

BIRTH TO 5: WATCH ME THRIVE!

A Community Guide for Developmental and Behavioral Screening

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
DEPARTMENT OF EDUCATION

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The purpose of this guide is to support communities in thinking about how to implement a collaborative, community-led universal screening effort. Recent studies tell us that as many as 1 in 4 children in the United States, ages 0-5, 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 systems⁴.

Effective promotion and support of healthy child development and wellness is best achieved early in a child's life with well-coordinated, multi-sector services and resources as well as ongoing partnership with families. Public awareness of typical child development and risks for delay, developmental and behavioral screening, early identification of delays as well as linkages to referral and follow-up services can be delivered anywhere young children and families spend time. Besides being delivered in the home, this can also include programs and services in the community such as child care, Head Start, mental health, early intervention and special education programs, primary health care, child welfare, and home visiting. Establishing a streamlined, coordinated system of screening, referral, feedback, and follow up is a complex undertaking, but lessons and examples are emerging from communities that are working toward realizing this vision. All efforts should prioritize partnering with families to *Learn the Signs. Act Early* so that all children have the best possible start to a bright future.

Accompanying this guide in the *Birth to 5: Watch Me Thrive! Toolkit* is:

- A compendium of standardized developmental and behavioral screening tools
- A variety of *guides* targeted towards specific early childhood-relevant providers from multiple sectors in your community to assist in the screening process
- Developmental and behavioral screening *resources* that include information about healthy development and 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 the development of all children

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). [The National Academy for State Health Policy](#); Reynolds, A. & Temple, J. (2008). Cost-effective early childhood development programs from preschool to third grade. *Annual Review of Clinical Psychology*, 4, 109–139.

- A screening passport, similar to an immunization card, to help parents keep track of screenings, results, and action plans and share this important information with all the professionals working to support children and families

We hope this guide, together with the compendium and resources, can help members of your community come together to build a unified system for ensuring that all children develop in a healthy way and reach their full potential.

Broad Community Goals and Strategies for Successful Developmental and Behavioral Screening Initiatives

Developmental screening initiatives are most effective when coordinated across systems, programs and agencies. Within their health and early care and education sectors, many states and communities are working together to raise awareness of early child development, positive parenting practices, parents as first teachers, and the importance of developmental screening for all. This Community Guide offers the following principles for leaders and communities to strengthen supports, messaging and practices:

- ✓ Raise public awareness about the importance of celebrating developmental milestones with children and families, universal developmental screening, risks for developmental delay and supports for those at risk.
 - Promote individual, family and community factors that create positive environments to help young children and families thrive.
 - Use resources in this toolkit to empower parents and caregivers in managing their children’s needs and promote healthy development.
 - Involve traditional and non-traditional partners in community outreach. Partner with the local children’s museum, libraries, health centers, parenting groups, grocery stores, barber shops, Head Start programs, child care providers, early intervention programs, school districts, government agencies, and community- and faith-based organizations to deliver child health and development resources and messages.
- ✓ Engage community leaders.

Use existing or build strong coalitions by bringing together parents, teachers, business leaders, government officials, school administrators, early care and education, and health providers, and other leaders working to enhance childhood development. For example, Act Early Ambassadors, Local Interagency Coordinating Councils, local pediatric/family practice chapters/organizations, Early Childhood State Advisory Councils, and Head Start Advisory Councils might be existing groups and/or leadership to build upon. Personal relationships across sectors are essential to success.

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 instrument that asks questions about a child’s development, including language, motor, cognitive, social, and emotional development. A screening does **not** provide a diagnosis, rather, it indicates whether a child is on track developmentally and if a consultation with a specialist is needed. The results of a screening can help parents and community providers plan how to best support development of the child. Connecting parents and caregivers with developmental and behavioral specialists is an important next step if a child needs a formal evaluation and additional support from a specialist like a developmental pediatrician or a child psychologist.

✓ Discover common stakeholder interests and goals.

Success does not rely on a single sector, audience, or strategy. Creative, strategic integration of broad program strategies across multiple sectors and audiences is what differentiates successful community systems from unsuccessful ones.

- What are local needs with respect to timely developmental and behavioral screening, referral, and follow-up? What barriers are parents and providers facing?
- How can your community conduct timely evaluations and offer families assistance in a way that supports and enhances parental roles, honors community and cultural context, and aligns with the highest standards for quality services?
- How can providers/organizations in your community come together to ensure that screenings are happening, that care is coordinated, and that information is shared in ways that most benefit children and families?
- With these goals and needs in mind, how can individual program resources be leveraged to benefit the community as a whole?
- How can you work within current funding levels?
- How can efficiencies be improved and redundancies reduced?
- What kinds of policies, practices, systems, and/or technology can be put into place to help accomplish these goals?



Influences on 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 exactly 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 or challenges for any number of reasons.

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 maltreatment, abuse, neglect, exposure to alcohol or 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!*

Provide cross-disciplinary training to relevant providers who interact with young children in the administration of standardized, reliable screening tools.

- Training should focus on talking with families about child development, developmental screening, and the results of screenings in ways that support caregivers and/or parents, inspire confidence, and motivate action when necessary.
 - “Building on and building up” parent and caregiver capacity to support child development is a fundamental principle that should underlie all trainings.
 - Shared training and professional development opportunities also encourages relationship building between important partners in the screening system. Strong relationships facilitate communication, referral, and follow-up.
- ✓ Build systems, communication, privacy assurances, and infrastructures that 1) support expanded screening across early childhood programs and providers while minimizing the risk of duplicate screenings, and 2) ensure that referrals are successful, feedback loops are utilized, follow up and monitoring occurs, and action plans are shared with all who support young families and their children.
- Re-imagine the roles of early care and education providers, home visitors, early intervention service providers, pediatricians, mental health specialists, and social workers based on the needs and risks of the families in your community. Family and child needs may range from education to screening to referral. Because of varying levels of expertise, specific providers may be better suited to certain roles rather than others.
 - Follow-up and integration of treatment plans across all settings that touch the life of the child is important to make real progress.
 - Examine available local data. Define pathways for linkage/referral to specialists and community resources. Based on data as well as community and family input, come together and design a common

plan to improve conditions for young children. Coordinating community systems around developmental screening can provide opportunities to address gaps in services and supports for young children that might present with developmental challenges but are not eligible for services.

- Incorporate formal methods to involve the input of parents and families.
- ✓ Improve communication processes across early care and education and primary care.
 - Choose common, standardized screening tools across sectors that care for young children.
 - Create coordinated data systems, intake procedures, and referral networks.
 - Define common terminology across child- and family-serving organizations.
 - Solicit and use stakeholder feedback to determine what terms to use in common forms or templates.
- ✓ Destroy myths that may act as barriers to action.

Budget cuts across child- and family-serving systems may limit resources available to collaborating agencies. With limited funds, member organizations may be more concerned with their individual financial needs than attending to the needs of the collaborative. They may rely on past practice as a reason to believe something cannot be done. They may believe that what could be done exceeds current capacity to do so.

On the other hand, when people need to do more with less they are sometimes more open to thinking creatively about sharing resources, leveraging funding across agencies, and working together to be more cost efficient. This might provide new opportunities for partnerships where there was reluctance previously. Think beyond business as usual. Inspire change by the collective value of improving the lives of all children by a focus on early development.

- ✓ Take advantage of medical/health home, health information exchange, and health care reform initiatives.



Regardless of income, job, age, or health status, the Affordable Care Act (ACA) has provided new opportunities for Americans to obtain affordable health insurance through the online [Health Insurance Marketplace](#) or in-person with the help of Navigators, application assisters, certified application counselors, agents, brokers, and local health centers. Medicaid and the Children's Health Insurance Program ([CHIP](#)) are examples of two coverage options that support screening, referral, and follow-up. 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 screenings. For more information on essential benefits covered under the Affordable Care Act, please visit [the Healthcare.gov website](#).

Under the ACA, Section 1945 Health Home State Plan Option provides 90% federal matching funds for States to provide [health home](#) options to coordinate care for Medicaid enrollees with chronic health conditions that include mental health, substance abuse, asthma, diabetes, heart disease, and being overweight. Services provided by health homes include comprehensive care management, care coordination, health promotion, comprehensive transitional care/follow up, patient and family support and referrals to community social support services, and use of health information technology.

With Centers for Medicare and Medicaid approval, your state may be able to use the health home option in Medicaid to target individuals with developmental and behavioral health needs. For example, Missouri and Rhode Island have included developmental disabilities as conditions that can confer eligibility for health home services. States also have flexibility in determining eligible health home providers and may include individual pediatricians and community health teams. Please visit the [Health Home Information Resource Center](#) or contact healthhomes@cms.hhs.gov for more information.

The ACA also provides demonstration opportunities through Centers for Medicare and Medicaid Innovation funding payment and service delivery models that aim to achieve better care for patients, better health for our communities, and lower costs through improvement for our health care system. For examples of currently funded models at State and local levels, please visit the [CMS Innovation Map](#).

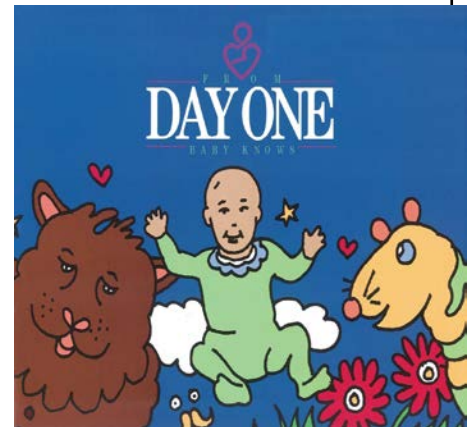
✓ Think big, but start small.

Don't work on too many complex problems and ideas at once. First, focus resources on a single outcome—for example, increasing awareness of the importance healthy child development and universal developmental and behavioral screening.

Community Examples

New Mexico

New Mexico has made developmental screening a focus for at least 10 years as a part of the [Early Childhood Comprehensive Systems](#) grant initiative. In 2004, the quality and frequency of developmental screenings of New Mexico's children, birth to age five, was unknown. As a result, the [Early Childhood Action Network](#) recommended that the status of developmental care be assessed and that recommendations be developed. The focus of this effort was to define a statewide, systematic approach to ensure every child birth to age five receives periodic and high quality developmental screening and that all children with developmental concerns receive timely referral, high-quality evaluations, and early intervention, special education, or related services. Three public forums were held with key early childhood stakeholder groups to determine what was needed to ensure no child reached kindergarten with an undetected developmental condition. As a result of these sessions and Project Linking Actions for Unmet Needs in Children's Health (LAUNCH) funding, recommendations were developed that resulted in the following activities/products:



- In 2009, NM Project LAUNCH partnered with *Envision New Mexico* and *Parents Reaching Out* to print and distribute Developmental Screening Record Booklets in English and Spanish. These booklets, created by Dr. Sherri Alderman, a Developmental-Behavioral Pediatrician, are intended to be a guide for parents to follow and talk about their child's development with his or her provider. The New Mexico booklets

have been used by other states as a template for their own developmental screening passports. More than 15,000 booklets have been distributed by multiple organizations throughout the state.

- To augment workforce development, NM Project LAUNCH has been offering training in the use of Ages & Stages Questionnaire-3 (ASQ) and ASQ: Social Emotional to child care providers, Pre-K teachers, Head Start and Early Head Start teachers, home visitors, early intervention service providers, and case managers throughout the state. To date, NM Project LAUNCH has trained 415 early childhood development providers. Participants are better equipped to present the screening tool to families, both to identify their child's strengths and finding areas where extra support can make a real difference. With LAUNCH funds, the program has supplied over 180 ASQs, training videos, user guides, and activity books.

New Mexico has also created a unique series of books and videos to help parents understand the social and emotional development of their babies and toddlers. The books, *From Day One a Baby Knows* and *Day Two: A Toddler's World and You*, and six accompanying DVDs have become part of the LAUNCH legacy. The DVDs are designed to be used by providers who work directly with families or shown in waiting rooms. Over 20,000 books and almost 1,000 DVDs have been distributed. Both the books and the videos can be accessed on line at [New Mexico Department of Health website](#).

North Carolina

Harnessing collective power of partners inside and outside of the medical community is part of what makes the North Carolina Wellness Council unique in its preventative system of care approach to supporting families. The community has adopted several screening tools to advance the family-centered health movement. It began with a [Project LAUNCH](#) grant awarded to the Department of Social Services that allowed all child-serving agencies to be trained and supplied with standardized, validated social-emotional screenings for children, birth to five years of age. Through a community-wide protocol, children with positive screens are referred to early intervention for further evaluation and evidence-based treatment options are now available to support parent-child interactions and close developmental gaps. The Wellness Council has expanded this effort by supporting screening for caregiver depression, not only in primary pediatric practice sites, but across multiple child-serving agencies that serve families through home visitation.

Serving the most vulnerable populations with available resources has become an ever increasing community effort. Between 2010 and 2012, the Alamance Regional Medical Center's Emergency Department has seen an increase from 2,055 to 2,686 visits with a behavioral medical diagnosis. The need for a better solution for families led to a collaborative effort between Cardinal Innovations (Behavioral) Healthcare Solutions, Healthy Alamance, Alamance Regional Medical Center, local providers, and law enforcement to adopt preventive measures through use of standardized screenings in each of their settings. Screening for substance use and depression across human service and law enforcement systems has advanced the community's capacity to help families access the help and support they need before things reach crisis proportions. The greatest challenge/opportunity is providing the necessary assessment of an office's understanding of the periodicity schedule and meeting them where they are in providing technical assistance. Building off of this starting point has meant that all sites look different in their adoption of screening tools and implementation of various screening tools.

Texas

Texas Health Steps, or Early and Periodic Screening, Diagnosis, and Treatment services for children, requires that health care providers serving Medicaid recipients incorporate the Ages and Stages Questionnaire (ASQ-3) and/or the Parent Evaluation of Developmental Status (PEDS) during well-baby check-ups. In response to this

policy, [El Paso Project LAUNCH](#) provides intentional and ongoing training and technical assistance for providers to support administration, interpretation, and follow-up on screening. These efforts include:

- Training on the ASQ and ASQ Social and Emotional (ASQ:SE) for a variety of providers including early intervention service providers and Texas Health Steps staff, social workers, primary care providers and their staff, substance abuse prevention and treatment staff, and medical vocational school students.
- In-office training for primary care providers and office staff on the ASQ and ASQ: SE and/or PEDS, Edinburgh Postnatal Depression Screening, and the CAGE-AID (substance abuse screen).
- Training for medical residents as part of their developmental rounds including an overview of the tools, how to deliver results, and services offered in the community, followed by shadowing LAUNCH staff conducting the ASQ-3 and ASQ-SE with families.

El Paso Project LAUNCH also employs an Early Childhood Liaison to provide training and technical assistance for providers and conduct screenings for children and families across the community. LAUNCH raises awareness through outreach to families on the need to screen children regularly to ensure their developmental and social-emotional health is on track.

El Paso has also tried to address common challenges in strengthening the screening system. For example, some medical providers express discomfort with screening because of a lack of knowledge of community-based programs and time to investigate referral options. As a result, Project LAUNCH conducted trainings to support participants in understanding the referral process and developing a specific method applicable to their setting. LAUNCH also created a Wellness Resource Directory that identifies community-resources across a continuum of care.

Washington State

Washington State has been working toward Universal Developmental Screening (UDS) and has concentrated on building a cross-agency, cross-sector statewide system. To support UDS, local health jurisdictions were required to use part of their 2013 Maternal Child Health block grant funds to either reduce [adverse childhood experiences](#) or increase developmental screening work in communities. To support these investments, WA has become an affiliate state for *Help Me Grow* and provides free, statewide access to screening, resources, and referral that include a website, toll-free phone number and on-line or paper screening. In addition, through both the [Yakima Project LAUNCH](#) and the state Project LAUNCH, several pilots have been implemented. Highlights include:

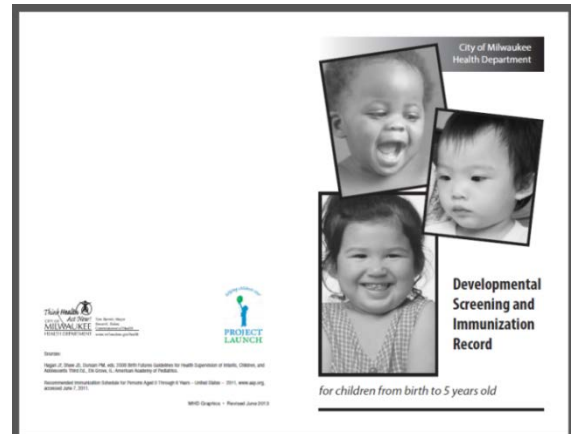
- A county-wide, cross-sector developmental screening workgroup that recently spread to early learning regions.
- In-person training with medical providers to incorporate standardized developmental screening into their practice. As a result, there has been transformation from initial hesitancy on the part of the providers to engagement and practice change.
- Training by health consultants working with child care providers to incorporate developmental screening into their curricula and family support services.
- Online screening system housed at a regional multi-disciplinary specialty clinic with family access and opportunity to link with providers.

Wisconsin

Focused on sustainability and systems change well beyond their five year grant, [Wisconsin Project LAUNCH](#) has developed relationships with existing and new collaborations such as Milwaukee Public Schools (MPS), Wisconsin Early Childhood Collaborating Partners, *Milwaukee Succeeds*, and *YoungStar*.

- ***Ages and Stages Questionnaire (ASQ) Community of Practice (CoP)***

While working closely to implement the ASQ as part of MPS Child Find, an idea emerged to create a cross-sector CoP to promote strategies for implementing best practices, including use of the ASQ. The result has been the development of an ASQ CoP for trainers and champions of the ASQ in Southeastern Wisconsin. The ASQ CoP has convened as part of three quarterly “Early Childhood Days of CoP.”



- ***Milwaukee Succeeds***

Project LAUNCH has worked collaboratively within *Milwaukee Succeeds*, a cradle-to-career initiative that aims to ensure success for every child, in every school. LAUNCH has taken a leadership role within the School Readiness goal’s Parent Education and Support Network. The hope is to ensure that Milwaukee’s parents are knowledgeable and skilled in ways that optimize child development and well-being, prenatally to age 5, through evidenced-based quality programs and universal developmental screening at regular intervals. They seek to increase the use of standard screening tools by multiple child-serving service areas while providing consistent messages that parental engagement and high-quality early care and education is critical for optimal child development. In addition, they are in the process of identifying a community-wide system to aggregate and report on screening results and referrals to early intervention services. They are looking to reduce any redundancy in screenings and improve the efficiency of interventions. Although they are in the early stages of this work, a great deal of community buy-in exists.

- ***YoungStar***

YoungStar was created to improve the quality of child care for Wisconsin children. It established a quality rating system for child care, assigning a rating from 1-5 stars. The ratings incentivize programs to improve their services through subsidy reimbursements. LAUNCH has advocated for the screening evaluation criteria to be strengthened and is currently working with *YoungStar* to draft language to change screening-related criteria in 2015.

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](#) 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*