

Birth to 5: Watch Me Thrive!

A Primary Care Provider's Guide for Developmental and Behavioral Screening

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Recent studies tell us that as many as 1 in 4 children in the United States, ages 0 to 5, are at moderate or high risk for developmental, behavioral, or social delays.¹ Young children who live in low-income families are even more likely to have a developmental delay.² These challenges are linked to later behavior problems and poor academic achievement.³ Supporting the healthy development of young children can reduce the prevalence of developmental and behavioral disorders that are linked to high costs and long-term consequences for health, mental health, education, child welfare, and justice systems.⁴

As a primary care provider and medical home for children, you are attuned to developmental stages and changes in growth and development. You are in a unique position to evaluate your patients at each well-care visit and offer anticipatory guidance on growth and development. This informed and trusting relationship

with families is important. If developmental concerns are caught early, you can help to ensure that children receive the extra support they need and are linked to appropriate services. Partnering with families to [Learn the Signs. Act Early](#) will help children have the best possible start to a bright future.

This guide, specifically designed for primary care providers, offers information on how you can best support the young children and families served in your practice. A comparable guide has been designed and distributed to early care and education providers, home visitors, early intervention service providers, mental health service providers and child welfare workers. Families may bring their child to you after a screening from one of these providers for further screening, to discuss implications of screening results, or referral to a developmental and behavioral specialist.

Accompanying this guide is:

- A compendium of standardized developmental and behavioral screening *tools* and
- The [Birth to 5: Watch Me Thrive! Toolkit](#), which includes information about healthy development, developmental concerns, how to select an appropriate screening tool, where to go for help, how to talk to families, and tips on how to best support children. Those interested in specific topics, such as autism spectrum disorder (ASD) or attention deficit/hyperactivity disorder (ADHD), will find

¹ Data Resource Center is a project of the Child and Adolescent Health Measurement Initiative at Oregon Health & Science University and is sponsored by the Maternal and Child Health Bureau, Health Resources and Services Administration. (2011/2012).

² Boyle, C, Boulet, S, Schieve, L., et al. (2011). Trends in the Prevalence of Developmental Disabilities in US Children, 1997–2008, *Pediatrics*, online, 1034-1042.

³ Glascoe F. (2001). Are over-referrals on developmental screening tests really a problem? *Archives of Pediatric Adolescent Medicine*, 155(1), 54-9.

⁴ Johnson, K. & Rosenthal, J. (2009). Improving Care Coordination, Case Management, and Linkages to Service for Young Children: Opportunities for States. (Portland, ME: The National Academy for State Health Policy, April 2009). <http://www.nashp.org/making-the-case/#sthash.c4r0aYIK.dpuf>; Reynolds, A. & Temple, J. (2008). Cost-effective early childhood development programs from preschool to third grade. *Annual Review of Clinical Psychology*, 4, 109–139.

resources on these topics, as they relate to developmental and behavioral screening and referrals, included.

If you are part of a group practice or network of providers, we encourage you to work with your colleagues or director to implement universal developmental and behavioral screening of each child in the practice. We hope this guide, together with the screening tool compendium and toolkit, will support your work in helping all children develop in a healthy way and reach their full potential.

What influences child development and behavior?

Starting at birth and continuing throughout childhood, children reach milestones in how they play, learn, speak, act, and move. Skills such as taking a first step, smiling for the first time, and waving "bye-bye" are called developmental milestones. Children develop at their own pace, so it can be difficult to tell when a child will learn a given skill. However, the developmental milestones give a general idea of the changes to expect as a child gets older. Developmental and behavioral screening plays an important role in early detection and appropriate supports for children who may be experiencing delays for any number of reasons.

Child Maltreatment, Abuse, and Neglect

We recognize that in the course of conducting screening, providers may discover situations of concern, in particular where they suspect child maltreatment or neglect. We know that adverse experiences like these have been shown to negatively affect brain and cognitive development, attachment, and later academic achievement and have enduring physical, intellectual, and psychological repercussions into adolescence and adulthood.

Medical providers are required by law to report suspicions of abuse or neglect to state child protective service (CPS) agencies. If you suspect a child is being abused or neglected or if domestic or sexual abuse is disclosed, contact your local CPS or law enforcement agency so professionals can assess the situation. Keep in mind that CPS agencies are better equipped to investigate the home situation and have the resources to provide needed family support. Many States have a toll-free number to call to report suspected child abuse or neglect. To find out where to call, consult the *Child Welfare Information Gateway* publication, [State Child Abuse Reporting Numbers](#).

For additional resources, check out Childhelp[®], a national organization that provides crisis assistance and other counseling and referral services. The [Childhelp National Child Abuse Hotline](#) is staffed 24 hours a day, 7 days a week, with professional crisis counselors who have access to a database of 55,000 emergency, social service, and support resources. All calls are anonymous. Contact them at 1.800.4.A.CHILD (1.800.422.4453).

Many factors can influence child development, including biology and early experiences with caregivers and peers. Factors like warm and secure relationships, enriching learning opportunities, and proper nutrition, exercise, and rest can make a big difference in healthy child development. On the other hand, poverty, unstable housing, parental stress and adverse events such as household dysfunction, maltreatment, abuse, neglect, exposure to alcohol and substance abuse, violence, and/or trauma can have serious negative impacts on child development and behavior. To learn more about the effects of adverse early childhood

experiences, check out the [Early Childhood Trauma](#) and [Identifying and Providing Services to Young Children Who Have Been Exposed to Trauma](#) resources in the [Birth to 5: Watch Me Thrive! Toolkit](#).

What is developmental and behavioral screening?

Developmental and behavioral screening is a first line check of a child’s development, using a developmental and behavioral screening tool. A developmental and behavioral screening tool is a formal research-based checklist that asks questions about a child’s development, including language, motor, cognitive, social, and emotional development. The results of a screening can help you plan how to best support the development of the child in your care. A screening does **not** provide a diagnosis, rather, it indicates whether a child is on track developmentally and if an evaluation with a specialist is needed.

Connecting families to a doctor or specialist is an important next step if a child needs a formal evaluation. A formal evaluation is a much more in depth look at a child’s development, usually done by a trained specialist like a developmental specialist, child psychologist, occupational or physical therapist, or speech-language pathologist, and may involve child observation, standardized tests, and parent interviews or questionnaires. Under the Individuals with Disabilities Education Act, an evaluation is used to determine eligibility for early intervention services if the child is under the age of three or for special education and related services if the child is over the age of three.

What is developmental surveillance?

Developmental surveillance is the tracking of a child’s developmental screening results over time. It is different from screening in that it is a flexible, continuous process during which primary care professionals attend to parental or caregiver concerns, obtain a relevant developmental history, document observations of children using clinical judgment, and share opinions and concerns with relevant professionals. Pediatricians may use age-appropriate developmental checklists to record milestones during well child visits as part of developmental surveillance.⁵

How often should children be screened?

Children’s development should be monitored or observed every day in the home, child care settings, and anywhere else children spend their time. The American Academy of Pediatrics (AAP) recommends *developmental and behavioral screening* with a standardized developmental screening tool when a child is 9, 18, and 24 or 30 months of age. These screenings may be done in early childhood settings, schools, community based intervention programs, or in the child’s medical home, the model of comprehensive children’s health care recommended by the AAP. Although there are specific ages that screening is recommended, screening should be done at any age if you and/or the child’s family are concerned about a child’s development.

A team approach

⁵ Dworkin P. (1993). *Detection of behavioral, developmental, and psychosocial problems in pediatric primary care practice. Current Opinions in Pediatrics*, 5:531–536.

Birth to Five: Watch Me Thrive! Passport



One tool for helping parents to monitor developmental progress is the use of a screening passport, which is similar to an immunization card or booklet. This tool can help parents keep track of their child's screening records and share screening information with providers. A passport is included in this toolkit and can be shared with parents.

Developmental and behavioral screening and support is a team effort. There are many different professionals that interact with children and families. Parents and families are at the center of children's support teams. Other important members of the team include health care providers, early care and education providers, early intervention service providers, home visitors, and behavioral health specialists, among others. As a member of the team, you should encourage and remind families to communicate developmental or behavioral concerns, screening results, and support plans to all members of the team. With everyone on the same page, children can get the support they need in *every* setting.

A developmental and behavioral screening passport, similar to an immunization card, is a tool to help families keep track of their children's screening records. It can be used to inform all members of the team of the child's screening record. A passport is included in this toolkit. Encourage families to use it and share it with all of the professionals on the child's team.

Building an integrated child-serving system

Many communities take a more formal approach to ensuring that all of the providers in a child's life are connecting and offering care in a coordinated manner. This toolkit includes a guide for helping communities take practical steps to better integrate care. For example, pediatricians, home visitors, child care, and early intervention service providers might put a system in place to ensure that they are communicating often so the care they provide to a young child is consistent and supportive of that child's needs. Some communities develop policies, protocols, and even technology to make good team work possible and easy. See the *Community Guide* included in this toolkit for examples that might be of interest to you and your community.

When should I talk to families about development and screening?

As the child's medical home provider, you will discuss healthy development with the child's family at the initial visit and during each well-care visit. This should also occur for a child who comes in for a sick visit or injury and missed the most recent well-care visit according to the practice's periodicity schedule. If a developmental and behavioral screening is to be conducted, explain the screening and offer assurance that it is a regularly performed screen for all children, like a hearing or vision screen. Engage the family in the screening process, and share information on helpful resources and services as needed.

Is developmental and behavioral screening covered by public and private health insurance?

In 2012, close to half of all children under the age of 21, or about 44 million children, were enrolled in public health insurance coverage, Medicaid or the Children's Health Insurance Program (CHIP), predominantly in managed care delivery systems. Medicaid requires states to provide comprehensive health and



developmental history and physical examinations of children at regular intervals, based on state-specific periodicity schedules, under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. CHIP programs are also required to cover screening services, including developmental and behavioral screening. Regardless of health insurance type, all children and families have access to **preventative care**

without a copayment or coinsurance, even if the yearly deductible has not been met. Children's preventative health coverage includes services like vision, hearing, developmental, behavioral, and autism spectrum disorder screenings. For more information on essential benefits covered under the Affordable Care Act, please visit www.healthcare.gov.

How do I engage the family in the screening process?

Use the [Bright Futures Tool and Resource Kit](#) to guide you in talking to parent(s). You also can connect families to parent training information centers, family-to-family health information centers, or parent-to-parent programs that connect new parents of children with special needs with experienced parents for emotional support and help finding information and resources. Information on these family support centers is also available in the toolkit. Here are a few helpful tips:



Talk to families before screening:

- When talking to families, it is best to use the language used at home, so use a medical interpreter as needed.
- Start off by pointing out something positive. Name a skill or behavior the child is doing well and note their progress.
- If you are concerned about a child's development, point out the specific behavior the child is struggling with and ask if they observe the same behavior(s) at home. Ask if their child care provider or other family member has observed similar behaviors. It is okay to say, "I may be overly concerned, but I just want to make sure".
- Use and share the [Learn the Signs. Act Early](#) developmental factsheets to support your observations on the child's strengths and challenges.
- Explain what developmental and behavioral monitoring and screening is and note that it is a normal process to make sure children are on track in their development.
- Stress that a screening does **not** provide a diagnosis.
- Ask the family if they know whether their child has been screened in the past. If so, discuss the results of that screening.
- If a family informs you that their child has not been screened in the past or they have concerns about their child, ask the family for permission to perform a screening using a standardized tool and explain the survey will take about 5 minutes. Feel free to let the parent or caregiver know that the American Academy of Pediatrics recommends that children be screened for general development at 9, 18, and 24 or 30 months of age or whenever a parent or provider has a concern.
- Provide families with informative materials and direct them to additional screening resources.
- Engage the family in a discussion. Give them time to listen, reflect, and provide input.
- Remind them that you are their partner on their child's developmental journey.

Walking families through the screening process

- If a family informs you that their child has not been screened in the past or they have concerns about their child, ask the family for permission to perform a screening using a standardized tool and explain the survey will take about 5 minutes. Feel free to let the parent or caregiver know that the American Academy of Pediatrics recommends that children be screened for general development at 9, 18, and 24 or 30 months of age or whenever a parent or provider has a concern.
- If the family gives written consent, find a confidential space to conduct a developmental and behavioral screening using a tool that is appropriate for the families you serve. Most tools are surveys about children’s development that parents can fill out themselves or have read to them.
- Score the developmental and behavioral screening in accordance with the instructions in the tool’s manual.

Talk to families after an “at risk” screening result:

- Remind families that this is **not** a diagnosis. An “at risk” screen simply means the child should be evaluated more thoroughly by another specialist. Even if you are not concerned, an “at risk” result indicates further evaluation is needed. Standardized screening tools detect many delays before delays are overtly apparent.
- Connect the family to a specialist who can conduct a more in-depth evaluation. The toolkit can help you find local resources and specialists. Have your staff help to facilitate any referral, such as assisting with appointment scheduling, transportation, language or physical needs.
- Work together to create a list of questions to ask the specialist or early intervention service or early childhood special education provider as a result of the screen.
- Suggest activities that families can practice with their child to help in development. The tips and learning modules in the toolkit offer many ideas for activities.
- Use the information in this toolkit to answer families’ questions.

Talk to families after a “low risk” or “no risk” screening result:

- Discuss the results with the family and remind them that *monitoring* a child’s development should be ongoing in the home, child care settings, and elsewhere.
- Give them materials that describe their child’s next developmental level. The *Learn the Signs, Act Early Milestones Moments* booklets included in the toolkit can serve this purpose.
- Use the screening results to talk about the child’s strengths and challenges. The toolkit offers ideas for activities that families can do with their child to help in development.
- If a child has a “low risk” or “no risk” screen and you still have concerns, discuss your concerns with the family and the need to administer another test or refer the child to a specialist who can do a more thorough evaluation.

How do I refer families to the right place after screening?

Depending on the outcome of the screening, you may have several choices to make regarding what to do next. If you have no concerns, and you are the child’s medical home, you will continue to provide surveillance and routine screening as appropriate. If you or the family has reason for concern, regardless of the result of the screening, you should facilitate a referral to someone who can help. It is not a good idea to “wait and see”, or to assume that your concerns, or those of the child’s family, are unfounded.

If a child has an “at risk” screening result or you have concerns based on developmental surveillance, you should facilitate a referral to an appropriate medical sub-specialist, including a developmental pediatrician, neurologist, psychologist, or other medical provider. If you believe that a developmental/educational assessment is needed, you should facilitate a referral to the early intervention service or special education program where the family lives. Depending on the results of the screening, you may also wish to refer a child for both an developmental and behavioral assessment and further medical evaluation.

If you have completed a screening with a child under age 3 and you believe the child is at risk of delay as a result, further developmental assessment is indicated. Connect the family to a local early intervention service program. Early intervention service programs under Part C of the Individuals with Disabilities Education Act (IDEA) are available in every state and territory of the United States and offer child evaluations free of charge if the program determines the child is suspected of having a disability to determine if a child is eligible for services under IDEA. The *Birth to Five: Watch Me Thrive! Toolkit*

Find the Right Screening Tool

- ✓ **Ages:** What age groups do I serve and what screening tools are made for those ages?
- ✓ **Time:** How much time does it take to use this screening tool? Which tool is practical within a child care or Head Start program?
- ✓ **Cost:** What is the cost for the screening tool and its ongoing use within early care and education programs?
- ✓ **Training:** Is there training required to use this screening tool? How much training is required? What type of training is recommended?
- ✓ **Languages:** Does the screening tool need to be available in different languages to fit the needs of the families I serve?
- ✓ **Culture:** Is it culturally appropriate?

accompanying this guide provides a description of the early intervention system and a state-by-state directory of early intervention coordinators, often called “Part C coordinators”. If the child is 3 years of age or older, you can help connect the family to their neighborhood public school, which can provide information on evaluation under Part B of IDEA, even if the child is not yet in kindergarten.

You also can connect all families to parent training information centers or family-to-family health information centers. Information on these family support centers is also available in the toolkit.

It is important to track any referral to specialists, to ensure that the child actually receives the follow-up service and that the results of any diagnosis and/or treatment are received and notated in the child’s health record. If your patient was referred to your practice from another source for developmental and behavioral screening, it is important to provide feedback to that provider, in accordance with Health Insurance Portability and Accountability Act (HIPAA) Health requirements on protection of the child’s confidentiality.

How can I use screening results to individualize support for the children I care for?

The results of a developmental and behavioral screening can help you identify your patient’s strengths and challenges. Use the *Birth to 5: Watch Me Thrive! Toolkit* to learn more about individualized support based on a child’s individual needs and circumstances. For example, some screening tools can be administered by the family at home or in the waiting

room. This then provides an opportunity for you and the family to discuss areas of strength and concern, and determine a plan of action during the visit. It’s important to recognize that a child may have already

been screened, evaluated, and given specialized services, like speech or occupational therapy. Be sure to ask the family if they are aware of other screening, and if so, ask for a copy of the results of those screenings, as well as any action or intervention already in place. You should be aware of, and coordinate with, screening activities conducted by other providers, including schools, Head Start and child care providers.

How do I select the right screening tool to fit my needs?

The compendium of screening tools that accompanies this guide may help you learn more about the tool your medical home is currently using or help you find a screening tool to fit your needs. This list describes the evidence base behind certain standardized screening tools. Information is included on the cost, time to administer, training requirements, ease of use, and other factors that can help you find the right tool. You should not interpret this list as recommending or requiring the use of a particular tool. Rather, it should be used to learn about a selection of screening tools that are supported by research and help you make informed decisions about the best fit for you and your practice.

Many local early intervention service programs, early care and education programs, and medical homes have adopted their own standardized developmental screening tools for use; it may be helpful to inquire with the local referral and child service agencies to determine if a common tool could make referrals and implementation of any recommendations easier across the system of care.

It is also important to learn about the validity and reliability of the screening tool in use or being considered for use. Read about the tool in the compendium of screeners that accompanies this guide to make sure the tool is of high quality and accurate in tracking development.

How do I use this list of screening tools?

The list of screening tools that accompanies this document is made up of two sections:

- A section of summary tables and
- A section of individual profiles.

If you are looking for a new tool, start at the summary tables as they provide an overview of many different tools. The tables may help you narrow the range of tools to consider. Once you narrow down the screening tools that may fit your needs, you might choose a smaller set of tools to read about in more detail in the individual profile section. If your practice already uses one of these tools, you can go straight to the profile section to read more about it.

Making a difference

Research indicates that the first five years of a child's life are critical to brain development, academic achievement, and later life outcomes. The short time it takes to conduct a developmental and behavioral screen can change the trajectory of a child's life forever. By incorporating a system of regular developmental and behavioral screening, YOU can play an important role in making sure all children thrive. We hope you find this User Guide, Screening Compendium, and the [*Birth to 5: Watch Me Thrive! Toolkit*](#) is useful in supporting young children and their families on their developmental journey. Visit www.hhs.gov/WatchMeThrive for a complete set of resources.



Birth to 5: Watch Me Thrive!

*Celebrating Developmental Milestones • Implementing Universal Screening •
Improving Early Detection • Enhancing Developmental Supports*