

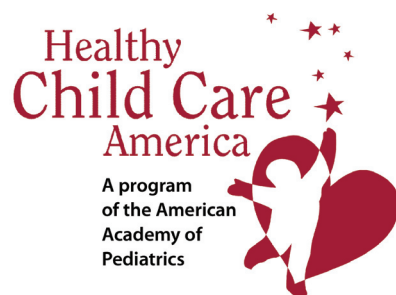
Developmental Screening in Early Childhood Systems

Summary Report

Meeting hosted by:

American Academy of Pediatrics
Healthy Child Care America
Child Care and Health Partnership
www.healthychildcare.org

Sheraton Suites • Elk Grove Village, IL
March 25, 2009



American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™



GOAL:

To strategize new ways to reach out to children and families in the community and child care settings to promote high-quality developmental screening in the context of the medical home.

OVERVIEW:

The American Academy of Pediatrics (AAP) is a national organization comprised of over 62,000 members, 66 state and local chapters, 30 national committees, 49 sections, 6 councils, and a staff of nearly 400. On March 25, 2009, AAP's Healthy Child Care America (HCCA)/Child Care and Health Partnership (CCHP) program hosted a summit on "Developmental Screening in Early Childhood Systems" in Elk Grove Village, Illinois.* Recognizing that it is now possible to do high-quality and low-cost developmental screenings, invited participants representing a full range of academic, government, health and education-related professions from across the country were given the opportunity to review the current recommendations and common language integral to the effective implementation of developmental screening, learn about existing approaches and efforts in several representative states, and then discuss the challenges and barriers faced in the process.

* This summit was hosted by the AAP's HCCA/CCHP, a program jointly funded under a cooperative agreement (U46MC04436) with the US Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB), and the Child Care Bureau (CCB).

The AAP's Developmental Screening Initiatives & the Medical Home

V. Fan Tait, MD, FAAP

In keeping with the AAP's overarching mission to attain optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults, the AAP's 2009-2010 Strategic Plan has established early brain and child development as one of the organization's top 4 agenda items (along with special health care needs, foster care, oral health, and mental health).

In efforts that pre-dated this formal recognition, the AAP has helped lay the groundwork for future developmental screening efforts through its collaboration with the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities to promote optimal child development within public and private health systems – a collaboration that resulted in 2 crucial components of the developmental screening implementation effort:

1. Development of the AAP policy statement (and algorithm) regarding developmental screening and surveillance.¹
2. Subsequent funding of the AAP's Developmental Surveillance and Screening Policy Implementation Project (D-PIP).²

The AAP is not only committed to promoting high-quality developmental screening, but doing so in a coordinated fashion in both the pediatrician's office *and* within a family-centered systems network of community-based services. The ultimate goal of this "medical home" approach is to effectively provide developmental screening, assessment, and services to those children who need it. Making these services more accessible to families within their communities involves communication and working relationships within diverse communities and between wide-ranging organizations such as those represented at this summit. It also requires attention to such factors as accessibility, cultural competence, and ongoing quality improvement. With this concept and commitment in mind, it becomes particularly important for all who are involved in, or have a vested interest in, high-quality developmental screening in early childhood to work in concert with one another using

common language and shared goals. To do so effectively first requires a closer look at what is involved in the actual implementation of developmental screening.

Developmental Screening: Implementation in Early Childhood Settings

Elaine Donoghue, MD, FAAP

The implementation of well-performed developmental screening in the early childhood setting can be very useful in the identification of children with otherwise undiagnosed developmental delays. It is important to recognize that this implementation requires adequate preparation, communication, and follow through. To effectively conduct developmental screening in child care, it is therefore important to address the following 5 objectives.

1. Clarify rationale for developmental screening

To emphasize the importance of developmental screening in early childhood, the AAP's 2006 developmental screening policy included the strong statement that "*early identification of developmental disorders is critical to the well-being of children and their families.*"¹ Yet we know that a significant number of developmental delays continue to go undiagnosed. Studies show that only 20% to 30% of children with disabilities are identified before entering school. In addition, Early Intervention programs currently serve 2.3% of children under the age of 3 years, in contrast to the approximately 10% of children who actually have developmental delays.³ This translates into a missed opportunity to significantly improve the developmental outcomes for the large number of children who are not diagnosed and treated early.

2. Define common terminology

It may sound simple, but ensuring that everyone involved in the implementation of developmental screening uses agreed-upon terminology is not trivial, as even the words "developmental screening" are often misunderstood to mean more than the administration of a brief tool to

identify possible developmental delays. If this basic concept is not defined at the outset, then one runs the risk of others making the inaccurate assumption that developmental screening is synonymous with achievement testing, social-emotional screening, readiness testing, instructional assessment, or diagnostic assessment. Particularly for early childhood professionals, the common misperception of developmental screening to mean assessment or even diagnosis can, in and of itself, lead to significant resistance when it comes to interest in or willingness to implement a developmental screening program in a child care setting.

Therefore, to clearly establish what developmental screening involves and offers, it is important to establish clear definitions for the following components of the discussion.

- **Developmental delay:** The condition in which a child is not developing and/or achieving skills according to the expected time frame
- **Developmental disorder:** A childhood mental or physical impairment (or combination thereof) that results in substantial functional limitations in major life activities
- **Surveillance:** The process of recognizing children who may be at risk of developmental delays
- **Screening:** The use of standardized tools to identify a child at risk of a developmental delay or disorder
- **Evaluation:** The complex process aimed at identifying specific developmental disorders that are affecting a child¹

3. Review goals of screening

Adequate preparation is essential in establishing the process to be used in any developmental screening implementation. Careful consideration should be given to the goal(s) one hopes to achieve, as it will have a significant impact on the selection of an appropriate screening tool. If a pre-determined goal is to screen for a specific disorder, such as autism, then the screening tool used will inherently be different from a scenario where the intended goal is to implement a broader, more general developmental screening program. Either way, the choice of a proper screening tool must be made to meet the determined goal. The choice of a screening tool must also involve careful consideration of the steps (and barriers) involved in its implementation, since the required frequency of screening, the ages and characteristics of the children to be screened, the amount of time required to perform the screening, as well as consideration of who will be involved in actually performing the screening, are all key factors in determining the future success of any screening plan.

4. Plan the implementation process

Planning the implementation of developmental screening involves several key components: establishing a time line, figuring out how to inform and involve parents, staff training, and the identification of community resources *before* screening begins. Equally important is the identification of potential barriers that may impede the implementation process, including, but not limited to, staff and/or parental resistance, liability concerns, time constraints, availability of both the community resources and services needed and a means of communication necessary among all involved in the process. For example, staff resistance is a commonly faced barrier, as staff may feel that being asked to conduct developmental screening is beyond the scope of their

practice, expertise, or job description. Some may lack training, while others may fear that screening children is synonymous with “labeling” them. In all instances, clearly explaining the goals and the necessary steps required to attain them, agreeing upon realistic expectations, and ensuring adequate training of all involved helps ensure success.

The final step in the planning process is to pre-determine the actual steps involved in documentation of the screening results — whether that involves putting results in children’s files, for example, or entering them into a registry — and then determining the who, what, when, and where of communicating both the positive and negative results to parents/guardians, as well as the network of community based professionals that constitute each child’s medical home. One of the clearly identified challenges of such an undertaking is bringing together Early Intervention professionals and pediatricians to ensure the necessary sharing of screening results.

In recognition of the fact that delivering concerns can be challenging and that doing it well is particularly helpful for the families of those children identified in the process, providing specific communication training for staff involved in this crucial part of the process can also be quite valuable.

For positive screens in particular, referral procedures need to be in place, as the evaluation and subsequent treatment of any positive screens may require any or all of the following steps:

- **Developmental diagnostic evaluations:** may involve multidisciplinary evaluations, such as gross motor, fine motor, speech and other evaluations
- **Medical diagnostic evaluation:** includes vision and hearing testing, review of newborn metabolic screens and growth charts, updated histories (medical, environmental, family, and social) and tests that may include imaging studies, genetic and/or metabolic testing
- **Early development intervention:** incorporates developmental therapy, service coordination, social work services, transportation (and other) services, family training, counseling, and/or home visits as needed

Given that these requisite evaluations and interventions require the involvement of a large number of specialists, health care professionals, and community services, the application of the medical home concept and chronic condition management — including the coordination of referrals, follow-up on therapy(ies), and handling of transitions — becomes very apparent and critically important.

5. Prepare to assess effectiveness

Ongoing assessment of any process, including any implemented developmental screening process, will help to ensure continuous quality improvement. Assessments should be based on a process of *formative evaluation* involving the following basic steps:

- **Plan:** Plan out the process
- **Do:** Implement the pre-determined plan
- **Study:** Take time to assess if stated goals are being met, and look for parts of the process that may not be working as planned
- **Act:** Seek ways to correct or improve any less than satisfactory steps in the process (and then return to step 1 and repeat).

This “PDSA” process of formative evaluation was used throughout the AAP’s Developmental Surveillance and Screening Policy Implementation Project (D-PIP), which was based on the AAP’s 2006 Policy Statement and algorithm regarding developmental screening and surveillance.

Review and Discussion of National Activities and Trends in Developmental Screening

Marian Earls, MD, FAAP

Before taking a closer look at what several representative states had accomplished, Marian Earls, MD, FAAP presented summit participants with an overview of the many key national activities and trends in developmental screening, recognized as having provided a foundation for current and upcoming efforts.

American Academy of Pediatrics⁴ key initiatives include:

- The National Center of Medical Home Initiatives:⁵ The mission of the National Center is to work in cooperation with federal agencies, particularly the Maternal and Child Health Bureau (MCHB), to ensure that children with special needs have access to a medical home. In a medical home, a pediatrician or family practice physician coordinates a team to make sure children get all medical and non-medical services needed.
- Developmental Screening Policy Statements: 2001 & 2006. *Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening* (Pediatrics.2006. 117:405-420) includes an algorithm about how to proceed with surveillance, screening and evaluation, a chart of standardized developmental screening tools and a table of Current Procedural Terminology codes to help simplify the process for child health care providers. The algorithm takes pediatricians step-by-step through the screening process and how to proceed if the results are positive/concerning.
- The Task Force on Mental Health: ⁶ In 2004, in response to the growing need to address children’s mental health concerns in primary care, the AAP Board of Directors formed the American Academy of Pediatrics Task Force on Mental Health. The Task Force recommendations for primary care competencies focus on the “primary care advantage” and the use of “common factors” to do surveillance for social emotional development and mental health. The Task Force will also be recommending use of evidence-based screening tools.
- Bright Futures Guidelines: Bright Futures ⁷ is a national health promotion and disease prevention initiative that addresses children’s health needs in the context of family and community. Health Promotion themes in the new Bright Futures include Family Support, Child Development and Mental Health. In addition to use in pediatric practice, many states implement Bright Futures principles, guidelines, and tools to strengthen the connections among state and local programs, pediatric primary care, families, and local communities.

- 2007 Autism Screening Guidelines. Two clinical reports from the AAP help pediatricians recognize autism spectrum disorders (ASDs) earlier and guide families to effective interventions, which ultimately improves the lives of children with ASDs and their families. The first clinical report, “*Identification and Evaluation of Children With Autism Spectrum Disorders*” provides detailed information on signs and symptoms so pediatricians can recognize and assess ASDs in their patients. Educational strategies and associated therapies, which are the cornerstones of treatment for ASDs, are reviewed in the second AAP clinical report, “*Management of Children With Autism Spectrum Disorders*”. The report strongly advises early intervention as soon as an ASD diagnosis is seriously considered rather than deferring until a definitive diagnosis is made.

The Commonwealth Fund⁸ initiatives include:

- Assuring Better Child Health and Development Program (ABCD):⁹ Funded through The Commonwealth Fund and administered by the National Academy for State Health Policy (NASHP), ABCD is designed to assist states in improving the delivery of early child development services for low-income children and their families. Three phases thus far:
 - ABCD I (2000-2003) – 4 states
 - ABCD II (2003-2006) – 5 states
 - Setting the Stage for Success (2006-2007) – 5 states
 - ABCD Screening Academy (July 2007) – involving 23 states
 - ABCD III (Initiated in 2009) – 5 states
- Rethinking Well-Child Care Initiative:¹⁰ A collaborative effort between the AAP and The Commonwealth Fund, this project considers both parents’ and pediatricians’ expectations and experiences in “rethinking” well-child care.

THE NEW MEXICO EXPERIENCE

Paving Community Pathways: Community-Wide Quality Improvement Strategies to Promote Developmental Services for Young Children in New Mexico

Sherri Alderman, MD, MPH, IMH-E, FAAP

New Mexico’s Developmental Screening Initiative¹¹ (DSI) represents a statewide intervention model based on the shared philosophy around the following key concepts:

- the broad definition of health as a community-wide system of care;
- the common mission to optimally serve children and their families and help all children develop and realize their potential;
- the concept that early intervention is, in fact, prevention;
- and the involvement of multiple sectors (medical, education, caregivers) in a collaborative, coordinated effort

With the implementation of New Mexico’s DSI, the result has been the successful delivery of a full array of early childhood services to the racially and economically diverse communities that span this largely

minority, at-risk state.

New Mexico's DSI took shape in December of 2006 at the coming together of existing early childhood developmental screening efforts (Commonwealth Fund and ABCD "Setting the Stage") in the state, and following a statewide symposium that resulted in the publication *Improving Developmental Care for Young Children and Their Families in New Mexico*.¹² The formal initiative was also preceded by several key initiatives that established New Mexico's commitment to early childhood, including the creation of a Children's Cabinet by the Governor that clearly established children's issues as a priority by mandating that cabinet members meet regularly and participate in town hall meetings. The introduction of New Mexico's Early Childhood Comprehensive Systems Initiative (MCHB) and the Early Childhood Action Network (2004)¹³ further served as a building block for the DSI.

Despite significant state interest in the Children's Cabinet and its mission, identifying and acknowledging potential barriers to the DSI's implementation was critical to the program's success. The geography and demographics of New Mexico alone presented a potential barrier to the goal of reaching families with young children most in need of Early Intervention services. While the percentage of children under the age of 5 is comparable to the national average (7.2% vs 6.9%), the state's roughly 2 million residents are widely distributed across a very geographically large area, resulting in a state population density of only 15 per square mile (with a range as low as <1 and as high as 477/sq mile). Additionally challenging was the fact that New Mexico is an economically disadvantaged state, with 14% of families living below the national poverty level and 15% of children under the age of 5 uninsured. And finally, New Mexico has been referred to as a "minority majority" state in acknowledgment of the fact that nearly one-half (44%) of its population is Hispanic and another 9% are American Indian, numbers which are much greater than the national 15% and 1%, respectively, and make cultural competence especially important. Not surprisingly, a language other than English is spoken in one-third of households.

With New Mexico clearly recognized as an "at risk state," some of the identified challenges fortunately also translated well into strengths that helped to support New Mexico's DSI. As a neutral entity, the DSI was supported by both New Mexico's Department of Health/Family Infant Toddler Program/Early Intervention (Part C), and New Mexico's Human Services Department/Medicaid, both of which offered valuable infrastructure to the initiative. Early Intervention services were already available for children at risk for developmental delays, Early Intervention agencies already existed in every county across the state, and developmental screening is reimbursed separately from Early Periodic Screening, Diagnosis and Treatment (EPSDT) by both New Mexico Medicaid and most private insurance companies. Additionally, key stakeholders in New Mexico's DSI included members from multiple state departments, professional organizations, state agencies and organizations, and private foundations. This cross-agency participation provided the initiative with very broad, diverse support.

The DSI intervention model itself was a relatively simple one, based on the often cited philosophy that "it takes a village to raise a child" and on a commitment to a medical home concept where children and their families, as the ultimate recipient of the community services, are at the center of all community pathways. Four specific components

make up the DSI model, and allow it to be applicable in each of the state's diverse communities.

1. **Neutral facilitator:** A neutral facilitator, one who is respectful and supportive of the community and their resources but not directly affiliated with any specific agency or organization, is appointed to initiate the implementation process. This facilitator enters each community as a catalyst, helping each community to determine what services currently exist, assess how best to optimize them, and suggests new and complimentary services that may be of interest to the community.
2. **Community-based training:** As part of the DSI implementation, an all-day meeting is arranged with all interested members of the community. In addition to community-specific information, the agenda typically includes trainings on how to raise the standard of practice regarding developmental screening and the use of the PDSA model of improvement. In order to best understand the needs of each community, site visits are arranged prior to these trainings. Meetings with each of the community's existing agencies and the provision of a neutral facilitator who can first assess how agencies work together. This allows for a subsequent all-day training that can be customized to address and meet the specific needs of each community, as well as allows for the identification of champions within the community.
3. **Flexibility:** Committing to deliver developmental screening to where the children are in any given community requires flexibility, not only in who delivers the services but also where they are conducted. Depending on the specific community, this can involve a varied list of health care professionals. This may range from public health nurses or social workers to emergency department personnel and can take place in the emergency room in one community or in a child care setting in another.
4. **Community ownership:** If the neutral facilitator in New Mexico's DSI model serves as a catalyst, it is the community itself that serves as the glue that helps ensure the initiative's ongoing success. While the DSI model only allows for 12 months of support, the fact that each community ultimately sets its own agenda, has its own champion(s), and establishes new cross-agency professional relationships all helps create an established infrastructure that can continue well past the 1 year of formal DSI engagement.

THE NORTH CAROLINA EXPERIENCE

Assuring Better Child Health & Development "ABCD" Developmental & Behavioral Screening: A Quality Improvement Initiative in Primary Practice

Marian Earls, MD, FAAP

Chris Collins, Assistant Director for the Office of Rural Health and Community Care

North Carolina's developmental screening and surveillance efforts represent a comprehensive "best practices" model that builds on the state's physician-driven enhanced primary care case management pro-

gram, Community Care of North Carolina (CCNC).¹⁴ It is characterized by 2 major components:

1. The introduction and integration of a practical, standardized, and validated screening tools at well-child visits
2. Collaboration with local and state agency staff and families in developing this system for identifying and serving children

North Carolina's current commitment to a well-coordinated system of developmental screening and surveillance was introduced in the year 2000. At that time, North Carolina was 1 of 4 states to receive Commonwealth Fund support to develop and implement a program to enhance child development services, now known as the first phase of the ABCD project. Furthermore, at this time North Carolina was facing several challenges. To begin with, 44% of children in North Carolina were living in low-income families. In addition, in 2001 the AAP was in the process of recommending formal developmental screening and surveillance at well-child visits, but the time it took to offer the most commonly used developmental screening tool of the time was prohibitive for busy primary care practitioners and lacked desired specificity and sensitivity. Across the Medicaid system, the average rate of developmental screening was low (15.3%).¹⁵

To add to the problems facing North Carolina at the outset, the Early Intervention eligibility criteria was changing to be less inclusive, and reorganization of the Division of Mental Health, Developmental Disabilities and Substance Abuse to address only "target" populations (those with severe and persistent mental illness) meant that children at risk or with mild-to-moderate mental health problems would not meet criteria for services. Particularly for very young children, access to children's mental health care professionals was limited. While an estimated 8% to 13% of the total population of North Carolina's children age 0 to 3 years qualified for Early Intervention services, only 2.6% were getting them.¹⁶

North Carolina's solution to these problems was to utilize the infrastructure of the state's existing Community Care Networks to pilot a quality improvement initiative in one network and then replicate to more networks. The primary care providers in one network in North Carolina's 15-network, 100-county CCNC system developed the office process and systems for referral. The data from the pilot, shared with the ABCD state advisory group led to dramatic results. This advisory group was comprised of leadership from key agencies who had the capability of making policy changes including Medicaid, Early Intervention Part C, public health, State Interagency Coordinating Council, Department of Public Instruction: Preschool, Smart Start, Family Support Network, North Carolina Pediatric Society, and the North Carolina Academy of Family Practice. Only one year after implementation, there were practices in 3 networks participating and there was an increase in the percentage of 0- to 2-year-olds receiving developmental screenings during their health checks from a range of 6% - 23% to 70%.¹⁷

Several factors played into the effectiveness of ABCD's implementation throughout the CCNC system. The fact was that the infrastructure was already in place within and between the 15 local networks such that local networks oversaw care for Medicaid, State Children's Health Insurance Program, and uninsured children/families. Care managers helped ensure a uniformly coordinated effort of implementation at the practice level.

Not only was North Carolina's Medicaid already integrally tied to the medical home through the required use of Primary Care Provider (PCP) access code numbers, but these PCP access codes also resulted in the pre-existence of a mandatory channel of communication between specialists and PCPs. Per member per month (pmpm) payments given to both providers and networks helped support care managers who could assist with referrals and resource needs resulting from ABCD implementation. Well established "Quality Improvement" benchmark protocols implemented throughout the system were easily utilized to implement and assess ABCD's developmental and behavioral screening protocols.

Policy changes in the state also helped to play a role in the initiative's improved effectiveness. In 2003, North Carolina's public health system uniformly transitioned clinics away from use of the Denver Developmental Screening Test to a menu of standardized, valid developmental screening tools (primarily Ages and Stages Questionnaire (ASQ)). The following year, Medicaid changed EPSDT policy to reflect this change, requiring a valid, standardized developmental screening tool when screening children not only ages 0 to 3 years (at the 6-, 12-, 18-, or 24-month and 3-year-old visits), but extending the range to include 4, and 5-year-old visits as well.

The initial stages of North Carolina's ongoing quality improvement project also involved evaluation and consideration of how the model could be both improved upon and replicated. A description of the initial process of implementation was published in the July 2006 issue of *Pediatrics*.¹⁷ Data on a cohort of children referred from 2000 to 2003 revealed that 94.5% of children made it to their referral and 97% to 98% of those referred qualified for services. A longitudinal study of another cohort of children (2001-2003) who began having screens at 6 months of age has been published in the October 2009 issue of *Clinical Pediatrics*. In this cohort of 526 children, 18% had at-risk scores but only 11% to 12% were referred. The study includes a survey of the providers to assess which factors influence referral choice.

With regard to replication, what began as a model within a few practices soon spread to other Community Care practices, as well as some non-CCNC practices in 11 counties throughout the state. Introduction into the largest CCNC network added practices in an additional 32 counties, and the changes made to the state's Medicaid and public health policies helped to get the process replicated in other practices as well.

Partnering with early childhood systems has helped North Carolina's unified efforts at providing effective developmental screening and delivery of services to children throughout the state. From the outset, public health nurses, most notably child care health consultants (CCHCs), were trained. In 2001, one of the state's Smart Start Partnerships joined the ABCD project and extended the program's reach to encompass the 7 westernmost counties in the state, with Smart Start staff conducting outreach to 150 additional practices. In 2005, the initiative was also integral in the addition of developmental and behavioral screening results to the state's kindergarten health assessment.

There are now Smart Start ABCD projects in 8 North Carolina counties, with Smart Start staff working in pediatric and family practices to assist with screening, referral, and follow-up. Data from those projects show an increase of screening from 80% to 98%. Most recently, a collaboratively developed EPSDT outreach, technical assistance, and reporting system has also provided data on rates of screening on EPSDT

claims by practice for the whole state. From this data, it is evident that greater than 90% of all primary care practices are screening, and 84% of all claims for the ages indicated have developmental screening included. In fact, for the North Carolina Part C program, primary care physicians now constitute the state's single largest referral source.

Moving forward, both the state's "ABCD Advisory Group" and the program's "Quality Improvement Group," (which includes primary care providers, CCNC managers, Smart Start Staff, Department of Medical Assistance (Medicaid) managed care consultants, and EPSDT staff) will continue to meet quarterly with the shared goal of having North Carolina's technical assistance and Smart Start work continue to further enhance statewide referral systems and primary care practice linkages to community resources.

THE RHODE ISLAND EXPERIENCE

Watch Me Grow — Rhode Island: Developmental Screening & Services for Infants and Toddlers

Kristine Campagna, MEd – Manager, Newborn Screening and Early Childhood Programs, Rhode Island Department of Health

Andréa Martin – Child Care Coordinator, Watch Me Grow Rhode Island

*Watch Me Grow Rhode Island (RI)*¹⁸ is a partnership between the Rhode Island Department of Health and the Rhode Island Chapter of the AAP based on the stated goal of ensuring that all Rhode Island's children are healthy and ready to learn. With a 3-tiered developmental services pathway that includes the implementation of primary surveillance and screening, confirmatory secondary screening, and the communication and coordination necessary to ensure subsequent intervention, *Watch Me Grow RI* serves as an example of how the medical home approach can effectively be applied to the coordination of early childhood developmental services through the use of existing resources, common language, and a shared commitment to children and families.

Despite its geographically small size, Rhode Island is faced with some sizable challenges when it comes to providing children's services. With the highest percentage in New England of children living in poverty, single-parent households, and births to mothers with less than 12 years of education, not to mention the highest percentage of children ages 3- to 21-years-old receiving special education services^{19, 20}, the state's efforts are geared towards 3 main goals:

1. Improved rates of developmental screening and early identification of developmental and behavioral concerns
2. Facilitation of early access to the state's developmental intervention services in order to effectively reduce the impact of identified developmental delays/risks
3. Improved communication between parents, child care providers, health care providers, and community services to create a more comprehensive medical home by which families in need can be educated and supported

Prior to the start of *Watch Me Grow RI*, additional problems not unique to the state but clearly apparent included the fact that children were being expelled from child care for behavioral problems. The Rhode

Island Child Care Support Network, a network already in existence for over 15 years that included CCHCs and early childhood mental health consultants, was all too familiar with the frustration that resulted when child care providers knew "something wasn't right," but had no formal way of helping the child. Child care providers were eager for solutions and already asking for ways to assess children's development. Creation of *Watch Me Grow RI* was thus based on:

1. the recognition of missed opportunities for screening and guidance in child care
2. the identified lack of coordination between the early education and child care programs and health care providers
3. a clear community interest and commitment
4. the availability of newly created AAP developmental screening policy statement (2006)

In 2006, a survey regarding screening practices in the medical home offered a useful picture of the developmental surveillance methods and services/supports in place in Rhode Island. As a result, *Watch Me Grow RI* identified areas that needed definite improvement. Prior to the program's implementation, there was a distinct lack of standardization in the methods of developmental surveillance being implemented. Questions/conversations were identified as the dominant method of developmental surveillance (78.2%), the use of any sort of surveillance questionnaire or checklist was utilized by just under one half (48.5%) of those surveyed, and the use of a standardized developmental screening tool barely ranked above 20% (21.8%). Similarly, 33% reported a lack of behavioral/mental services or support as the largest support deficit.²¹

With support from the Early Childhood Comprehensive System (ECCS) grant, *Watch Me Grow RI* began by building on existing services to improve the frequency and quality of developmental screening in Rhode Island, both within the pediatricians' offices and by introducing the concept of developmental screening to child care providers. For the existing medical home within the pediatricians' offices, this included preparing office staff, providing pediatricians with a training manual and DVD, and helping ensure that pediatricians were properly trained on EPSDT coding for developmental services. This training both helped to ensure that pediatricians could be reimbursed for their services, but also allowed for more accurate data collection in the tracking of Rhode Island's developmental services. To that end, money to support the initial contact with all medical practices came from a Healthy Tomorrows Grant.²²

Making use of the existing infrastructure, *Watch Me Grow RI* also sought to make child care providers an integral part of the medical home network. Child care providers were invited to participate and were trained not only on the use of standardized developmental screening tools (ASQ and Early Childhood Screening Assessment), but also on fundamental procedural components that were key to the program's effectiveness, including how to inform families of the project, obtain parental permission to screen, share screening results with both the parent(s) and the pediatrician, and play a role in developing a plan for next steps. *Watch Me Grow RI* supplies a child care coordinator at approximately 20 hours per month who meets with and supports all of the 40 sites.

Newly mandated developmental screening has also moved forward Rhode Island's efforts with required screens at 9, 18, and 30 months. In Rhode Island, child care providers screen at 6 months, and if no red

flags turn up on the screen, it simply stays in the child's file. Additional screening takes place at 8, 12, and 24 months and pediatricians and child care providers alike have provided positive feedback about the program. Pediatricians welcome the ongoing input and standardized developmental information and child care providers report that their participation "provides child care a voice," "an opportunity for parent involvement," "informs our planning and practice," and serves as a useful "tool for communicating to families using the same common language."

Challenges involve the detailed coordination of communication and services inherent in the establishment of a medical home for each child. This includes staffing to support expansion and ongoing support for child care providers, information-sharing between the 40 currently involved sites, the physicians' offices, and *Watch Me Grow RI*, as well as maintaining the funding necessary to cover the cost of the ASQ (currently covered by grant money). Data collection, tracking of referrals, and ensuring the availability of intervention services are key to *Watch Me Grow's* continued efforts, while next steps include continued integration of health consultation and early childhood mental health consultation, expansion regionally, and linkage and integration with the state's BrightStars Quality Rating Scale which would include developmental screening as one of its quality rating factors and subsequent incentives to receive enhanced funding.

CHALLENGES & NEXT STEPS

Discussion of State Action Plans for Developmental Screening in Early Childhood Systems

Following the overview and state-specific presentations regarding developmental screening state initiatives, summit participants were then asked to discuss and respond to the following 4 questions:

1. What are the challenges your state faces in the implementation of a statewide developmental screening initiative?
2. What are ways that your state can overcome these challenges?
3. What are the next steps for your state?
4. What lessons learned do you have to share?

As a result, the group, representing 16 geographically and demographically diverse states, generated the following responses which served to reinforce the general implementation challenges and processes presented by Dr Donoghue at the outset of the summit.

Developmental screening in early childhood systems involves interdisciplinary coordination and cooperation seems to pose one of the most significant challenges to implementation and generated considerable discussion. Coordination of early childhood systems inherently requires everyone involved to think outside of the traditional silos within which early childhood health and education professionals commonly operate. Resistance to doing so seems to be based on several factors that clearly exemplify the overarching challenges faced in the creation of any truly effective medical home, including:

- A need for identification of health care professional champions who are able to understand and effectively interface with ECCS programs; although, this might be an AAP Chapter Child Care

Contact.

- A need for additional and adequate training on both the logistical factors involved in implementation, as well as on the basics of what constitutes normal and abnormal development (including consideration of cultural differences).
- Child care agencies and organizations that are faced with limited financial resources, staff, time, education levels, and a potential lack of understanding as to the benefits of screening.
- Establishing means for consistent reimbursement for the health and early childhood professionals involved in the process.
- Inadequate connections, in the sharing of abnormal screening results, lack of Early Intervention resources in response to an increase demand when screenings are implemented, and also in the transition from ECCS programs and Early Intervention to the school system(s).

In addressing implementation challenges, participants acknowledged the need for tenacity and recognized the need to work at both the micro and macro levels. Also, fundamentally important to overcoming challenges is the identification and use of existing interagency relationships and channels of communication. Equally important is the engagement of all individuals and organizations involved in the process using such suggested methods as simply asking groups to participate by asking "what can we do for you?," enlisting parent groups as advocates, or arranging community-based forums. To engage primary care practices and to establish medical home principles, there needs to be proactive establishment of relationships among practices and community agencies, Part C, preschools, etc. With such relationships, reliable systems for linkages among the medical home, child/family, and community are possible.

With the ultimate goal of determining how states could realistically and effectively implement developmental screening in early childhood systems, participants acknowledged that the sharing of both the state-specific successes and challenges was of great value. Next steps for several states included the identification of a state champion, the determination to engage families in all aspects of the process, and looking within one's state for the possibility of mandated screening in early childhood as a means of reinforcement of the critical importance of these efforts.

IN CLOSING

The fact that there are clearly recognized benefits for the children and families impacted by early developmental screening, subsequent referral and Early Intervention, and a coordinated approach to facilitating these services within a well-established medical home, the day-long discussion of both successes and challenges faced by those states and organizations already engaged in the process was of great value. The benefit of screening and surveillance extends not only to those children who are identified at-risk and referred for services. All children benefit from the discussion with parents about the child's development, appropriate developmental and behavioral expectations, and ways to promote the child's healthy development, particularly social-emotional development. This is an opportunity to truly partner with parents and promote their parenting skills. In strategizing new ways to effectively

accomplish this nationally important agenda, a summary of important next steps consists of:

1. Commit to better and earlier evaluation of children who are at risk, both developmentally and medically.
2. Be prepared to work together across disciplines, identifying and bringing together key stakeholders.
3. Address potential shortages or lack of availability of Early Intervention resources.
4. Seek out reliable and valid screening tools.
5. Identify optimal times and locations for screening.
6. Plan and provide professional training and education.
7. Standardize simple and effective processes for referral and

feedback between medical homes and community providers who serve young children.

8. Ensure appropriate payment for surveillance, screening, and evaluation.
9. Expand evidence on the effectiveness of developmental surveillance.

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Definitions and Abbreviations

AAP: American Academy of Pediatrics

ABCD: Assuring Better Child Health and Development Program, funded through The Commonwealth Fund, administered by the National Academy for State Health Policy (NASHP), and designed to assist states in improving the delivery of early child development services for low-income children and their families. 3 phases thus far (I – 2000-2003 involved NC, UT, VT and WA; II – 2003, and III - 2009)

ASQ: Ages & Stages

ASQ-SE: Ages & Stages – Social Emotional

CCDF: Child Care and Development Fund assists low-income families, families receiving temporary public assistance, and those transitioning from public assistance in obtaining child care so they can work or attend training/education, and was authorized by the Child Care and Development Block Grant Act. A portion of funds are used to improve the quality of child care, offer additional services to parents, and support child care research, demonstration, and evaluation activities, as well as offer a technical assistance network to address the needs of the state, territory and tribal administrators.

CSBS-DP: Communication and Symbolic Behavior Scales – Developmental Profile

Developmental Evaluation: “Aimed at identifying the specific developmental disorder or disorders affecting the child.”

Developmental Screening: “The administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder.”

Developmental Surveillance: “A flexible, longitudinal, continuous, and cumulative process whereby knowledgeable health care professionals identify children who may have developmental problems.”

D-PIP: The AAP Developmental Surveillance and Screening Policy Implementation Project was funded thru collaboration with the CDC’s National Center on Birth Defects and Developmental Dis-

abilities in order to promote optimal child development within public and private health systems and was created as an implementation project of the AAP 2006 Policy Statement (and algorithm) regarding developmental screening and surveillance.

ECCS: Early Childhood Comprehensive System has the defined purpose of supporting “states and communities in their efforts to build and integrate early childhood service systems...” and has access to health care and medical homes, social-emotional development and mental health, early care and education, parenting education, and family support as its core components.

ECSA: Early Childhood Screening Assessment (RI)

HCCA/CCHP: Health Child Care America/Child Care and Health Partnership is a collaboration of health professionals and child care providers working together to improve the early education, health, and safety of children in out-of-home care, and is the result of a shared vision between the Health Resources and Services Administration’s Maternal and Child Health Bureau (HRSA-MCHB) and the Administration for Children and Families’ Child Care Bureau. Goals include strengthened partnerships between health and child care professionals, providing the necessary information and support to improve access, promote social-emotional-cognitive development in early education and child care, provide technical assistance, enhance quality with health and safety resources, and support the needs of health professionals.

M-CHAT: Modified Checklist for Autism in Toddlers

NAEYC: National Association for the Education of Young Children

NAECS/SDE: National Association of Early Childhood Specialists in State Departments of Education

PEDS: Parents’ Evaluation of Developmental Status

PSC: Pediatric Symptom Checklist

SCQ: Social Communication Questionnaire

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