training sessions for all staff to present the rationale for using new tools. Include scientific evidence that supports their use. Provide opportunities for questions and review the new tools and how they will be used.
 - Include instructions on any new roles or responsibilities for staff or clinicians.
 - Staff might welcome a session on how to talk about sensitive topics or how to handle difficult situations that may come to light as a result of using the new tools (e.g., maternal depression, family violence).

Determine what to do with completed screenings

- Determine if you need to store completed screenings and where to store them.
- Consider how to incorporate information from the screening into future care. If you are planning to compile data from a sample of screenings to inform quality improvement, determine who will tally and present the data.
- If screening your patients in a structured way uncovers areas where you want to increase your ability as a practice to handle concerns either individually or systematically, develop plans for enhancing those aspects of your practice.

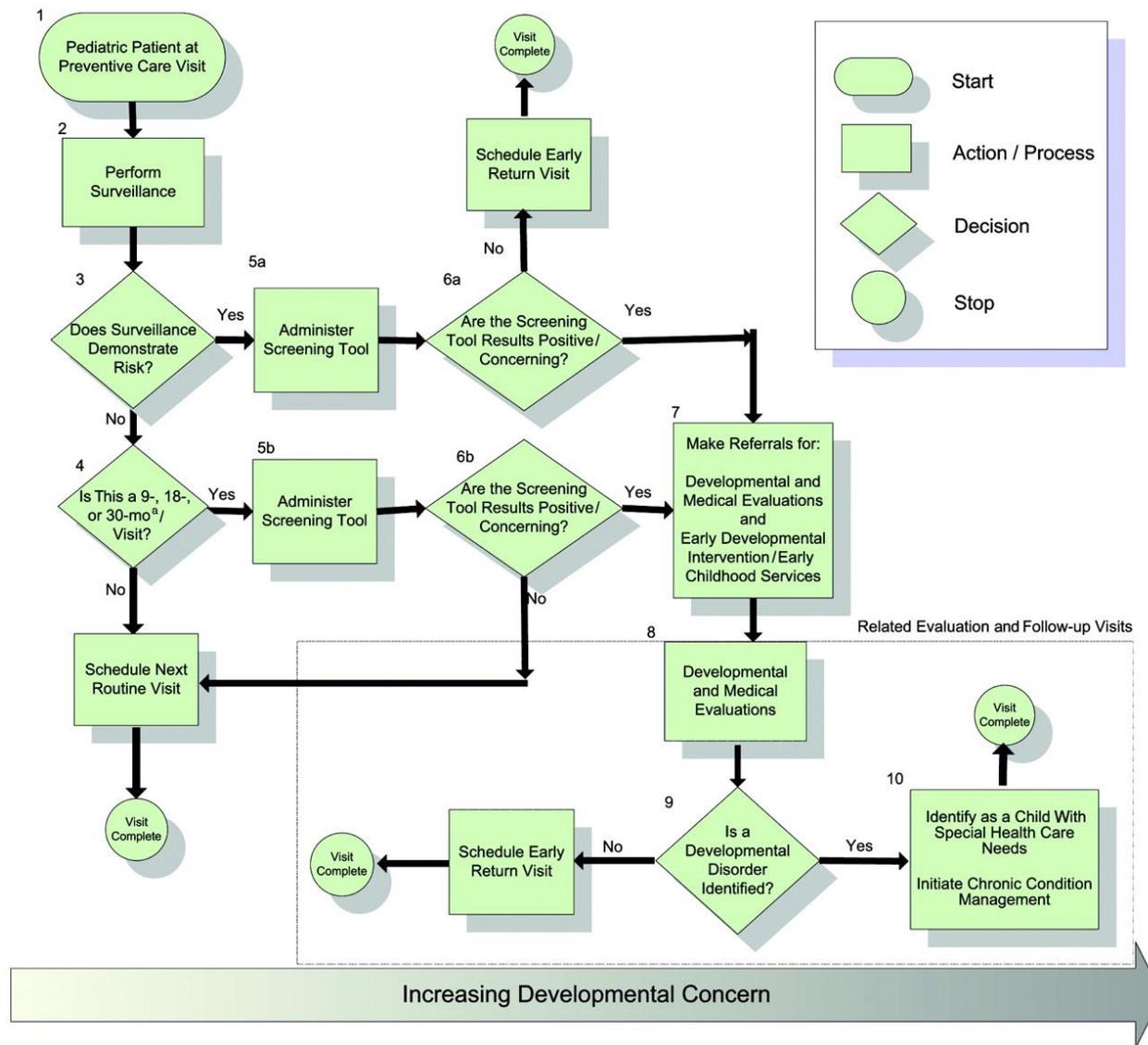
Consider what new resources or referrals your practice may need

- If using structured screening tools is new to your office, you may need to identify community resources for referrals for issues that are revealed by the structured screening approach. Gathering data about the most common concerns of your patients may help you decide which referrals and community resources are the most likely to be needed and used by your patients.

MONITORING PROGRESS

Ask for patient feedback during encounters

- An easy, low technology way to assess your practice's performance is simply to ask families for feedback while they are in the office. When you ask for your patient's input, be prepared to respond.
- Consider running a "feedback drive" once or twice each year in your practice. During your practice's "feedback drive," each clinician and staff person could be instructed to solicit feedback from a set number (e.g., 2 or 3) of patients per day during the course of the drive. A simple feedback tool could be attached to the chart to remind clinicians to collect and provide a place for the data to be recorded. All the completed feedback tools can be summarized and used by the practice to better understand how the patients in the practice perceive their care.
- Regardless of the method you use to collect data from patients on a regular basis, be sure to set aside time at regular practice meetings to share feedback from patients with others on your clinic staff.



Council on Children With Disabilities et al. *Pediatrics* 2006;118:405-420

PEDIATRICS[®]

Pediatric Patient at Preventive Care Visit

1. Developmental concerns should be included as one of several health topics addressed at each pediatric preventive care visit throughout the first 5 years of life.⁶

2. **Developmental surveillance** is a flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems. There are 5 components of developmental surveillance: eliciting and attending to the parents' concerns about their child's development, documenting and maintaining a developmental history, making accurate observations of the child, identifying the risk and protective factors, and maintaining an accurate record and documenting the process and findings.

Perform Surveillance

Does Surveillance Demonstrate Risk?

3. The concerns of both parents and child health professionals should be included in determining whether surveillance suggests the child may be at risk of developmental delay. If either parents or the child health professional express concern about the child's development, a developmental screening to address the concern specifically should be conducted.

4. All children should receive developmental screening using a standardized test. In the absence of established risk factors or parental or provider concerns, a general developmental screen is recommended at the 9-, 18-, and 30-month^a visits. Additionally, autism-specific screening is recommended for all children at the 18-month visit.

Is This a 9-, 18-, or 30-mo^a Visit?

Administer Screening Tool

5a and 5b. **Developmental screening** is the administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder. Developmental screening that targets the area of concern is indicated whenever a problem is identified during developmental surveillance.

6a and 6b. When the results of the periodic screening tool are normal, the child health professional can inform the parents and continue with other aspects of the preventive visit. When a screening tool is administered as a result of concerns about development, an early return visit to provide additional developmental surveillance should be scheduled even if the screening tool results do not indicate a risk of delay.

Are the Screening Tool Results Positive/Concerning?

Make Referrals for: Developmental and Medical Evaluations and Early Developmental Intervention/Early Childhood Services

Developmental and Medical Evaluations

7-8. If screening results are concerning, the child should be scheduled for developmental and medical evaluations. **Developmental evaluation** is aimed at identifying the specific developmental disorder or disorders affecting the child. In addition to the developmental evaluation, a **medical diagnostic evaluation** to identify an underlying etiology should be undertaken. **Early developmental intervention/early childhood services** can be particularly valuable when a child is first identified to be at high risk of delayed development, because these programs often provide evaluation services and can offer other services to the child and family even before an evaluation is complete.²⁵ Establishing an effective and efficient partnership with early childhood professionals is an important component of successful care coordination for children.⁴⁰

9. If a developmental disorder is identified, the child should be identified as a child with special health care needs and chronic condition management should be initiated (see No. 10 below). If a developmental disorder is not identified through medical and developmental evaluation, the child should be scheduled for an early return visit for further surveillance. More frequent visits, with particular attention paid to areas of concern, will allow the child to be promptly referred for further evaluation if any further evidence of delayed development or a specific disorder emerges.

Is a Developmental Disorder Identified?

Identify as a Child With Special Health Care Needs
Initiate Chronic Condition Management

10. When a child is discovered to have a significant developmental disorder, that child becomes a child with special health care needs, even if that child does not have a specific disease etiology identified. Such a child should be identified by the medical home for appropriate chronic condition management and regular monitoring and entered into the practice's children and youth with special health care needs registry.⁴¹



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Tools for Discussing Screening Results

Sugar-coaters and Straight Talkers: Communicating About Developmental Delays in Primary Care

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KEY WORDS

child development, developmental concerns, communication, primary care

ABBREVIATION

EI—early intervention

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WHAT'S KNOWN ON THIS SUBJECT: Revised recommendations on developmental surveillance and screening in the medical home mean that providers will increasingly need to communicate with parents about developmental concerns. Little information exists to guide providers in communicating with parents regarding this complex topic.



WHAT THIS STUDY ADDS: This study provides new information and recommendations on conceptualizing communication between parents, primary care providers, and EI specialists regarding child development and developmental concerns.

abstract

OBJECTIVES: The goals were to investigate parents' and early intervention (EI) specialists' beliefs and experiences regarding discussing child development in primary care and to identify communication barriers and opportunities.

METHODS: Focus groups were held with (1) mothers of young children with typical development, (2) mothers of young children who received EI services, and (3) EI specialists. Seven groups ($N = 46$ participants) were conducted in the greater Cleveland, Ohio, area. Meetings were audio-recorded, transcribed, coded, and analyzed, to identify themes.

RESULTS: Most mothers reported a preference for a nonalarmist style of communication when developmental delays are suspected. In contrast, some mothers preferred a more direct style, including the use of labels to help them understand their child's development. The importance of preparation to accept information about developmental delays emerged as a theme in all groups. Elements contributing to preparedness included information about expected developmental skills, suggestions for promoting skills, and a specific time frame for follow-up evaluation. Mothers of children with disabilities perceived that early reassurance of normalcy by providers in response to their concerns led to self-doubt and increased difficulty accepting the diagnosis.

CONCLUSIONS: Mothers and EI specialists have clear ideas about factors that promote or impede communication regarding child development. This information can inform primary care providers' approaches to monitoring and screening the development of young children and to communicating with parents regarding suspected developmental delays. *Pediatrics* 2009;124:e705–e713

TABLE 1 Examples of Questions Used in Focus Group Meetings

	Parent Groups	EI Specialist Groups
Sources of information	Who has been most helpful in helping you to learn about your child's development? How has your child's doctor been helpful to you in terms of understanding your child's development?	Where do parents usually get information about child development? How often are parents the ones to have a concern about their child's development when they are presenting for an EI assessment?
Communication with physicians	If the doctor thinks that a child's development might be somewhat behind, is it better to bring it up with the parent right away, or is it better to wait and make sure that there is really a problem? If a child's development is behind what is expected for age, what words or explanations would help a parent to understand what is going on?	What do parents tell you about the role their child's physician has played in identifying a developmental delay or problem? What words or explanations help parents to understand a child's development when there is a delay? How does communication between EI specialists/educators and doctors happen?
Evaluation	If a child's development seems to be behind, what would help a parent decide to get an evaluation or testing and to get treatment services?	What helps parents decide to get an evaluation or testing and to get treatment services? What are the important factors that determine whether families will come for services after the initial EI assessment?

Systematic developmental screening of children historically has not been implemented in most primary care practices.^{1,2} Revised recommendations for developmental screening from the American Academy of Pediatrics make it likely that screenings will be used increasingly.^{3,4} Developmental surveillance and screening have the potential to facilitate discussions regarding developmental concerns, leading to earlier detection of developmental delays.⁵ Parents' developmental concerns are predictive of actual developmental problems,^{6,7} and early discussions likely determine whether children with suspected delays are referred promptly for evaluation and treatment. Although surveys identified time and costs as principal barriers to screening,^{1,2} other potentially important factors include parents' beliefs regarding communication about child development and the complexity of communication about developmental concerns. Effective communication contributes to the education of all parents in a practice, improving satisfaction with care.⁸

Few studies have examined initial communication regarding developmental concerns in primary care or parent-provider communication regarding suspected developmental delays be-

fore an exact diagnosis is known.^{6,7,9,10} Although, in theory, parents can contact early intervention (EI) services directly for an evaluation, primary care providers act as de facto gatekeepers because parents often are unaware of the existence of these services. Although a significant body of literature on communicating difficult news to patients and parents exists, it mainly addresses disclosure of diagnoses.¹¹⁻¹⁵ In developmental/behavioral pediatrics, the focus is on disclosure of diagnoses in subspecialty or inpatient settings.¹⁶⁻²⁵ Applicability to communication regarding suspected developmental delays in primary care likely is limited.

Qualitative methods are especially helpful for furthering understanding of beliefs regarding complex topics that have undergone little study.^{26,27} In primary care, qualitative methods have been used to examine related topics, including maternal disclosure of parenting stress and depressive symptoms²⁸ and perceptions of providers as sources of parenting advice.²⁹

We sought to understand the communication needs, beliefs, and experiences of key stakeholders (parents and EI providers) regarding child de-

velopment and the initial identification of developmental delays in primary care. The objectives of this study were to identify and to understand new barriers and opportunities for this communication, to address a gap in the literature.

METHODS

Focus Groups

Focus groups were conducted to explore beliefs, opinions, and experiences regarding communication between parents, EI specialists, and primary care providers about child development and suspected developmental delays. A focus group is a planned discussion designed to elicit perceptions regarding an identified area of interest, in a nonthreatening environment.³⁰

A structured list of questions and follow-up probes was developed to address (1) the ways in which parents raise developmental questions and concerns and (2) beliefs, experiences, and recommendations regarding communication with primary care providers about child development and developmental concerns (Table 1). Two researchers in psychology, 1 researcher in family medicine, and 4 early childhood education profession-

TABLE 2 Demographic Characteristics of Focus Group Participants

	Parents					EI Specialists	
	Non-EI			EI		Group 1	Group 2
	Group 1	Group 2	Group 3	Group 1	Group 2		
No. of participants	6	2	3	7	11	9	8
Participant characteristics							
Age, mean \pm SD, y	23 \pm 4	36 \pm 8	39 \pm 2	43 \pm 6	40 \pm 8	43 \pm 10	48 \pm 5
Female, <i>n</i>	6	2	3	7	11	9	8
Non-Hispanic, <i>n</i>	5	2	3	7	11	9	8
Race, <i>n</i>							
Black	3	1	1	3	0	1	4
White	2	1	2	4	9	7	4
Other/ $>$ 1 race	1	0	0	0	2	1	0
Married, <i>n</i>	3	1	3	3	10	NA	NA
Education, <i>n</i>							
High school/general equivalency diploma or less	4	0	0	0	4	NA	NA
Some college, technical school, or associate degree	2	1	1	4	5		
4-y college or graduate school	0	1	2	3	2		
Family characteristics							
No. of children, mean \pm SD	2.7 \pm 1.0	3.0 \pm 2.8	1.3 \pm 0.6	2.6 \pm 1.0	2.1 \pm 1.0	NA	NA
Age of youngest child, mean \pm SD, y	2.4 \pm 1.5	2.2 \pm 1.2	1.4 \pm 1.4	5.7 \pm 2.4	7.7 \pm 4.0	NA	NA
Age of child in EI, mean \pm SD, y	NA	NA	NA	7.5 \pm 1.7	8.5 \pm 4.7	NA	NA
Child had check-up in past 12 mo, <i>n</i>	6	2	3	7	10	NA	NA
EI specialists' training							
Professional training, <i>n</i>	NA	NA	NA	NA	NA		
Early childhood education						2	7
Elementary education						0	2
Special education						0	4
Social work						6	0
Other						1	1
Time working in field, mean \pm SD, y	NA	NA	NA	NA	NA	13 \pm 9	21 \pm 3
Characteristics of EI clients/workplace							
Type of community where work, <i>n</i>	NA	NA	NA	NA	NA		
Urban, low income						1	1
Suburban						8	2
Both						0	5
No. of children evaluated per week, mean \pm SD	NA	NA	NA	NA	NA	9 \pm 1	10 \pm 4
Qualifying category for service, estimate \pm SD, %	NA	NA	NA	NA	NA		
Suspected/established delays						83 \pm 8	75 \pm 16
Environmental factors						14 \pm 11	22 \pm 18
Other						3 \pm 7	3 \pm 9

NA indicates not applicable.

als reviewed the questions for content and clarity.

Participants

Separate focus groups were held with 3 types of participants, that is, (1) mothers of children who were receiving/had received EI services (EI parents), (2) mothers of children $<$ 5 years of age who had not received EI services (non-EI parents), and (3) EI specialists. Non-EI parent groups were included to represent the perspective of most parents. Semi-structured interviews were conducted

with primary care providers, and results will be summarized in a separate report. Other authors have used an approach involving separate groups with multiple stakeholders to study an issue in primary care.³¹

Two community-based EI agencies distributed informational flyers to recruit EI parents. Non-EI parents were recruited through flyers posted at a parent education center, a public library system, an urban university hospital-based pediatric practice, and a suburban pediatric practice. EI specialists

were recruited from 2 EI agencies in Cuyahoga County, Ohio. Meetings were held in community settings in the Cleveland, Ohio, area.

Seven focus groups were conducted between May 2004 and January 2005, including 2 with each type of participant and an additional non-EI parent group because of low attendance (Table 2). Each participant took part in one 90-minute meeting and received token compensation (\$25).

Informed consent was obtained. The institutional review boards of the Uni-

versity Hospitals of Cleveland and Boston Medical Center approved this study.

Data Collection

Participants completed a demographic information form. Focus groups were conducted by an experienced facilitator (Ms Mercer). Dr Sices and a research assistant were present at each meeting. Meetings were audio-recorded, and written notes were taken.

Data Analysis

Audio recordings were transcribed and analyzed by using a combined approach of initial immersion/crystallization (reading full transcripts and listening to recordings to obtain an overall sense of themes) and later text editing to identify themes.^{32,53} Three team members coded each transcript independently by using codes based on core topics, met to discuss coding, and resolved discrepancies through consensus. Data were organized by using NVivo 2 software (QSR International, Doncaster, Victoria, Australia).

RESULTS

Themes

Emerging themes focused on ways in which parents and providers initially raise developmental concerns and factors that influence parent-provider communication regarding development and early developmental concerns.

Communication of Developmental Concerns

Discussion of Child Development and Raising of Concerns

Parents in non-EI groups reported that they would raise developmental concerns by asking providers, "Should she be doing this by now?," rather than stating a concern explicitly. Although some mothers in EI groups recalled

mentioning an initial concern directly to the provider, others recalled commenting that their child was not performing certain skills.

Several non-EI mothers thought that they would monitor developmental concerns for several months before raising them at a regular check-up. Although some mothers in both EI groups reported that they had raised a concern as soon as it arose, others acknowledged that fear or denial might make a parent wait. EI specialists thought that how providers ask questions affects the quality of parent responses, "I think that when you're in that rushed setting in a doctor's office, if someone comes in and says, 'Is your child doing this?,' you kind of know what the answer is supposed to be, so the parents will just say, 'Yeah, yeah, they are doing that.'"

Recommendations for Explaining Suspected Delays

"Sugar-coaters"

Non-EI parents preferred a non-alarmist style of communication and appreciated providers who acted as partners in addressing concerns. One parent offered recommended wording, "I really think that most children are doing this by now."

Although participants in EI parent groups also considered it important not to alarm parents, they emphasized the importance of communicating the need to take action, "It seems like he might be behind, but keep an eye on this. . . . Why don't you read this? And call me back in a couple of weeks and let me know that this isn't getting any better," or "[Your child's] development may be behind; let's do further testing." One parent noted, "You don't have to scare the parent, but just by saying 'Let's be safe, let's do the speech screening. . . . You may be pleasantly surprised, it may be nothing.'"

"Straight Talkers"

Several EI parents recommended a more-direct approach, "getting it out in the open right away . . . and going from there." One parent stated, "Don't sugar-coat it. That's not going to help me 10 years down the road if you try to sweet talk your way through this. Be honest, be straightforward."

Disclosure of Potential Delays

EI parents and EI specialists emphasized the importance of preparing to hear about developmental delays. One parent explained, "I liked how [the pediatrician] didn't want to alarm me at first. . . . I had time to prepare myself, 'Okay, when you go in, in 2 months, let's see what goes on.' Well, I saw that regression still occurring so I knew . . . I was going to hear something. It was nice to have that preparation and it didn't just hit me like a wall." EI specialists agreed that "sometimes the families are not ready" to hear about a delay and questioned the need for services.

EI parents reported that positive experiences during initial discussions about developmental delay fostered acceptance of the diagnosis. The parent of a child later diagnosed as having cerebral palsy reported that her provider "asked all of the right questions and when I said, 'No, he's not,' he was pretty calm, which made me calm. Then he said, 'It's probably nothing, but let's go further with this.'" Another recalled that the provider effectively addressed her concerns about language development; after reviewing a checklist at 15 months, he said, "I don't want to say anything; I want to see him at his 18-month appointment and we'll see what happens." At 18 months, with evidence of continued delay, he said, "I think there's a lot of red flags. I think there's a problem; I'm not going to say exactly. I suspect perhaps autism or some sort of developmental delay."

Her child received a diagnosis within a few months.

Barriers to Communication

Blame and Denial

Themes related to blame emerged in a number of groups. In one non-El parent group with lower-income mothers, several mothers expressed concern about being blamed for their child's delay. When providers reviewed developmental milestones, some mothers feared that they would "consider you neglecting your kid when they [the child] don't know something"; therefore, the mothers answered yes even if their child was not demonstrating the skill. These parents worried that providers would suspect neglect and might report them to child protective services if their child exhibited delay.

Blame emerged as a theme in both El parent groups. A mother commented on her experience discussing her child's development with the provider, "I think it would have been better to do it together as a team as opposed to him making me feel like it was my fault . . . that [my child] wasn't progressing the way he should have been."

Importance of Being Heard

A number of El parents reported that providers responded to developmental concerns in supportive ways, providing written information, referrals to specialists, information about El and other resources, and care coordination. Provider characteristics appreciated by mothers included compassion, open-mindedness, and the ability to "follow [the parent's] lead." One mother recalled the provider saying, "Well, I don't know; we would have to figure this out together," and she appreciated that honesty. Another felt "blessed with a pediatrician . . . [who] took our concerns extremely seriously."

Conversely, a number of El parents reported difficulty getting providers to acknowledge and to act on their concerns, "Some things just didn't add up to me and, yes, I brought them up right away, but I wasn't always taken real serious about it." A mother of a child later diagnosed as having autism reported, "I had to yell at the doctor one day and say, 'My daughter is not talking anymore. Are you telling me that's OK? You write this down and tell me that it's normal.'" This theme was echoed by El specialists, "If [the parent has] been to a pediatrician who said, 'Oh, he'll outgrow it,' and we just sit there and listen, sometimes that's the best thing we can do. . . . Just that they're taken seriously."

"Watch and Wait" and False Reassurance

Certain El parents thought that they had been reassured improperly after raising developmental concerns, with explanations such as, "He's just a boy. . . . If he's not talking by 2 we'll worry about it" and "She'll outgrow it. . . . Give her another year." El specialists similarly reported, "You get the parents who say, 'I brought this up to my pediatrician, and he said there is nothing to worry about.' . . . The parent feels exasperated by the time I'm there because they have tried to bring attention [to the problem]."

Concerns about the timeliness of physicians' responses to expression of concern emerged in both El parent groups, "I think our first pediatrician just took too long." Although non-El parents stated that they would worry if providers raised developmental concerns, they would not blame them if the child was not found to have delays in further evaluations. Participants in both El specialist groups also said that parents are relieved in these situations and do not discredit providers.

Missed Opportunities to Collaborate on Communication

Participants in both El parent groups highlighted the importance of direct communication between primary care providers, specialists, and therapists, to avoid giving parents conflicting assessments. El specialists noted that parents often received conflicting messages, asking, "Why didn't the pediatrician tell me this?" or "Why are you telling me this, and they haven't noticed this?" El specialists expressed frustration that the "communication triangle" between themselves, parents, and providers caused some parents to refuse El services.

El specialists thought that communication with providers was strained by differences in assessments of children and in the status of the 2 professions, "I think probably I've seen more handicapped children than some of the typical pediatricians have. And so you always walk this fine line between do I call this doctor and say, 'Maybe you should think about doing x, y, z,' and then offending him or her." El specialists thought that certain parents had difficulty communicating developmental concerns to providers. Knowing this, they coached parents with "key words." One specialist coached the mother of a child she strongly suspected had spastic quadriplegia and was dismayed when the parent reported back, "Well, the doctor said she's moving and we just need to give it a little more time."

El specialists identified opportunities to improve communication, including established relationships between El specialists and nurses in some practices and hospital-based El social workers at some institutions. Participants provided insights and specific recommendations for facilitating effective communication regarding developmental concerns (Table 3).

TABLE 3 Summary of Themes and Recommendations

Theme	Issue	Recommendations for Primary Care Providers
Raising concerns: parental expression of developmental concerns may be subtly stated	Parents may raise developmental concerns in subtle or indirect ways that may not be recognized by providers as actual concerns (for example, the parent may ask, "Should she be doing this by now?")	Recognize that significant parental concern may be stated not as concern but as subtle questions about skills and milestones; systematically inquire about parents' developmental concerns
Preparation: parents' readiness to hear about suspected delays is key to accepting information	Parents differ in their preferences for providers' communication styles regarding developmental concerns (less direct ["sugar-coaters"]: "I liked how [the pediatrician] didn't want to alarm me at first. . . . I had time to prepare myself"; more direct ["straight talkers"]: "Don't sugar-coat it. That's not going to help me 10 years down the road if you try to sweet talk your way through this. Be honest, be straightforward"); preparation to hear about concerns may depend on parents' level of awareness or preparation; parents may not be aware of developmental delays and may need time to prepare themselves to hear or to accept this information	Elicit and consider parents' level of awareness of developmental concerns in planning initial communication regarding suspected developmental delays; use nonalarmist style to communicate about possible developmental delays (preference of sugar-coaters, who may not yet be aware); be direct (but gentle) and avoid sugar-coating news about suspected delays (preference of straight talkers, who likely are already aware); when developmental delay is suspected, prepare parents by giving them emerging skills to look for in their child and to discuss at follow-up visits
Barriers/opportunities in communication Importance of being heard/being taken seriously	Some parents think their developmental concerns were not heard or taken seriously by the primary care provider ("[The pediatrician] was listening, but she wasn't hearing everything that I was saying"); false reassurance reduces trust in the provider when a delay is later diagnosed ("She'll grow out of it . . . Give it another year")	Communicate to parents that providers expect to hear concerns; explicitly acknowledge the importance of parents' concerns, to ensure parents feel they have been heard
Worry that child's lack of skills will be seen as evidence of parental neglect	Some parents worry that providers will view children's lack of skill attainment as evidence of parental neglect and may answer yes to milestones questions when child is not yet performing the skill ("They would consider you neglecting your kid when they [the child] don't know something")	Use review of milestones with caution; some parents may think their child's lack of skill attainment can be cause for referral for parental neglect; consider routine use of parent-completed questionnaires to elicit information about development and to give parents the message that they are not being targeted
Feeling blamed for child's delay	Parents may feel blamed by providers for their child's developmental delay ("I think it would have been better to do it together as a team as opposed to him making me feel like it was my fault . . . that [my child] wasn't progressing the way he should have been")	Anticipate that parents may feel blamed or accountable for developmental delays and address this concern directly
Feeling supported and part of team with provider	Parents who reported positive experiences in initial discussions of developmental delays in primary care cited rapport with the provider, the provider's openness, and feeling they were working with the provider as part of a team; primary care providers help parents understand and accept developmental problems in their child by providing information, referrals, and care coordination	Providers can contribute to parents' adjustment when developmental delays are suspected by providing access to information and referrals (including EI services); parents appreciate having primary care providers stay involved once the child is referred, providing care coordination while involving parents as members of the team
Communication triangle: parent acts as communication channel between providers and EI specialists	Parents may hear different messages from primary care providers and EI specialists about the child's developmental status; this can lead to confusion and mistrust (for example, the parent may ask the EI provider, "Why didn't the pediatrician tell me this?")	Facilitate communication by establishing direct links between EI services and practices (eg, through a designated nurse/staff person in the practice or through other models such as hospital-based social workers)

DISCUSSION

As primary care providers implement developmental screening in response to revised American Academy of Pedi-

atric guidelines³ to monitor children's development and to promote early identification of developmental delays, understanding the perspec-

tives of parents and EI specialists can facilitate communication with families in this complex area of practice. Results and recommendations (Table 3)

may be useful for conceptualizing this communication.

Although some parents reported that they would communicate developmental concerns directly to providers, most described indirect methods, such as mentioning skills the child was not yet demonstrating or asking about expected skills for age. This finding is corroborated by a recent study that analyzed audio-recorded visits in primary care.¹⁰ Although parents may think they have communicated a developmental concern, the level of concern may not be recognized by providers. It is important that providers recognize that parental expressions of concern may be stated subtly, indirectly, or briefly. A related theme that emerged was the perception of not being heard. Previous studies indicated that providers' failure to acknowledge or to address patient concerns is unfortunately widespread.^{34–36}

These findings reinforce the value of eliciting parents' developmental concerns in a systematic way,⁶ for example, by using a validated measure such as the Parents' Evaluation of Developmental Status.^{10,37} Although parents theoretically can contact EI services directly, they may not be aware of the services, depending on providers for this information. Respect for providers' opinions also means that, even when they are aware of resources, parents may not access them without the provider's recommendation.

Parental preferences for direct (straight talk) versus indirect (sugar-coating) communication approaches seemed to be related to preparation to hear about suspected delays. Some parents needed weeks to months to prepare to hear such news, beyond the brief "warning shot/forecasting" recommended for medical encounters.³⁸ Nonalarmist wording by providers, maintaining optimism and acknowledging that the child's development

might not be delayed, was recommended. Parents also recommended providing information regarding what to observe, possible next steps for further evaluation, and a plan to check in with the provider within a short time.

Other parents cautioned against sugar-coating and favored a direct approach, emphasizing the importance of straight talk. By inquiring systematically about parents' developmental concerns, providers can obtain information regarding parents' readiness to hear about suspected developmental delays and can tailor communication to the level of preparation.

Negative communication experiences included parents' feeling blamed by providers for the child's developmental delay. In 1 group, mothers reported that they might respond in the affirmative to questions regarding developmental milestones even when their child was not yet demonstrating a skill, out of concern that lack of attainment would be seen as evidence of neglect. Dumont-Mathieu et al²⁹ reported similar findings from focus groups with parents from ethnocultural minority groups; parents raised concerns that asking pediatricians for parenting advice might be seen as evidence of inadequate parenting skills, and they expressed fear that pediatricians' mandatory reporting role could lead them to refer the family to child protection authorities. Therefore, in practices serving families from communities affected disproportionately by negative interactions with child protective services, providers' review of developmental milestones might be counterproductive if messages regarding parents' lack of culpability for a child's failure to attain milestones are not included systematically. This provides another argument for caution in the routine use of milestone information elicited by providers in

decision-making regarding children's developmental status.³⁹

For sensitive topics, self-completed questionnaires may be more effective at producing disclosure than in-person interviews.⁴⁰ Emphasizing the importance of parental input by using parent-completed screening questionnaires distributed routinely to all parents in the practice and informing parents that providers expect to hear concerns may help address this issue.

Communication through parents, rather than directly between professionals, was noted to be problematic. In some cases, medical providers and EI specialists gave parents different messages regarding the child's development, leading to feelings of ambivalence, confusion, or even mistrust. Direct communication between primary care providers and EI specialists and having families return to the primary care provider to discuss the EI evaluation could help to address this concern.

This study has limitations. It represents the experiences of participants in one community and may have limited generalizability to other communities in the United States. EI parents' children were 7 years of age, on average, and their experiences may not reflect the experiences of parents of younger children who are currently entering EI. Focus groups with 3 types of participants (parents with or without children in EI and EI specialists) provided a comprehensive view of the issue in a single community, but it is possible that we did not reach saturation of themes with this approach.

Further research is needed to determine the generalizability of these results. In particular, work is needed to determine parent and child factors that predict preferences for more- or less-direct provider communication styles regarding developmental concerns. Provider awareness of the

complex issues related to communication regarding child development can help improve parent-provider communication in this complex area of practice.

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Sugar-coaters and Straight Talkers: Communicating About Developmental Delays in Primary Care

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Explaining the Results of a “Failed” Screen

Some clinicians are understandably reluctant to inform parents of screening test results. However, as noted elsewhere in this newsletter, keep in mind that when screens relying on collaborative information from parents are used, the parents will be interested in the results. This makes the process of delivering difficult news easier than you might fear. Here are some guidelines on what to say:

- Prior to administering a screening tool, have a member of your staff **explain** to the parent **why they are being asked to complete the questionnaire**. This should help ensure that parents understand what is happening and better prepare them for the results.

For example: “Here at BEST PRACTICES PEDIATRICS, we feel it’s important to monitor each child’s developmental progress, and your input is a valuable part of this process. So, we would like for you to complete this brief developmental questionnaire about Mary’s skills as you see them. There also is space to let us know about any questions or concerns you might have about Mary’s development or behavior. If you have any questions about any of the items, please don’t hesitate to ask. After you finish, please give us the form, and I’ll make sure that Dr. Jones reviews it before she meets with you.”

- **Remember the purpose of screening**, ie, screening does not diagnose developmental disorders. As per the policy statement on early detection, positive (ie, abnormal) results of screening should yield (a) referral for early intervention services (even if a diagnosis is not yet identified) and (b) further medical/diagnostic evaluation (eg, through consulting subspecialty services or evaluation teams). This is also important for parents to understand.
- **Use language consistent with the child’s need for more comprehensive assessment**. Phrases like the following can be used: “*may be delayed,*” “*this suggests...*,” “*this may indicate...*,” “*may be having difficulties compared to other children his age,*” “*may be behind other kids,*” “*seems to be learning more slowly,*” “*could be having difficulty learning.*” These are effective terms but not devastating ones. They encourage families to seek additional evaluation without causing paralytic fear often associated with terms like “disabilities” or “handicaps.” If the parent specifically asks about a particular disability, you can acknowledge that possibility, but then emphasize that the main goal of the screening is to identify children at risk, regardless of the cause. This identification could lead to early intervention, which evidence shows is clearly beneficial. Other diagnostic work-ups may also be indicated, depending on the parents’ and your levels of concern.
- **Provide telephone numbers and descriptions of services**. It is likely that families who have the necessary information to follow through are better able to do so. Descriptions of programs may enable families to visualize participation and increase the chance they actually will.
- **Offer ongoing support**. Parents may be faced with family members who have minimal investment in your recommendations for further evaluations and services. This may be the result of observing the problem but rationalizing its meaning, (eg, “*his dad was just like that as a boy and he’s doing fine now*” or “*It’s just a phase, she’ll grow out of it*”). You may want to:
 - Alert the accompanying parent to anticipate possible resistance (in themselves and significant others) and, acknowledge their fears or likely bouts of wishful thinking (eg, observing their child very carefully for signs that contradict delays)
 - Invite parents to return with dissenting family members so that you can re-explain your findings.
 - Let parents know that if they get “cold feet” and decide not to go, you want to be informed, (eg, “*It’s just as if I prescribed medicine and you decided not to give it to him, I’d want you to talk with me about it. Treat this prescription/recommendation in the same way. Don’t be afraid to talk with me if you have reservations about following through.*”)
- **Consider providing all families the names and numbers of local parent support networks**. This is particularly important for parents who are observably anxious or have numerous other life stressors. However, parents may not always reveal when they are distressed and it is probably best to have a uniform approach to offering parents on-going support.
- **If at all possible, avoid giving screening results over the telephone**. If this is not possible, alert parents that the information may be confusing and invite them to call back later if they have questions. This should reduce problematic recall and anxiety. Whether conveying results in person or over the phone, provide written information (eg, a brochure about the referral source, a copy of the referral letter you write, etc). This should help ensure that parents fully understand the results and implications.
- **Identify a social worker to help families** who are likely to have multiple barriers to following through with recommendations (eg, single parents with low incomes and multiple life stressors).
- **Provide accurate written and verbal information**. Communication about less than optimal screening test results should clearly

continued on page 10

indicate that screens only tell whether a child is *more likely* to have a problem and that screens, while often correct, are not perfect: Children with true difficulties may not be identified and children who are coming along normally may fail a screen. Specifically, parents who raise serious concerns but whose children perform well on additional screening should benefit from being told that your office will follow their children carefully and give them some suggestions about how to help in the interim (eg, a parent education sheet on how to stimulate children's language). In this way, you have prepared parents for the possibility that screens may over- as well as under-identify difficulties, and you will have capitalized on a "teachable moment" by giving parents guidance in how to promote their child's development.

- **Follow carefully those children who fail screens but are not found to have problems.** Most are performing below average and have many psychosocial risk factors.⁸ They need developmental promotion, but also referrals to services for children at risk, such as Head Start, quality child care, after-school tutoring, and summer programs. Their parents also may need additional training or social work services.

When children pass screening tests, **offer praise and reassurance** that learning and development appear to be coming along well. Also ask parents if there is information on child-rearing or behavior that would help them.

Delivering Difficult News

by Frances P Glascoe Ph.D.

Description

Information for physicians on delivering diagnosis/results to patients.

Learning objectives

Communicating difficult news effectively

Laura Rosen Cohen's powerful account of her feelings during her baby's stormy postnatal course gives us a painful but needed chance to experience the profound, the unknown, and to reflect on the stressful limits of our professional skills.

Can we do things better? How should we tell a parent when we don't know the outcome, especially when some of the possibilities are devastating? Fortunately, there is much clinical literature on this topic and highlights are offered here.

1. **Use a quiet, comfortable, private place**, i.e., sufficient numbers of chairs, not in a hallway, no strangers present, and never over the telephone. Make sure both parents are present if possible.
2. **Allow enough time so that parents can ask questions and express emotions.** Minimize interruptions. Allow parents to talk and let them know you recognize this as a difficult time and that you will offer them as much moral support and information as possible.
3. **Explain risk in several ways** (e.g, verbally using terms such as "probably" and "possibly" as well as numerically (e.g., percentages, or ratios such as 1 out of 3) to ensure comprehension and informed decision-making.
4. **Sit close to the parent in order to best attend to emotional cues** (not lecture style from behind a desk but instead alongside parents-as a partner in the communication process. Touch parents if they are distressed and if appropriate. Touch the child if present and allow and encourage the family to touch and hold their child.
5. **Provide a brief but not strongly negative "warning shot"** (e.g., "I'm afraid I have news that may be troubling" or if inviting parents to a conference to discuss findings, suggest that they may want to bring a spouse or close friend along).
6. **Explore what families already know** about the condition so sufficient amounts of information can be offered at an appropriate level of sophistication. Many parents are rapidly becoming experts and can have collegial level discussions about their child. If parents are not native English speakers, ensure a competent translator is present.
7. **Present the news in a thoughtful, caring way** that shows respect and empathy for the family. Families who are most satisfied with how difficult news is presented, rank sympathy and warmth as one of the most desirable of physician attributes.
8. **Get to the point quickly** and ensure that the communication is a conversation so that families have some control over the pace with which information is presented. To do this pause often to allow for questions and ask frequently about comprehension (e.g., "Is there anything we've talked about so far that you would like me to go over again, or in more detail?").
9. **Communicate in a jargon free manner** and pair technical language with euphemisms to ensure comprehension and enhance parents ability to obtain more information as needed. Frank and clear communications have been shown to increase acceptance of difficult information.

10. **Try to be comfortable with parents' emotions** and explore emotional reactions in order to offer comfort and marshal supportive services (e.g., parent support groups or the opportunity to talk with other parents whose children have or may have a similar condition). Have this information available, maybe even in an envelope that can be taken home and read after the initial shock wears off.
11. **Establish a Plan.** When a test or procedure is indicated, tell parents three things: 1) "We would like to test for 'X'"; 2) "The test involves 'X'"; and 3) "If the results are positive, here is how we will manage the case..."
12. **Avoid acutely negative prognostications.** Research shows that physicians are more likely than any other professional (i.e., social workers, early childhood special educators, speech, occupational and physical therapists) to project gloomy outcomes particularly for developmental disabilities. Given that nonmedical professionals typically provide the bulk of interventions and are far more optimistic about outcomes, one possibility is to defer projections about future functioning to these clinicians (e.g., "there is a wide range of outcomes and every child is different, we can't predict the future, but we can put services in place such as OT, PT etc., in order to ensure that he/she achieves her maximum potential, and we will monitor her/his progress so that we don't miss anything. In the meantime, we'll plan for early intervention and periodic developmental follow-up to see how he or she is progressing").
13. **Provide summary information.** Some parents will have difficulty recalling what was said. Ask whether they would like an oral, written, video- or audiotaped summary of the conference. Most parents appreciate the offer of audiotapes although some apparently do not want them. Still, patients provided audiotapes recall much more information than those without.
14. **Offer to discuss the issues again at a second meeting** or over the telephone—a suggestion made by more than 70% of parents interviewed about their experiences in receiving a developmental diagnosis for their children. Parents most likely to need a repeat consultation are those who are highly distressed (because recall is likely to be especially poor). Even so, in one study, more than half of parents had difficulty recalling difficult news suggesting that repetition should be offered to all. The offer of a second conference also enables parents to invite other family members with them who are in disagreement, confused, etc.
15. **Take note of anxiety** . When continuing and elevated anxiety levels are observed or reported, these should be interpreted as a possible marker for generalized difficulties with anxiety. Such families should be provided repeated opportunities to understand the results and offers of parent-to-parent support groups or mental health counseling when indicated. Blanket reassurances should be avoided and parents should be told that rescreening or further updates and evaluations will be conducted.
16. Clinicians, especially those in training are well advised to **practice first** (e.g., with simulated patients) and under supervision from a clinician with exemplary communication skills.

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Tools for Referral

Community Resource Template



EVALUATION AND DEVELOPMENTAL SERVICES					
Early Intervention (EI) Program					
EI Coordinator Name:					
Telephone Number:					
Fax Number:					
Email Address:					
Address:					
Neurodevelopmental Pediatricians/ Developmental-Behavioral Pediatricians					
	Name	Telephone	Fax	Address	Email Address
1					
2					
3					
Child Psychologists					
	Name	Telephone	Fax	Address	Email Address
1					
2					
3					
Child Neurologists					
	Name	Telephone	Fax	Address	Email Address
1					
2					
3					
Other Evaluation/Developmental Referral Sources (OT, PT, Speech, Audiology, etc)					
	Name	Telephone	Fax	Address	Email Address
1					
2					
3					
4					
5					

Community Resource Template



FAMILY ASSISTANCE AND FAMILY SUPPORT SERVICES					
Family Voices State Contact					
Name:					
Telephone:					
Fax:					
Email:					
Address:					
Family Resource Centers					
	Name	Telephone	Fax	Address	Email Address
1					
2					
3					
Family Support Groups					
	Name	Telephone	Fax	Address	Email Address
1					
2					
3					
Other Family Support Networks:					
1					
2					
3					
4					
5					

Early Intervention Program Referral Form

Please complete this form for referring a child to Early Intervention (Part C) if you prefer to do so in writing. Also please indicate the feedback that you want to receive from the Early Intervention Program in response to your referral. Diagnosis of a specific condition or disorder is not necessary for a referral.

Parent/Child Contact Information

Child Name: _____
Date of Birth: ____/____/____ Child Age: (Months) ____ Gender: M F
Home Address: _____
Parent/Guardian _____ Relationship to Child: _____
Primary Language: _____ Home Phone: _____ Other Phone: _____

Reason(s) for Referral to Early Intervention

(Please check all that apply)

- Identified condition or diagnosis (e.g., spina bifida, Down syndrome): _____
- Suspected developmental delay or concern (Please circle areas of concern):
Motor/Physical Cognitive Social/Emotional Speech/Language Behavior Other _____
- At Risk (Describe risk factors): _____
- Other (Describe): _____

Referral Source Contact Information

Person Making Referral: _____ Date of Referral: ____/____/____
Address: _____
Office Phone _____ Office Fax: _____ E-mail _____

Early Intervention Program Contact Information

Program Name: _____
Address: _____ City: _____ State: _____ Zip: _____
Office Phone _____ Office Fax: _____ E-mail _____

Feedback Requested by the Referral Source

Date Referral Received: ____/____/____ Date of Initial Appointment with Child/Family: ____/____/____
Name of Assigned Service Coordinator: _____
Office Phone: _____ Office Fax: _____ E-mail: _____

After initial appointment, please send the following information:

- Status of Initial Family Contact Changes in Services Being Provided
- Developmental Evaluation Results Periodic Progress Reports/Summaries
- Services Being Provided to Child/Family Other (Describe): _____
- (Including: names of providers and frequency of services) _____

Release of Information Consent

I, _____ (Print name of parent or guardian), give my permission for my pediatric health care provider, _____ (print provider's name), to share any and all pertinent information regarding my child, _____ (print child's name), with the early intervention program.

Parent/Legal Guardian Signature _____ Date: ____/____/____

This form is available on the National Center of Medical Home Initiatives for Children with Special Needs website. Go to <http://www.medicalhomeinfo.org/health/EI.html> to download this form and learn more about Early Intervention.

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Tools for Billing



**Standardized Screening/Testing Coding Fact Sheet for
Primary Care Pediatricians: Developmental/Behavioral/Emotional**

I. CODING

Developmental screening and assessment are often complemented by the use of standardized instruments, which vary in length. This coding fact sheet provides guidance on how pediatricians can appropriately report standardized developmental screening and testing services.

A. How To Report Developmental Screening/Testing

96110 *Developmental screening (eg, developmental milestone survey, speech and language delay screen), with scoring and documentation, per standardized instrument*

The use of standardized developmental screening instruments (eg, PEDS, Ages and Stages, M-CHAT) is reported using Current Procedural Terminology (CPT®) code **96110** (*Developmental screening*). Code **96110** is reported when performed in the context of preventive medicine services. This code also may be reported when screening is performed with other evaluation and management (E/M) services such as acute illness or follow-up office visits.

In 2012, the **96110** code descriptor was revised to differentiate it from the “testing” that is referenced under code **96111**. *Screening* asks a child’s observer to provide his/her observations of the child’s skills, which are then recorded on a standardized and validated screening instrument. Screening is subjective and only reports the assessment of the patient’s skills through observation by the informal observer. On the other hand, testing measures what the patient is actually able to do on a standardized psychometric instrument at that time. Screening does not imply a diagnosis; only the means by which information is collected on the patient.

Because clinical staff typically performs the 96110 service, the Medicare Resource-Based Relative Value Scale (RBRVS) relative values reflect only the practice expense (clinical staff time, medical supplies, medical equipment) and professional liability insurance -- there is no physician work value published on the Medicare physician fee schedule for this code.

On the less common occasion where a physician performs this service, it may still be reported with code **96110** but the time and effort to perform the screening itself should not count toward the key components (history, physical exam, and medical decision making) or time when selecting an E/M code for a significant, separately identifiable service performed during the same patient encounter. When a screening test is performed along with any E/M service (eg, preventive medicine or office outpatient), both the **96110** and the and E/M service should be reported and modifier **25** (*significant, separately identifiable evaluation and management service by the same physician on the same day of the procedure or other service*) should be appended to the E/M code to show the E/M service was distinct and necessary at the same visit **or** modifier **59** (*distinct procedural service*) should be appended to the developmental

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screening code, showing the developmental screening services were separate and necessary at the same visit.

Additionally in 2012, code **96110** was revised to clarify that the instrument used must be standardized and that the code may be reported more than once on a single date of service. The code descriptor states “per standardized instrument.” Therefore, if you are performing multiple standardized screens on a patient (eg, an M-CHAT and ASQ), you will report **96110** with 2 units (or on separate line items). Modifier **59** may be required to indicate that the services are distinct.

In 2015, the descriptor for code **96110** was revised to remove reference to “with interpretation and report” and replace it with “scoring and documentation” since this more accurately reflects the work performed. A notation was also added which refers the physician to code **96127** for emotional/behavioral assessment. This code will be discussed below.

96111 *Developmental testing (includes assessment of motor, language, social, adaptive and/or cognitive functioning by standardized developmental instruments) with interpretation and report*

Developmental testing using standardized instruments (eg, Bayley Scales of Infant Development, Woodcock-Johnson Tests of Cognitive Abilities (Third Edition) and Clinical Evaluation of Language Fundamentals (Fourth Edition) are reported using CPT code **96111**. This service may be reported independently or in conjunction with another code describing a distinct patient encounter provided on the same day as the testing (eg, an evaluation and management code for outpatient consultation). A physician or other trained professional typically performs this testing service. Therefore, there are physician work RVUs published on the Medicare physician fee schedule (Resource-Based Relative Value Scale or RBRVS) for this code.

When **96111** is reported in conjunction with an E/M service, the time and effort to perform the developmental testing itself should not count toward the key components (history, physical exam, and medical decision making) or time for selecting the accompanying E/M code. Just as discussed for **96110**, if the E/M code is reported with **96111**, modifier **25** (*significant, separately identifiable evaluation and management service by the same physician on the same day of the procedure or other service*) should be appended to the E/M code **or** modifier **59** (*distinct procedural service*) should be appended to the developmental testing code, showing that the developmental testing services were separate and necessary at the same visit.

In 2005, the CPT code descriptor of **96111** was revised to reflect the deletion of the test examples as well as the "per hour" designation. Thus, effective January 1, 2005, physicians reported the service without regard to time. The typical testing session, including the time to perform the interpretation and report, was found in the American Academy of Pediatrics (AAP) survey used to value the service to be slightly over an hour.

B. When To Report Developmental Screening/Testing

96110

The frequency of reporting **96110** (*Developmental screening*) depends on the clinical situation. The AAP Bright Futures “Recommendations for Preventive Pediatric Health Care” schedule recommends

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developmental/behavioral surveillance at each preventive medicine visit, and the AAP “Developmental Surveillance and Screening of Infants and Young Children” policy statement recommends that physicians use validated/standardized developmental screening instruments to improve detection of problems at the earliest possible age to allow further developmental assessment and appropriate early intervention services.

Thus, the use of screening instruments seems to enhance the task of developmental assessment typically done in the preventive medicine setting. The exact frequency of testing therefore depends on the clinical setting and the provider’s judgment as to when it is medically necessary. When physicians ask questions about development as part of the general informal developmental survey or history (eg, surveillance) or complete checklists, this is not formal “screening” as such, **and is not separately reportable**. Examples of validated/standardized screening instruments along with clinical vignettes are provided below.

96111

Longer, more comprehensive developmental assessments of patients suspected of having problems are typically reported using CPT code **96111** (*Developmental testing*). These tests are typically performed by physicians, psychologists or other trained professionals and require upwards of an hour of time. They also are accompanied by an interpretation and formal report, which may be completed at a time other than when the patient is present.

Like code **96110**, the frequency of reporting code **96111** is dependent on the needs of the patient and the judgment of the physician. When developmental surveillance or screening suggests an abnormality in a particular area of development, more extensive formal objective testing is needed to evaluate the concern. In contrast to adults, the limited ability of children to maintain focused selective attention and testing speed may mean that several sessions are needed to properly evaluate the problem. Code **96111** is reported only once per date of service. There must be an accompanying report describing and interpreting all testing.

Additionally, subsequent periodic formal testing may be needed to monitor the progress of a child whose skills initially may have not been “significantly low,” but who was clearly at risk for maintaining appropriate acquisition of new skills.

II. CLINICAL VIGNETTES

96110 Vignette # 1

At a follow-up visit for bilateral otitis media, the pediatrician notes the patient missed her 12 month well-child visit. He requests and the child’s father completes the Ages and Stages Questionnaire (ASQ.) The father endorses no concerns in any developmental domain. The pediatrician reviews the father’s completed ASQ and asks him if his daughter is using single words to convey her wants and is using words to label common objects. The father assures him that she is doing this and, in fact, other non-family adults have commented on her clear articulation. No concerns at all are reported and this is consistent with what the pediatrician has observed in the office visits. He tells the father they will continue to monitor for any evidence the child is not acquiring skills at an expected rate. All this is noted in a few sentences in the chart note.

CPT	ICD-9-CM	ICD-10-CM
99392-25* Preventive medicine service established patient, age 1-4	V20.2 Routine infant or child health check	Z00.129 Encounter for routine child health examination w/o abnormal findings
96110 Developmental screening	V20.2	Z00.129

*NOTE: Some payers may require alternate reporting wherein the modifier 59 is appended to the developmental screening code, however according to CPT guidelines, that is not appropriate.

96110 Vignette #2

At a 24-month well child check, the mother describes her toddler as "wild," completes the PEDS (Parent Evaluation of Developmental Status), and responds positively to the question "Do you have concerns about your child's language skills?" The nurse scores the PEDS and places the answer sheet on the front of the chart with a red arrow sticker next to it. When the pediatrician examines the child, he is alerted to ask the mother about her observations of the child's language ability. He then confirms the delay in language, and makes a referral to a local speech pathologist.

CPT	ICD-9-CM	ICD-10-CM
99392-25* Preventive medicine service established patient, age 1-4	V20.2 Routine infant or child health check	Z00.121 Encounter for routine child health examination w/ abnormal findings
96110 Developmental screening	V20.2 315.31 Expressive language disorder	Z00.121 F80.1 Expressive language disorder

*NOTE: Some payers may require alternate reporting wherein the modifier 59 is appended to the developmental screening code.

If the pediatrician spent significant extra time evaluating the language problem, then an E/M service office/outpatient code from the **99201-99215** series may be reported using a modifier 25, linked to the appropriate ICD-9-CM or ICD-10-CM code(s) as appropriate (eg, **315.31**, *Expressive language disorder*; **315.32**, *Mixed receptive-expressive language disorder*; **315.39**, *Other developmental speech or language disorder for ICD-9-CM* or **F80.1**, *Expressive language disorder*; **F80.2**, *Mixed receptive-expressive language disorder*; **F80.89**, *Other developmental disorders of speech or language*).

96110 Vignette #3

At a five-year health maintenance visit, a father discusses his daughter's difficulty "getting along with other little girls." "Doctor, she wants friends, but she doesn't know how to make — much less keep — a friend." Further questioning indicates the little girl is already reading and writing postcards to relatives, but has not learned how to ride her small bicycle, is awkward when she runs and she avoids the climbing apparatus at the playground. Her father wondered if her weaker gross motor skills affected her ability to play successfully with other children. She seems very happy to sit and look at books about butterflies — her all consuming interest! The child's physical exam consistently fell in the range of 'normal for age' in previously health maintenance visits. The pediatrician asks her nurse to administer the Australian Scale for Asperger's Syndrome and the father's responses yield 16/24 items with an abnormal score being >3. The pediatrician reviews the form, writes a brief summary, and discusses her observations with the father. A

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referral is made to a local physical therapist who has a playground activities group and to a local psychologist who has expertise in diagnosing autism spectrum disorders.

CPT	ICD-9-CM	ICD-10-CM
99393-25* Preventive medicine service established patient, age 5-11	V20.2 Routine infant or child health check	Z00.121 Encounter for routine child health examination w/ abnormal findings
96110 Developmental screening	V20.2 315.4 Developmental coordination disorder 313.9 Unspecified emotional disturbance of childhood	Z00.121 F82 Specific developmental disorder of motor function F98.9 Unspecified behavioral and emotional disorders with onset usually occurring in childhood and adolescence

*NOTE: Some payers may require alternate reporting wherein the modifier 59 is appended to the developmental screening code.

96111 Vignette #1

An eight-year-old boy with impulsive, overly active behavior and previously assessed "average" intelligence is referred for evaluation of attention deficit disorder. He has by prior history reading and written expression skills at first grade level, and received speech and language therapy during his attendance at Head Start when he was four years old.

Behavior and emotional regulation rating scales completed by the parent and teacher were reviewed at an earlier evaluation and management service appointment. History, physical and neurological examination were also completed at that visit.

On this visit, standardized testing was administered to confirm auditory and visual attention, short term and working memory as well as verbal and visual organization. Testing was administered for standard scores as well as structured observations of behavior. These scores and observations were integrated into a formal report to be used to individualize his education and treatment plan. Testing and the report took approximately 75 minutes. The family schedules a follow up visit to discuss this report and the final diagnosis and treatment plan with the physician.

CPT	ICD-9-CM	ICD-10-CM
96111 Developmental testing	314.0x Attention deficit disorder x = 0 for no hyperactivity x = 1 for hyperactivity	F90.- Attention deficit disorder 4th digit 0 = inattentive type 1 = hyperactive type

96111 Vignette #2

A 5 4/12 year old boy just beginning kindergarten was seen for developmental testing. At a previous visit, his mother's responses on the Pediatric Evaluation of Developmental Status (PEDS) suggested expressive language delays. After greeting the parent and child and explaining to the child that he and the doctor would do some 'non-school' activities to see how he 'used words to tell others about (his) good ideas', the child and the examiner spent fifty minutes together completing the tasks on the Peabody Picture Vocabulary Test-Fourth Edition, and the Clinical Evaluation of Language Fundamentals-Fifth Edition. The

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examiner scored the two tests in five minutes and there was a significant discrepancy detected between the Receptive Language Composite and the Expressive Composite on the CELF- 5. Both test scores were abnormal, however, indicating a mixed receptive–expressive language disorder.

CPT	ICD-9-CM	ICD-10-CM
96111 Developmental testing	315.32 Mixed receptive expressive	F80.2 Mixed receptive-language disorder expressive language disorder

96111 Vignette #3:

A 9 year old girl, being treated for ADHD and receiving language therapy to improve her weak receptive and expressive language skills, comes in for a medication visit. Her mother and teacher both feel the current dosage of her stimulant medication is effective and neither perceives a need for any changes. Your services meet the “limited” level of complexity for the visit. However, while asking about her school performance, the child’s mother volunteers, “I know she has been seeing the speech pathologist once a week for 7 months now, but I can’t see any signs her vocabulary is increasing.” You administer and score the Peabody Picture Vocabulary Test [Fourth Edition]. The performance standard score had increased by one standard deviation from her initial performance eight months ago. You show her mother the improvement and document the test administration, results and interpretation in the medical record.

CPT	ICD-9-CM	ICD-10-CM
99213-25* Office service, established patient, 15 minutes “typical time”	314.01 Attention deficit/hyperactivity disorder 315.32 Mixed receptive expressive language disorder	F90.1 Attention-deficit hyperactivity disorder F80.2 Mixed receptive-expressive language disorder
96111 Developmental testing	314.01 315.32	F90.1 F80.2

*NOTE: Some payers may require alternate reporting wherein the modifier 59 is appended to the developmental testing code.

III. DOCUMENTATION GUIDELINES

Each administered developmental screening instrument is accompanied by scoring and documentation (eg, a score or designation as normal or abnormal). This is often included in the test itself, but these elements may alternatively be documented in the progress report of the visit. Physicians are encouraged to document any interventions based on abnormal findings generated by the tests.

Following are examples of appropriate documentation for some testing tools:

96110

PEDS (Parents’ Evaluation of Developmental Status)

This questionnaire is designed to identify any parent/primary caretaker’s concerns about a birth through eight-year child’s developmental attainment and behavioral/mental health concerns. There are eight specific domain queries and one asking, “please list any concerns about your child’s learning, development

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and behavior” and a final “please list any other concerns.” The parent answers are scored into the risk categories of high, moderate, or low. The report form is included with the questionnaire.

ASQ (AGES AND STAGES Questionnaire)

This parent report instrument, covering ages 1 month through 60 months, includes objective information as the adult notes whether the child performs the skill identified. There are six questions in each of five domains: Communication, Gross Motor, Fine Motor, Problem Solving and Personal-Social. All questions are scored on a point system, with summary scores indicating the need for further evaluation. The ASQ also has a non-specific comprehensive section where general concerns are addressed. No score is provided for these answers, but the instrument developers note any “Yes” responses should prompt a referral.

96111

In general, the documentation of developmental testing includes the scoring, interpretation, and the development of the report. This typically includes all or some of the following: identifying data, time and location of testing, the reason for the type of testing being done, and the titles of all instruments offered to/completed by the child; presence (if any) of additional persons during testing, child’s level of cooperation and observations of child’s behavior during the testing session. Any assistive technology, prosthetics or modifications made to accommodate the child’s particular developmental or physical needs should be described, and specific notations should be made if any items offered resulted in a change in the child’s level of attention, willingness to participate, apparent ease of task accomplishment. The item results should be scored and the test protocol and any/all scoring sheets should be included in the medical chart (computer scanning may be needed for electronic medical records). A brief interpretation should be recorded and notation should be made for further evaluation or treatment of the patient or family. A legible signature should also appear.

How to Report Emotional/Behavioral Assessment

96127 Brief emotional/behavioral assessment (eg, depression inventory, attention-deficit/hyperactivity disorder [ADHD] scale), with scoring and documentation, per standardized instrument

This code (**96127**) was introduced in 2015 to allow for the appropriate reporting of standardized emotional and/or behavioral assessments.

Because clinical staff typically performs the 96110 service, the Medicare Resource-Based Relative Value Scale (RBRVS) relative values reflect only the practice expense (clinical staff time, medical supplies, medical equipment) and professional liability insurance -- there is no physician work value published on the Medicare physician fee schedule for this code.

On the less common occasion where a physician performs this service, it may still be reported with code **96127** but the time and effort to perform the screening itself should not count toward the key components (history, physical exam, and medical decision making) or time when selecting an E/M code for a significant, separately identifiable service performed during the same patient encounter. When an assessment is performed along with any E/M service (eg, preventive medicine or office outpatient), both the **96127** and the and E/M service should be reported and modifier **25** (significant, separately identifiable evaluation and management service by the same physician on the same day of the procedure or other

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service) should be appended to the E/M code to show the E/M service was distinct and necessary at the same visit or modifier **59** (distinct procedural service) should be appended to the developmental screening code, showing that developmental screening services were separate and necessary at the same visit.

When to Report Emotional/Behavioral Assessment

The frequency of reporting **96127** (emotional/behavioral assessment) is dependent on the clinical situation. The AAP Bright Futures “Recommendations for Preventive Pediatric Health Care” schedule recommends developmental/behavioral surveillance at each preventive medicine visit, and a formal assessment (eg, PHQ-2) for depression is recommended at every annual visit beginning at age 11 with a validated/standardized assessment instrument to improve detection of depression at the earliest possible age to allow for appropriate intervention services.

Thus, the use of assessment instruments as a screening mechanism seems to enhance the task of identifying those who may be suffering from an emotional or behavioral disorder. The exact frequency of testing therefore depends on the clinical setting and the provider’s judgment as to when it is medically necessary. When physicians ask questions about a patient’s emotional or behavioral health as part of the general informal history (eg, surveillance), this is not a formal “screen” as such, and is not separately reportable. Examples of validated/standardized screening instruments along with clinical vignettes are provided below.

Developmental Screening Vs Behavioral Emotional Assessment

At first glance, it may be difficult to discern if a standardized instrument falls under a developmental screen (**96110**) or an emotional/behavioral assessment (**96127**). Developmental screening really takes a look at a patient’s overall development and will include questions on motor skills, language skills, cognitive function, as well as may include questions on social, emotional and behavioral issues. However, the emotional and behavioral questions are being asked as part of an overall developmental inventory. An emotional or behavioral assessment instrument will look specifically at behavior and emotional health related to key symptoms of those conditions classified as behavioral or emotional conditions, such as ADHD, depression or anxiety.

96127 Vignette # 1

A 12 year old girl presents with her dad for her annual preventive medicine service. Patient’s history and interview do not show any concerns of depression, however following Bright Futures guidelines, the patient is given a PHQ-2. The patient answers the questions and the screen is normal.

CPT	ICD-9-CM	ICD-10-CM
99394-25* Preventive medicine service established patient, age 1-4	V20.2 Routine infant or child health check	Z00.121 Encounter for routine child health examination
96127 Behavioral/Emotional Assessment		

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96127 Vignette #2

A seven year old boy with previously diagnosed ADHD is being seen for a health maintenance visit. At the end of the visit his mother asks if she can discuss her son's medication. She hands you 2 Vanderbilt ADHD rating scales completed two weeks ago by his classroom teacher and tutor. You give these to your medical assistant to score while you obtain more interim history from Bobby's mother. After reviewing the scored teacher Vanderbilt form and discussing the results with Bobby's mother, you both decide to increase his stimulant medication. A follow-up appointment is scheduled for four weeks.

CPT	ICD-9-CM	ICD-10-CM
99392-25* Preventive medicine service established patient, age 1-4	V20.2 Routine infant or child health check	Z00.121 Encounter for routine child health examination w/ abnormal findings
99213-25 Office service, established patient, 15 minutes "typical time"	314.01 Attention deficit/hyperactivity disorder, combined type	F90.2 Attention-deficit hyperactivity disorder, combined type
96127 Behavioral/Emotional Assessment 96127-59	314.01	F90.2

*NOTE: Some payers may require alternate reporting wherein the modifier **59** is appended to the developmental screening code. Some payers may also require the **96127** to be reported in 2 units on one line item.

The Affordable Care Act and Standardized Screening

There is much confusion as to whether codes 96110 and 96127 fall under the no cost-sharing provision in the Affordable Care Act (ACA). The answer is - it depends. Only those services performed as part of routine screening services as either recommended under the United States Preventive Medicine Services Task Force (Recommendation A or B) or under the AAP's Periodicity Schedule are covered as part of the ACA no cost sharing. However, when 96110 or 96127 is performed and reported as part of a diagnostic service (ie, a problem is suspected) or when the screen is done outside of the routine recommendations (ie, more than the recommendations stipulate), the codes may fall under a cost sharing arrangement. Of course any plan that is not required to follow ACA provisions will have their own rules on this. One way to ensure that the developmental or behavioral/emotional screen service is covered under ACA provisions (as appropriate) is to link the service to either the "well baby/child" ICD code or the "screening for" code. Note that in order to report the "screening for" ICD code the patient has to be asymptomatic.

IV. SAMPLE ASSESSMENT/TESTING TOOLS

[NOTE: These are provided as examples only; the AAP implies no endorsement or restriction of code use to these instruments. If you choose to use an instrument not listed below, be sure they are validated/standardized.]

Instrument	Abbreviation	CPT Code
Ages and Stages Questionnaire-Third Edition	ASQ	96110
Ages and States Questionnaire: Social-Emotional	ASQ:SE	96127
Australian Scale for Asperger's Syndrome	ASAS	96127
Beck Youth Inventories - Second Edition	BYI-II	96127
Beck Anxiety Inventory	BAI	96127
Beck Depression Inventory	BDI	96127
Beery-Buktenica Developmental Test of Visual-Motor Integration-Sixth Edition	BEERY-VMI	96111
Behavior Assessment Scale for Children-Second Edition	BASC-2	96127
Behavioral Rating Inventory of Executive Function	BRIEF	96127
Child Behavior Checklist	CBCL	96127
Children's Depression Inventory	CDI	96127
Clinical Evaluation of Language Fundamentals-Fifth Edition	CELF-5	96111
Clinical Evaluation of Language Fundamentals-Preschool Version-2		96111
Columbia DISC Depression Scale		96127
Comprehensive Test of Nonverbal Intelligence Second Edition	CTONI-2	96111
Connor's Rating Scale		96127
Developmental Test of Visual Perception-Third Edition	DTVP-3	96111
Hamilton Anxiety Scale		
Hamilton Rating Scale for Depression	HRSD	96127
Kaufman Brief Intelligence Test-Second Edition	KBIT-2	96111
Modified Checklist for Autism in Toddlers	M-CHAT	96110
Multidimensional Anxiety Scale for Children	MASC	96127
Patient Health Questionnaire	PHQ-2 or PHQ-9	96127
Parents' Evaluation of Developmental Status	PEDS	96110
Peabody Picture Vocabulary Test-Fourth Edition	PPVT™-4	96110
Pediatric Symptom Checklist	PSC / PSC-Y	96127
Screen for Child Anxiety Related Disorders	SCARED	96127
Test of Auditory-Perceptual Skills-Third Edition	TAPS-3	96111
Test of Language Competence-Expanded Edition		96111
Test of Nonverbal Intelligence-Fourth Edition		96111
Test of Problem Solving 3: Elementary Version	TOPS 3: Elementary	96111
Test of Word Knowledge		96111
Vanderbilt Rating Scales		96127
Woodcock-Johnson® Test of Cognitive Abilities-Third Edition		96111
Kaufman Brief Intelligence Test-Second Edition	KBIT-2	96111

Breaking Out Emotional/Behavioral Assessments

The addition of code **96127** to *Current Procedural Terminology (CPT®)* in 2015 breaks out the services of emotional and behavioral assessments from developmental screening reported with code **96110**. This may change how your practice reports preventive medicine encounters including recommended screening and assessments.

In addition to adding the code for brief emotional and behavioral assessments, there is an editorial revision to code **96110** to better reflect that this code represents the practice expense of providing the screening instrument and clinical staff time involved in providing instructions for instrument completion, scoring, and documentation of the screening.

- ▲ **96110** Developmental screening (eg, developmental milestone survey, speech and language delay screen), with scoring and documentation interpretation and report, per standardized instrument form
- **96127** Brief emotional/behavioral assessment (eg, depression inventory, attention-deficit/hyperactivity disorder [ADHD] scale), with scoring and documentation, per standardized instrument

With these changes, code **96110** is now used only to report standardized screening to identify childhood and adolescent developmental levels. Code **96127** is used to report use of a standardized instrument to assess the patient's emotional and/or behavioral health. The related work of the physician's interpretation of the scored instrument in the context of the patient's history is a separately reportable evaluation and management (E/M) service. The Table includes some of the different conditions that may be screened for or assessed in relation to each service.

Examples of Developmental and Emotional/Behavioral Disorders^a

96110 Developmental Screening	96127 Brief Emotional/Behavioral Assessment
Asperger syndrome	Anxiety
Autism spectrum disorder	Attention-deficit/hyperactivity disorder
Developmental coordination disorder	Conduct disorders
Expressive language disorder	Depression
Speech articulation developmental disorder	Episodic mood disorders
	Oppositional defiant disorder

^aExamples only; not all-inclusive and not intended as practice recommendations.

When screening for or assessing alcohol or substance abuse, do not report **96127**. An assessment specifically for alcohol or substance abuse without intervention of 15 minutes or more is considered part of the preventive medicine service. Codes **99408–99409** are reported for alcohol and/or substance (other than tobacco) abuse structured screening (eg, Alcohol Use Disorders Identification Test [AUDIT], Drug Abuse Screening Test [DAST]) and brief intervention services, 15 to 30 minutes or more than 30 minutes.

Clinical Scenarios

On January 5, 2015, a child is seen in his pediatrician's office because his teacher has recommended evaluation for ADHD. History is obtained indicating no other health concerns since the child's last visit 3 months ago. The teacher has provided a completed ADHD rating scale. After a brief discussion of the mother's concerns about her son's behavior, the physician asks the mother to complete an ADHD screening instrument. A medical assistant provides the form and instructions for completing it to the mother and notes the completion and score in the medical record. The medical assistant also scores and documents the instrument completed by the teacher. The physician reviews the completed and scored screening instruments and spends 15 minutes discussing the finding of predominantly hyperactive ADHD and management and treatment options with the mother and patient. The diagnosis is predominantly hyperactive ADHD. Total face-to-face time of visit was 25 minutes.

The physician reports the appropriate level of E/M service; in this case, code **99214** may be reported based on 15 of 25 minutes (>50% of face-to-face time) spent in counseling or coordinating care. In addition, code **96127** may be reported with 2 units of service (one for each completed and scored instrument); or, if required by the payer, report the separate screening instruments using **96127** and **96127 59**. *International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM)* code **314.01** is used to report the diagnosis of predominantly hyperactive attention-deficit disorder.

On January 9, 2015, an 11-year-old is seen in a pediatrician's office for a new patient preventive service. A nurse provides screening instruments and instructions for completion to screen for depression and alcohol and substance abuse. Both instruments are scored by the nurse and provided to the physician for review in conjunction with the patient history. The physician completes the well-child examination and provides counseling and anticipatory guidance as indicated.

10 10

With *International Classification of Diseases, 10th Revision, Clinical Modification*, screening for behavioral or mental disorder is reported with **Z13.89**, encounter for screening for other disorder. This code is also used to report screening for alcoholism or depression.

The physician reports the preventive medicine service with code **99393**. Code **96127** is reported with one unit for the depression screening. Because no intervention was performed in conjunction with the assessment for alcohol or substance abuse, this service is not separately reported. *ICD-9-CM* diagnosis codes for all services are **V20.2** (routine infant/child health check) with secondary code **V79.0** (special screening for depression) linked to code **96127**.

A child is seen for her 30-month well-child visit in 2015. Her parents are provided screening instruments for

development and emotional and behavioral assessment. A medical assistant scores each completed form and provides these to the physician for review. The physician interprets the score of each instrument in the context of the patient's history and documents the impression. An age-appropriate history and examination and anticipatory guidance are also documented. The diagnosis is well-child examination.

The physician reports code **99392** for the well-child visit with additional codes **96110** and **96127** for developmental screening and brief emotional and behavioral assessment. Code **V20.2** is reported for all services with secondary codes **V79.3** (special screening for developmental handicaps in early childhood) and **V79.9** (special screening for unspecified mental disorders and developmental handicap) linked to codes **96110** and **96127**, respectively.

Note: At time of publication, code edits have not been published for code **96127**. Individual payer policy may affect reporting of brief emotional or behavioral assessment. 

New Policy Statement on Care Coordination & Free Access to Online Curriculum

Care coordination is an essential element of a transformed US health care delivery system that emphasizes optimal quality and cost outcomes, addresses family-centered care, and calls for partnership across various settings and communities.

The American Academy of Pediatrics (AAP) policy statement, "Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems," appeared in the May 2014 *Pediatrics* (<http://pediatrics.aappublications.org/content/133/5/e1451.full>). This policy, coauthored by the AAP Council on Children With Disabilities (COCWD) and the Medical Home Implementation Project Advisory Committee, specifically outlines the essential partnerships that are critical to this framework. Implementation of this framework aims for lower health care costs, less fragmented care, and an improved experience for children and families. The policy statement provides practical application of care coordination integration in practices and communities and is intended to be broadly focused, realizing that every community has different needs, assets, and service gaps based on location, population, and cultural factors. An accompanying article in the May 2014 *AAP News*, "Beyond the

Medical Home: Coordinating Care for Children" (<http://aapnews.aappublications.org/content/35/5/14.1.full>), also highlights the importance of this policy.

To further augment and facilitate application of the recommendations within this policy statement, the freely accessible online Boston Children's Hospital Care Coordination Curriculum (www.childrenshospital.org/care-coordination-curriculum) provides content that can be adapted to the needs of any entity (eg, a single practice, a network of practices, parent and family organizations, a statewide organization such as the Title V Maternal and Child Health program [<http://mchb.hrsa.gov/programs/titlegrants>]). By design, the majority of the content is universally relevant, but optimal use of the curriculum results when it is adapted and customized to reflect local needs, assets, and cultures.

More information on care coordination is available through the National Center for Medical Home Implementation Web site (www.medicalhomeinfo.org/how/care_delivery/#coordination). Visit the COCWD Web site (<http://bit.ly/1nDwBZd>) for additional policies and membership opportunities. 

Instrument	Abbreviation	CPT Code
Ages and Stages Questionnaire-Third Edition	ASQ	96110
Ages and Stages Questionnaire: Social-Emotional	ASQ:SE	96127
Australian Scale for Asperger's Syndrome	ASAS	96127
Beck Youth Inventories - Second Edition	BYI-II	96127
Behavior Assessment Scale for Children-Second Edition	BASC-2	96127
Behavioral Rating Inventory of Executive Function	BRIEF	96127
Connor's Rating Scale		96127
Modified Checklist for Autism in Toddlers	M-CHAT	96110
Patient Health Questionnaire	PHQ-2 or PHQ-9	96127
Parents' Evaluation of Developmental Status	PEDS	96110
Pediatric Symptom Checklist	PSC	96127
Screen for Child Anxiety Related Disorders	SCARED	96127
Vanderbilt Rating Scales		96127
Beery-Buktenica Developmental Test of Visual-Motor Integration-Sixth Edition	BEERY-VMI	96111
Clinical Evaluation of Language Fundamentals-Fifth Edition	CELF-5	96111
Clinical Evaluation of Language Fundamentals-Preschool Version-2		96111
Comprehensive Test of Nonverbal Intelligence Second Edition	CTONI-2	96111
Developmental Test of Visual Perception-Third Edition	DTVP-3	96111
Kaufman Brief Intelligence Test-Second Edition	KBIT-2	96111



Coding Corner

Coding for emotional/behavioral assessment vs. developmental assessment

from the **AAP Division of Health Care Finance and Practice Improvement**

With the addition of Current Procedural Terminology (CPT) code 96127 for emotional and behavioral assessment, questions have arisen regarding the appropriate code for some of the instruments administered to pediatric patients.

The confusion lies in whether to classify an instrument as a developmental assessment (CPT code 96110) or as an emotional and behavioral assessment (CPT code 96127). Since there may be overlap with some instruments, it is important to identify the appropriate code.

While the two codes represent two distinct assessments, both codes have many similarities. For example, neither requires that a physician or other qualified health care professional perform the assessment. Because clinical staff typically administer the assessment, neither code contains any physician work value. In addition, both codes require that the instruments are standardized, and both codes may be reported “per instrument.”

It is acceptable to report both codes in addition to preventive medicine service codes (e.g., 99392, 99393). Proposed National Correct Coding Initiative (NCCI) edits had precluded the reporting of 96127 with any evaluation and management (E/M) service other than a preventive medicine service. However, the Academy and other specialty societies requested that NCCI allow a mod-

ifier to override the edit, and NCCI agreed.

Therefore, when a significant and separately identifiable office or other outpatient E/M service (99201-99215) is performed in addition to a standardized behavioral and emotional assessment, report both with modifier 25 on the E/M service. Note that health risk assessments, such as for lead or tuberculosis, still are reported with CPT code 99420. This code also can be used for the Edinburgh Postnatal Depression Scale when it is reported under the baby and not the mother when payers allow this.

Refer to the chart below for a list of some commonly administered instruments in pediatric practices along with the recommended CPT code. The Academy does not endorse any instrument over another, and the inclusion of an instrument in this list is for educational purposes only.

Becky Dolan contributed to this article. Email coding questions to aapcodinghotline@aap.org.

Instrument	Abbreviation	CPT code
Ages and Stages Questionnaire - Third Edition	ASQ	96110
Ages and Stages Questionnaire: Social-Emotional	ASQ:SE	96127
Australian Scale for Asperger's Syndrome	ASAS	96127
Beck Youth Inventories - Second Edition	BYI-II	96127
Behavior Assessment Scale for Children - Second Edition	BASC-2	96127
Behavioral Rating Inventory of Executive Function	BRIEF	96127
Connor's Rating Scale	(No abbreviation)	96127
Modified Checklist for Autism in Toddlers	M-CHAT	96110
Patient Health Questionnaire	PHQ-2 or PHQ-9	96127
Parents' Evaluation of Developmental Status	PEDS	96110
Pediatric Symptom Checklist	PSC	96127
Screen for Child Anxiety Related Disorders	SCARED	96127
Vanderbilt Rating Scales	(No abbreviation)	96127

Coding for emotional/behavioral assessment vs. developmental assessment

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The online version of this article, along with updated information and services, is located on the World Wide Web at:

<http://aapnews.aappublications.org/content/36/1/19>

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Additional Resources and Tools that Facilitate Surveillance and Screening

Tools to Make Change and Implement Developmental Surveillance and Screening

- American Academy of Pediatrics (AAP) Section on Developmental and Behavioral Pediatrics: <http://www2.aap.org/sections/dbpeds/practice-screening.asp>
- AAP Council on Children with Disabilities: <https://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Surv-and-Screening.aspx>
- Quality Improvement in Healthcare Video (11 minutes): <https://www.youtube.com/watch?v=iq52ZjMzqyI>
- Institute for Healthcare Improvement: <http://www.ihl.org/Pages/default.aspx>
- Centers for Disease Control and Prevention Autism Case Training (Free MOC Part 2 points available): <http://www.cdc.gov/ncbddd/actearly/act.html>
- Bright Futures Office Systems Inventory Tool: https://brightfutures.aap.org/Bright%20Futures%20Documents/OfficeSystems_InventoryTool.pdf
- Bright Futures Preventive Services Prompting Sheet: https://brightfutures.aap.org/Bright%20Futures%20Documents/PreventiveServicesPromptSheet_Sample.pdf
- Changing Developmental Screening Practice in the Real World <http://www.nashp.org/sites/default/files/abcd/abcd.developmental.screening.dianna.ploof.pdf>

Tools for Families that Facilitate Surveillance and Screening

- Centers for Disease Control and Prevention (CDC) *Learn the Signs. Act Early.* order form: [Go to order form](#) » On the order form page a complete list of materials for this program will appear.
- CDC *Learn the Signs. Act Early.* Web page: <http://www.cdc.gov/ncbddd/actearly/>
- CDC *Learn the Signs. Act Early.* Milestone Checklists (also available in Spanish): <http://www.cdc.gov/ncbddd/actearly/milestones/index.html>
- Bright Futures Resources for Families: <https://brightfutures.aap.org/families/Pages/Resources-for-Families.aspx>

Choosing Screening Tools

- The Identifying Autism Module from the CDC Autism Case Training (earn CME credits for completing module and MOC Part 2 credits for completing all three modules): <http://www.cdc.gov/ncbddd/actearly/autism/case-modules/index.html>
- Modified Checklist for Autism in Toddlers Revised with Follow-Up (M-CHAT-R/F™) Training Video from the Tennessee Chapter, American Academy of Pediatrics: http://tnaap.org/training_videos
 1. Enter your contact information (this is only for tracking purposes)
 2. Check the “Developmental and Behavioral Videos” box
 3. Click on Submit
- Birth to 5: Watch me Thrive!: A Compendium of Screening Measures for Young Children: https://www.acf.hhs.gov/sites/default/files/ecd/screening_compendium_march2014.pdf

- AAP Screening Tools Grid
<http://www.starsbasic.com/uploads/4/3/8/5/4385398/dpipscreeningtoolgrid.pdf>

Tools for Referral

- Early Intervention Contacts: <http://www.cdc.gov/ncbddd/actearly/parents/states.html>