



A Project of the West Virginia Perinatal Partnership
and West Virginia Community Voices
www.wvperinatal.org

October 2013



Achieving Better Outcomes Through Child Developmental Screening and Referral



Many things we need can wait.
Children cannot
Now is the time their bones are being formed,
Their blood is being made,
Their mind is being developed.
To them we cannot say tomorrow,
Their name is today.

— Gabriela Mistral

This project was funded by the Claude Worthington Benedum Foundation, the Children's Health Insurance Program and the Office of Maternal, Child and Family Health.



5 Numbers to Remember About Early Childhood Development

- 700 new neural connections per second.
- 18 Months: Age at which disparities in vocabulary begin to appear.
- 90 to 100% chance of developmental delays when children experience 6 to 7 or more risk factors.
- 3:1 odds of adult heart disease after 7-8 adverse childhood experiences.
- \$4 - \$9 in return for every dollar invested in early childhood programs.

Center on the Developing Child,
Harvard University.
www.developingchild.harvard.edu

Dear Colleagues,

Nothing is more important than the health and well-being of our young children. Together we can support the potential of our youngest children through improvements in the quality and coordination of primary care and early intervention services.

The drive towards better care and better health outcomes offers us many exciting challenges and opportunities to improve health care and early intervention for West Virginia's youngest children. One clear challenge is to improve the rate at which children from birth to three receive developmental screenings as Bright Futures intended, and then, of course, to assure a delivery system in which they receive referrals, services and coordination of care.

This report is intended to be a first step in bringing the primary care physicians, advanced practice nurses, other midlevel practitioners, health payers, and the early intervention community together to plan for a multi-year effort to support and promote best practices in pediatric primary care and improved communication and referral between medical homes and early intervention services.

Thank you for your participation and interest in providing West Virginia's children with the best care possible.

Sincerely,

Mary Boyd, MD
and
Kathleen Martin, MD
Co-chairs



Achieving Better Outcomes Through Child Developmental Screening and Referral

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Recommendations

Early Childhood Screening and Referral Committee

October 2013

- 1. Establish baseline data and trend analysis for developmental screenings for all three public payers (Medicaid, CHIP, PEIA) and conduct follow-up audits and/or independent quality reviews every two years with a goal of 90 percent compliance by 2020.**

Identifying children with developmental, social or behavioral delays is the first step in providing early intervention. To assure that all children receive developmental screening at the ages of 9, 18, and 24-30 months, using a standardized tool as recommended by the American Academy of Pediatrics and Bright Futures, West Virginia must measure progress over time. Audits of pediatric records conducted by the Office of Maternal, Child and Family Health in 2012 and 2013 from all payer sources will establish the baseline against which future progress will be measured.

- 2. Support the health care provider community in integrating the Ages and Stages Questionnaire – 3 (ASQ-3) data into the electronic health record (EHR).**

While health care providers report using the ASQ-3 in their practice, the data often are not reflected in the health record. The transition to electronic health records (EHR) is challenging and models vary from practice to practice. Some providers report that ASQ is not reported in the electronic record because “there is no place for it.”

To support health care providers in documentation, the Office of Maternal, Child and Family Health should facilitate the development of an electronic documentation format (compatible with the most widely used EHR software) that corresponds to the 9, 18 and 30 month ASQ-3 information summary and provide technical assistance and training to integrate such a summary in the health records of all providers who see young children.

The Centers for Medicare and Medicaid Services (CMS) currently have demonstration grants in some states to develop a pediatric template, which incorporates global screening as part of a comprehensive preventive visit. West Virginia should build on lessons learned from demonstration projects.

- 3. Support the integration of further assessment and screening for special needs populations for health practices by providing training and quality initiatives for tools such as the Ages and Stages Questionnaire – Social and Emotional (ASQ – SE) and Modified Checklist for Autism in Toddlers (MCHAT).**

The Office of Maternal, Child and Family Health (MCFH) has provided the ASQ-3 kits free-of-charge to all health care practices and provided training as requested.



Recommendations

They should continue this practice. In addition, the payers (Medicaid, CHIP, PEIA and MCFH) should collaborate to create a web-based training on ASQ-3 and provide tips for implementation. The payers and MCFH should also develop Quality Improvement training (web-based as well as on-site) for providers on using developmental screening as a quality improvement project. Since all pediatric providers need a quality improvement project for professional certification, this approach would support the requirement for Maintenance of Certification (MOC).

4. Track and improve the referral rate to early intervention and other community programs and assure coordination through a common referral tool.

Coordination between health care providers and early intervention programs has been a problem nationally as well as in West Virginia. To assure optimal outcomes, the health care system and early intervention system must improve communication and coordination. State payers could incentivize managed care organizations (MCOs) by requiring such activities in the managed care contracts.

Agreeing on and using a common referral tool such as the draft form included in the Appendix is a first step in improving communication and coordination while meeting confidentiality requirements of both systems. The West Virginia Birth to Three Program should continue current efforts to modify national tools to meet the specific needs of West Virginia's health care and early intervention systems and take the lead in working with health care and early intervention providers to establish and disseminate this tool.

5. Expand home visitation services (in-home family education) to every county in West Virginia

West Virginia health care providers are concerned about the ability of parents to provide the resources necessary to assure healthy development. Health care providers believe that the education of parents of young children is a vital part of pediatric health care practice. Yet, the support that parents of young children need is most often outside the ability of a busy health care practice.

For many years, West Virginia has pioneered successful in-home family education programs using nationally-recognized models. These programs, however, remain limited. In 2012, 1,200 families in 29 counties received services through these programs. State policymakers should make every effort to expand these programs state-wide and provide training to health care providers about how to make use of such resources. About 60,000 children age zero to three live in West Virginia. More than half live in low-income families. Other developed nations make programs to educate parents of young children a regular part of their health care system. The experience of young children in their earliest years

Recommendations

greatly affects their lifelong success or failure. To support healthy development and help West Virginia's youngest children thrive, we must create a state-wide system of parent support and education.

A recent report from the National Association for State Health Policy (NASHP) and the PEW Center on the States discusses using Medicaid to finance Early Childhood Home Visiting Programs. An appropriate committee made up of payers, health care providers, and early intervention programs should review findings in the report and consider how West Virginia might expand current Medicaid support for home visiting programs. In addition, the Public Employees Insurance Agency (PEIA) and the Children's Health Insurance Program (CHIP) should be engaged in discussion of support for home visiting programs.¹

6. Support Help Me Grow as West Virginia's statewide comprehensive system for linking families to developmental information and needed services through health care practitioners, community outreach, and centralized information/referral.

In 2013, the Office of Maternal, Child and Family Health launched a new program called Help Me Grow. Help Me Grow is a system that builds collaboration across sectors, including child health care, early care and education, and family support. It is based on a national model developed in Hartford, Connecticut by Dr. Paul Dworkin. The program is operating in 19 states.

Through a comprehensive system that includes health care practitioners, community outreach and centralized information and referral centers, families of young children birth to five are linked with developmental information and needed programs and services. Ongoing data collection and analysis helps identify gaps in and barriers to accessing needed services. Help Me Grow was developed to address all the problems identified in this report and is a promising solution for system improvements that can support the healthy development of young children.

The Office of Maternal, Child and Family Health has made a commitment to this program and is coordinating implementation through the Early Childhood Advisory Council and the Health Check Medical Advisory Council. The ultimate success of the program will require support from all sectors of the health care and early education system including policymakers, health care providers, payers, the early intervention and educational system and parents. The health care provider community should be engaged in promoting Help Me Grow.



REPORT

Achieving Better Outcomes Through Child Developmental Screening and Referral

GOALS

The goal of the Child Developmental Screening and Referral project is to improve the health and developmental outcomes of young children in West Virginia by developing a consensus set of recommendations to improve screening and referral of children birth to three. In addition, the project goals are to

- Determine the current use of standardized and AAP recommended developmental screening tools among medical providers for young children birth to three.
- Identify barriers and opportunities for incorporating a standardized tool, such as Ages and Stages (ASQ), into pediatric practice.
- Identify concerns and problems in coordination of the medical home and early intervention program.
- Support and promote the use of pediatric HEDIS measures to evaluate level of screening in the pediatric population 0 – 3.²
- Research work in other states to support and promote best practices in developmental screening and referral.

METHODS

The project organized a state level committee of physicians, nurse practitioners, state agency staff and child advocates. Physicians, who see young children from birth to three, were selected from different areas of the state to serve as advisors or physician “champions” to the project coordinator.

The physician advisors facilitated conversations with their peers in their geographic region of the state and reviewed notes and documents as requested.

In addition, the Office of Maternal, Child and Family Health and their regional EPSDT coordinators conducted a survey between February and July 2013 of 200 providers in 36 counties, who see young children birth to three.

The regional conversations and survey were used to determine the current state of practice regarding developmental screening in West Virginia, identify barriers to effective screening and referral, and to make recommendations that will support and promote systematic screening and referral and ultimately better outcomes for West Virginia's youngest children.

NEED FOR THE PROJECT

The project evolved out of a concern that best practices in developmental screening are not followed in West Virginia and that early intervention programs and primary care providers are currently not well coordinated to assure appropriate follow-up and tracking of children with developmental delays.

Under the Children's Health Insurance Reauthorization Act (CHIPRA) of 2009, the Secretary of the federal Department of Health and Human Services (HHS) was mandated to establish a core set of pediatric measures. State Medicaid and CHIP programs are now starting voluntary reporting on a set of 22 initial measures, including Measure # 8, Developmental Screening.³ This screening measure was developed by the National Council of Quality Assurance, the certifying body for HEDIS set of quality measures commonly used by commercial health plans.

The purpose of the developmental screening measure is to demonstrate how many children in a health plan received a developmental screening with a validated screening tool as called for by the American Academy of Pediatrics (AAP) Bright Futures (2008) Guidelines. This standard says a child should have the screen at 9, 18 and 30 months. The data is reported as one overall percentage rate for all ages and with stratification for children in the plan who received the screen by their 1st, 2nd, and 3rd birthdays.⁴ The ability of both primary care practices and health plans to assure that children receive this screening according to the guidelines is what this measure reflects and can be used as a base line for quality improvement.

In 2012, WVCHIP reported this screening data for the first time at an overall rate of 34 percent.⁵ Chart audits conducted by the Office of Maternal, Child and Family Health of 286 pediatric providers in 2012 found that developmental screenings occurred less than 30 percent of the time at 9 month, 18 – 24 month and 30 month visits.⁶ (These were audits of all age appropriate screenings regardless of payer type.)

In addition to these reports, there is a perception in West Virginia and other states that the sharing of information and coordination between the medical home and early intervention services is less than optimal.

Promotion of best practices in pediatric care should command greater attention in West Virginia where 30 percent of young children under age six are growing up in poverty. It is this at-risk group that the screening guidelines are meant to

address. Living in persistent poverty has been shown to have adverse effects on the development of the young brain with life-long consequences for physical, social and emotional and behavioral health.⁷

At the federal level, the Centers for Medicaid and Medicare Services (CMS) are promoting the use of a core set of quality measures for all pediatric care covered by Medicaid and CHIP programs. Among the measures chosen by CMS was one that required screening using standardized screening tools for potential delays in social and emotional development.⁸

In West Virginia, the payers of child health services and especially the West Virginia Children's Health Insurance Program and Medicaid are moving forward in the development of new accountability standards that will influence payments to providers. These standards include documentation of use in the medical record of a standardized development screen, such as Ages and Stages as part of a child's comprehensive wellness visit.

Furthermore, the AAP is encouraging quality improvement through their maintenance of certification program. Use of a validated screening tool supports this activity as a strategy towards best practice.

To prepare for such changes, it is important for the health provider community to integrate a validated screening tool into their medical practice and document the screening in the medical record.

USE OF STANDARDIZED AND RECOMMENDED DEVELOPMENTAL SCREENING TOOLS

While there are a number of tools approved by the NCQA for developmental screening for young pre-school children, one of the most frequently used in West Virginia is Ages and Stages (ASQ) for developmental screening of children at 9 months, 18 months and 24-30 months.⁹

FINDINGS

AGES AND STAGES (ASQ)

While Ages and Stages is not universally used in West Virginia, it has gained broad acceptance and is now the primary tool used by West Virginia University Medical School and its affiliates in the Eastern Panhandle and Charleston; at Marshall University Medical School in Huntington; and the Osteopathic School in Lewisburg. Private practices are also using the tool but not 100 percent.

Between January – July 2013, a survey of 200 pediatric providers in 36 counties reported that 81 percent of those responding used the Ages and Stages Questionnaire for developmental screening. Those health care providers, who



currently do not use a standardized tool for screening, 91 percent indicated they would be interested in integrating the tool into their practice.¹⁰ While the tool appears to have wide acceptance, documentation in the medical record at the age-appropriate intervals continues to be a problem.

An audit of pediatric health records between January – April 2013 was conducted as a follow-up to the 2012 audit and found significant improvement indicating that current interventions are having the desired effect and should be continued.

Percent of pediatric providers screening with a standardized tool in 2012 and 2013

Age of Development Screening	2012 N=264	2013 N=225	Percent Improvement	Percent Using ASQ-3 (2013) ¹¹
9 Months	29%	46%	59%	71%
18 Months	28%	49%	75%	75%
30 Months	26%	63%	142%	73%

Source: James Jeffries, John Simmons, Saylem DePasquale, Office of Maternal, Child and Family Health/Health Check Program Report, September 2013.

Introduction of Ages and Stages into pediatric practice in West Virginia was supported by an American Academy of Pediatrics, West Virginia Chapter, project called Kidnitiative. With support from the Claude Worthington Benedum Foundation, Dr. Joan Phillips, trained 11 health care practices in the use of the tool in 2008. Both the AAP, West Virginia Chapter and Dr. Phillips were also instrumental in persuading Medicaid, CHIP and PEIA to assure additional payment for developmental screening when performed in conjunction with the child's regular well-child visit. In addition, the Office of Maternal, Child and Family Health supported the change by providing ASQ tool kits free-of-charge to medical practices.¹² Follow-up calls in 2012 to the practices trained in the ASQ found that most, but not all, continued use of the tool for developmental screening.

While practices which use ASQ report that the tool is easy to use and saves provider time, some barriers or perception of barriers continue to exist. Reported barriers to using the tool include integrating it into the electronic medical record and parent participation. Literacy levels of parents was also expressed as a concern by some providers. The ASQ-3 questionnaire has a reading level ranging from fourth to sixth grade and provides some illustrations as appropriate and most providers think the literacy level is appropriate. It is also important to note that this particular tool can be used by and is valid for parents and other caregivers use.

Other barriers according to the 2013 Office of Maternal, Child and Family Health Survey include:

- Lack of knowledge about the tools.
- No separate reimbursement (Note: since 2009, state payers removed. barriers to reimbursement for conducting a developmental screen as part of the well-child visit).
- Time required to conduct the screening especially combined with other well-child exam requirements.
- In some instances, the medical practice creates its own tool or modifies it for medical record documentation purposes.
- Practitioner belief that surveillance is sufficient.

Physicians reported that sending the tool to parents before the pediatric visit is found to be less successful than allowing parents time to fill out the tool in the waiting room. An efficient front office staff trained in the value of the tool is important in making sure that the tool is completed and scored before the health care provider sees the child.

The best way to integrate information from the tool into the Electronic Health Record (EHR) remains perhaps the biggest problem because there is no standardized EHR and possible copyright issues with the ASQ tool.

TARGETED AND SPECIALIZED SCREENING TOOLS

ASQ is a global developmental assessment tool and includes assessment for the social and emotional domain. Other and more specialized assessment tools are being developed for social and emotional development. A recent supplement to ASQ is the ASQ-Social Emotional (ASQ-SE) questionnaire. It is an ASQ companion tool to monitor social and emotional behavior of young children and address parental concerns. It is not as widely known in West Virginia and was reported to be in use in only 3.5 percent of medical practices surveyed in 2013 by the Office of Maternal, Child and Family Health. At least two Head Start Programs (Elkins and Logan) reported using the ASQ-SE among children in its program to make referrals for behavioral health services.¹³

In addition, the Modified Checklist for Autism in Toddlers (M-CHAT), a recommended tool commonly used to identify autism, is in use in some practices in West Virginia. Whether children are being screened for autism early enough and whether medical providers are sufficiently trained to use M-CHAT requires further research.

REFERRALS TO PART C EARLY INTERVENTION PROGRAMS

All providers are familiar with West Virginia's early intervention program, called Birth to Three, for infants and toddlers with developmental delays. Birth to Three gets high marks from health care providers. The referral process is widely known

and easy to use, and there is a great deal of confidence that children get evaluation and treatment they need. All West Virginia families are eligible for Birth to Three Services not just those with low incomes. In 2012, Birth to Three served 5,233 children.

In the regional conversations, some concerns were expressed about the length of time for follow-up. Providers also expressed frustration that they do not get reports from Birth to Three evaluation and treatment to include as part of the record for the child's medical home. This follows similar concerns expressed nationally about the need to work out issues around confidentiality of the education law and better communication strategies.

Part C of the Individuals with Disabilities Education Act (IDEA) requires primary referral sources to refer infants and toddlers suspected of having developmental delays to the WV Birth to Three early intervention system. IDEA also has confidentiality requirements that can make it more difficult to share the results of referrals.

The West Virginia Birth to Three Office has been working on a standard referral form (adapted from the American Academy of Pediatrics Part C Early Intervention Referral form) that would support increased communication between the medical home and WV Birth to Three. The form includes parental consent to share information, documentation of the health care provider's concerns about the child's development and diagnoses the child may have related to developmental delay. A draft of the new form has been shared with members of the Health Check Medical Advisory Board. With additional input, the form has been further revised.

Efforts should continue to find the most effective way of implementing a standardized Part C referral form, including the possibility of having the form available online. Ongoing opportunities for dialogue between the state and regional Birth to Three offices and health care providers would help build strong lines of communication in order to provide coordinated care for infants and toddlers with developmental delays. (See Appendix for draft standardized referral form.)

Birth to Three is a highly successful program that deserves strong support from the medical community as well as advocates for young children. State leaders are aware of the need to improve communication with health care providers and develop common referral tools. Better communication and support for the medical home should become a priority to support best practices and improved outcomes.

OTHER EARLY INTERVENTION PROGRAMS

Right from the Start

Many health care providers around the state expressed concern about poor parenting practices. Right from the Start is an early intervention program widely known among providers. It identifies pregnant women with problems and follows

them through their pregnancy, birth and baby's first birthday. Right from the Start is a professional model using nurses and/or social workers to do home visiting. It is organized regionally, available in every county and serves about 3,000 families annually. Women eligible for Medicaid are eligible for Right from the Start services (i.e. at 150 percent of the FPL or below).

Healthy Start/Helping Appalachian Parents and Infants (HAPI)

West Virginia's HAPI project is part of a national federally-supported Healthy Start initiative. HAPI works collaboratively with existing systems to provide comprehensive services to women, infants and families in eight counties in North Central West Virginia. The HAPI project has developed a highly integrated service delivery system with the Right from the Start Program (RFTS).

Services provided by the HAPI project include prenatal risk assessments for depression and substance abuse, prenatal oral health education and limited services, a comprehensive postpartum interconceptional health education curriculum and increased access to mental health and health care services.

In-Home Family Education Programs

In addition to Right from the Start, West Virginia has several early intervention programs described generically as in-home visiting or family education programs. These programs are available in 22 counties and serve about 1,200 families annually. For the most part, health care providers are not familiar with the in-home family education programs, which are dedicated to helping new parents with parenting skills and connecting them to services for young children in the community. All families are eligible for in-home family education programs not just those with low incomes.

Educating health care providers on the availability of these services and expanding services statewide should be a priority for the state. Considering that West Virginia has about 80,000 children zero to four and about half live in low income families, there exists enormous unmet need.

In making referrals to early intervention programs, some health care providers expressed a concern that the most vulnerable children and parents often refuse services in the home. To help parents understand the purpose and value of these programs will require an outreach and media campaign.

Some providers are starting to bring parents together in parent support groups as a means of parent education and peer support in their community. In general, pediatric providers in West Virginia believe that parent education is an important part of the medical home practice.

Children served by early intervention programs (2012):

11,301*

Birth to Three = 5,233
Right from the Start = 3,000
In-Home Family Education = 1,200
Early Head Start = 1,200
HAPI = 668

**There may be some overlap with some children being served by more than one program*



Early Head Start

Early Head Start is a federally-supported early intervention program that provides services in the home or at a Head Start Center and serves about 1,200 children annually in 23 counties across the state.

Early Head Start targets low-income pregnant women and families with children birth to three. To be eligible, most families must be at or below the federal poverty level. Early Head Start must also make at least 10 percent of their enrollment opportunities available to children with disabilities who are eligible for Part C services under IDEA.

CHILDREN WITH SPECIAL NEEDS

Foster Care

Among the state's most vulnerable children are those placed into the custody of the state and foster care. In the regional conversations, many providers said they rarely have any medical information on the foster care children brought to them. Foster parents also know little or nothing about the child's medical background. Lack of available health records results in cases of duplicate immunizations and other treatments.

In the last three years, medical care for foster children has received attention of state agencies responsible for such children and has been significantly improved through the Fostering Healthy Kids Project. In June of 2009, the Office of Maternal, Child and Family Health found the 4,000 children placed in foster care were not receiving comprehensive health services as intended through the federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program.

Baseline data gathered in June 2010 indicated that only 40 percent of children entering foster care placement had documented scheduled medical examinations within 30 days of placement. Three years later, in June 2013, 91 percent of foster children were receiving such services. In addition 97 percent had a documented health provider compared to 30 percent three years earlier.

The Office of Maternal, Child and Family Health continues to work on improving care coordination for foster children. A pilot project was implemented in Roane and Clay counties with about 30 foster care children with chronic health conditions and expanded to Kanawha County in June 2013.

Child Protective Services (CPS)

Pediatric providers in some parts of the state expressed concern about children referred to CPS. They said that they never know if follow-up occurs as a result of referral and what happens to the child. A recent legislative audit confirmed that the agency has many shortcomings and met its standard for timely investigation (within 14 days and within 72 hours in cases of imminent danger) less than half the time.

CHILD ABUSE AND NEGLECT IN WV

A national report released last fall (2012) found that children are dying from abuse and neglect at a higher rate in West Virginia than in other state, a problem that judges, social workers and others say is fueled by rampant substance abuse."

Children with Special Health Care Needs

West Virginia's Title V Program continues to provide medical care coordination through a long-standing program called Children with Special Health Care Needs (CSHCN). This programs has 11 care coordination teams throughout the state, who offer care coordination to West Virginia residents from birth to age twenty-one who have or are at risk of having a debilitating medical condition.

The program utilizes registered nurses and licensed social workers, who provide local community services in all 55 counties. Through in-home visits and face-to-face meetings, the participants are evaluated for their individual level of needs and a care plan is negotiated by those involved in the care of the client. Referrals and coordination of high quality medical care is arranged by the program. The program works with the client's medical home, serving as the care coordinator for the program participants served by the health care professional.

Developmental screening and coordination of care is especially important for children with special health care needs. In addition to the state's resources, Dr. Jim Lewis in Huntington, who operates a practice for children with ADHD and other children with special health care needs, has been a pioneer in coordination of care for such children and by successfully training parents as care coordinators. Trained parents assist other parents of children with special health care needs to access services needed outside the medical home. The Office of Maternal, Child and Family Health is working with Dr. Lewis to support parent collaboration groups. To replicate the model will require additional funding.

Care coordination for children with special needs continues to be a major challenge in West Virginia and in other states.

Findings from Other States and the Assuring Better Child Health and Development (ABCD) Initiative

In May 1999, the National Academy for State Health Policy (NASHP) and the Commonwealth Fund launched the Assuring Better Child Health and Development (ABCD) Program. The program was designed to assist states in improving the delivery of early childhood development services for low-income children ages 0 -3. Through 2012, the program worked in 25 states plus the District of Columbia and Puerto Rico identifying and supporting policy changes and improvements that strengthen the systems supporting health child development.

Over more than a decade, the ABCD states have:

- Increased identification of children with developmental delays or at risk for delays.



LEADERS OF ABCD STATES REFLECT ON NEED FOR EARLY INTERVENTION

As much as care coordination has become a focus of health delivery reform initiatives, a gap remains in coordination between health care delivery, public health, and other social determinants that impact child development. . . .

Screening and interventions for perinatal depression, family stress, violence, trauma and mental health issues are crucial for addressing long-term health and mental health of children and families.

The business case for investment in early child development through the identification and amelioration of these factors needs to be amplified.

February 7 & 8, 2013

- Improved referral, information-sharing, and feedback mechanisms (for example, uniform consent and referral forms meeting information needs of all service providers).
- Improved access to follow-up treatment.
- Improved care coordination across systems of care.

The legacy of the ABCD program lies in the successes of making practice, community, and policy level improvements.¹⁴ The experience of the ABCD states is now being used to inform federal policy.¹⁵

While West Virginia did not formally participate in the ABCD initiative, state policy and program leaders adopted many of the practices and policy improvements of the ABCD states during the past decade. The ABCD experience stressed that Medicaid and other state agencies can play an important role in promoting policy- and practice- level change in the identification, care and coordination of services for children with developmental delay.

WEST VIRGINIA INNOVATIONS ALIGNED WITH ABCD INITIATIVE

Since 2009, the West Virginia Medicaid, CHIP and the Public Employees Health Insurance Program (PEIA) have allowed reimbursement for conducting a developmental screen with a validated tool in conjunction with the well-child visit.

The Office of Maternal, Child and Family Health has supported providers in adopting the ASQ tool by providing free kits and training to its EPSDT providers. A Benedum-funded two-year project directed by Dr. Joan Phillips and the AAP, West Virginia Chapter conducted training in ASQ in 11 practices. A second one-year Benedum-funded project worked with community health centers to bring a child development focus to their pediatric practice.

More recently MCFH has initiated Help Me Grow, a national model designed to improve coordination of care between the medical home and the early intervention system. Currently active in 17 states, Help Me Grow promises to be able to provide the coordination necessary to support quality care and early intervention of West Virginia's young children. To meet its promise, Help Me Grow, will require efforts from all sectors. The medical community is key to helping parents understand the program and making the appropriate referrals.

Another initiative of MCFH in conjunction with the West Virginia Early Childhood Advisory Council is to address competencies in infant and toddler mental health. Following the guidance of the League of States and a Michigan program on infant mental health, West Virginia will create an Infant Mental Health Association and work towards core competencies for home visitors and supervisors.

HELP ME GROW CORE COMPONENTS

Child health care provider outreach to support early detection and intervention.



Community outreach to promote use of Help Me Grow and to provide networking opportunities among families and service providers.



Centralized telephone access point for connecting children and their families to services and coordination.



Data collection to understand all aspects of the Help Me Grow system, including the identification of gaps and barriers.

THE ENDURING INFLUENCE OF THE ASSURING BETTER CHILD HEALTH AND DEVELOPMENT (ABCD) INITIATIVE, JULY 2013

To assist the Perinatal Partnership and the Early Childhood Developmental Screening and Referral Committee consider next steps and a long-term plan, this section briefly summarizes the lessons from more than a decade of work of the ABCD states as described in the July 2014 Report, The Enduring Influence of the Assuring Better Child Health and Development (ABCD) Initiative.

These lessons include:

- Using the three public payers (CHIP, PEIA, and especially Medicaid) as drivers of quality improvement and system change. Approximately 70 percent of all West Virginia children are served by the three state payers. These payers can be leveraged to provide the measurement and quality of developmental screening practices through reimbursement methods, measurement practices, and managed care contracts to assure optimal performance at both the practice and plan levels.

- Improving child development requires partnering across systems, providers and support services. ABCD state teams worked together to successfully chip away at systemic barriers that made it difficult to navigate the multiple systems to provide care and support for children at risk or with developmental delays.
- Provider engagement and leadership is critical. ABCD states forged partnerships with their state chapter of the American Academy of Pediatrics.
- Families must be actively engaged as partners. Some ABCD states sought out and engaged parents to serve on leadership teams, get their feedback on materials and services and provide input into training curriculum. Several states incorporated indicators of parent satisfaction into their measurement strategies.
- Improvements at multiple levels (primary care practice, community and state policy) support and reinforce each other. Many state innovations began as small locally-based pilot projects.
- Data that demonstrates results builds a case for sustainability.

CONCLUSION

The challenge of realizing the full potential of developmental screening practices to improve health and learning outcomes for preschool children is daunting. However, after many years of tinkering around the edges, West Virginia seems poised to capitalize on smaller and intermittent improvements to develop an integrated system that meets the needs of its youngest and most precious resources.

Young children are especially at risk when systems are not aligned and there are failures in communication. The federal government and best practices of professional organizations are looking to primary providers to provide a health home and coordinate care. Yet, the support necessary for such coordination is lacking.

To optimize health and assure better developmental outcomes, all those responsible for the health and well-being of the state's youngest children must have shared goals and work over time to address system challenges and work towards continuing quality improvement.

This report aims to support such work by highlighting the problem (again), and providing consensus recommendations for next steps.

APPENDIX

AGES and STAGES QUESTIONNAIRE (ASQ-3)

The ASQ is a series of 19 parent-completed questionnaires designed to screen the developmental performance of children in the areas of communication, gross motor skills, fine motor skills, problem solving, personal-social skills, and overall development across time. The age-appropriate scale is completed by the parent or caregiver. The items on the scale represent behaviors that the child should be able to perform at that age. The original questionnaires were developed 15 years ago, they are well-researched and widely used around the world.

AGES AND STAGES QUESTIONNAIRE – SOCIAL EMOTIONAL (ASQ-SE)

The Ages and Stages Questionnaires: Social Emotional (ASQ:SE) were developed as a companion tool to the widely used Ages and Stages Questionnaires (ASQ), a system that uses parent reporting to screen for the development of infants and young children. The ASQ: SE was developed and continues to be studied in an effort to address the need for age-appropriate tools to monitor very young children's behavior and address parental concerns. In addition, the ASQ: SE provide an inexpensive, culturally versatile tool for states to participate in child-find activities for children at-risk for social-emotional and behavioral delays.

The Ages & Stages Questionnaires-Social Emotional (ASQ: SE) were developed to monitor a child's development in the behavioral areas of self-regulation, compliance, communication, adaptive, autonomy, affect and interaction with people. ASQ: SE questionnaire intervals correspond with the ASQ system, screening children from 3 months to 5 and 1/2 years of age. Questionnaire intervals are as follows: 6, 12, 18, 24, 30, 36, 48 and 60 months.

BIRTH TO THREE

WV Birth to Three is a statewide system of services and supports for children under age three who have a delay in their development, or may be at risk of having a delay, and their family. The Department of Health and Human Resources, through the Bureau for Public Health and the Office of Maternal, Child and Family Health, and West Virginia Birth to Three, as the lead agency for Part C of the Individuals with Disabilities Education Act (IDEA), assures that family centered, community based services are available to all eligible children and families.

To be eligible for WV Birth to Three services, an infant or toddler under the age of three can either have a delay in one or more areas of their development, or be at risk of possibly having delays in the future.

A child may have delays in one or more of the following areas:

- Cognitive - thinking and learning
- Physical - moving, seeing and hearing
- Social/emotional - feeling, coping, getting along with others
- Adaptive - doing things for him/herself
- Communication - understanding and communicating with others

A child may have risk factors such as:

- A condition which is typically associated with a developmental delay such as Down Syndrome; or
- A combination of biological and other risk factors. Some of these factors may include family stressors.

HELP ME GROW (HMG)

Help Me Grow is the State's new program to support identification, referral and coordination of care for children at risk. Help Me Grow is a national model currently in use in 13 states and scheduled to be implemented in all states through the Help Me Grow National Center. West Virginia's Help Me Grow Program will provide for a centralized telephone access point, a plan for community and child health provider outreach and education, and data collection and monitoring.

The Help Me Grow process will support developmental screening and referral through the following process:

1. The family enrolls in HMG with consent form to share information with providers.
2. The family completes the ASQ screen and submits to the Office of Maternal, Child and Family Health.
3. HMG staff scores the form and sends it to pediatric provider.
4. HMG makes necessary referrals for the family depending on child need.
5. HMG provides referral information to pediatric provider.
6. Pediatric provider has the ASQ screen and discusses it with family at next medical visit.
7. At each recommended screening (9, 18, 24-30 months) a new ASQ form is sent to the family for completion.
8. The family is provided with appropriate developmental milestones for their child(ren).
9. HMG collects demographic data, number of referrals, number of screens completed, number of providers using HMG, number of families enrolled.

IN-HOME FAMILY EDUCATION PROGRAMS

In-Home Family Education is a program that provides help to families with young children in their home. Parents can participate at no cost and there is no financial eligibility requirement. Trained staff come to the home, or wherever parents feel most comfortable. In-Home Family Education provides caring and supportive programs to families in almost half of all West Virginia counties. The goal is to improve child health, increase school readiness and give parents the information and support they need to connect them to services and make parenting decisions.

In-home family educators are trained paraprofessionals who operate under three national accredited programs known as Parents as Teachers (PAT), Maternal and Infant Health Outreach Workers (MIHOW), and Healthy Families.

To assess child and family needs, in-home family education staff use the

1. Edinburg Depression Screening tool to assess maternal depression.
2. Protective factors survey for child abuse prevention and parent stressors.
3. ASQ-3 and ASQ: SE for developmental delays and social, emotional development.
4. Caldwell Home Inventory to assess the home environment.
5. HITS domestic violence screening tool and Futures without Violence curriculum.
6. Curriculum developed by each program (MIHOW, Parents as Teachers, and Healthy Families America).

MODIFIED CHECKLIST FOR AUTISM IN TODDLERS (M-CHAT)

The M-CHAT™ is a scientifically validated tool for screening children between 16 and 30 months of age to assess their risk for autism spectrum disorder (ASD). It was developed by neuropsychologists Diana Robins and Deborah Fein and clinical psychologist Marianne Barton. The American Academy of Pediatrics (AAP) recommends that all children receive autism screening at 18 and 24 months of age, and the M-CHAT is one of the AAP's recommended tools.

RIGHT FROM THE START (RFTS)

RFTS is the state's Medicaid case management program for the highest risk families. It provides for home visitation services, helpful information and support for pregnant women, new mothers or fathers, or other caregivers at home. Visits support building strong and nurturing relationships between parents, caregivers and children to ensure that babies and young children grow up healthy, happy and safe. RFTS home visitors called, Designated Care Coordinators, are experienced, trusted, highly trained, caring registered nurses and licensed social workers who live and work in the community they serve. The nurses and social workers are employed by various agencies statewide throughout West Virginia. Visit frequency varies and there is no limit to the number of visits. Typically, visits begin for women during early pregnancy and continue until the second postpartum month. Infant visits begin soon after the baby is born and continue until the baby reaches age one year. Visits are tailored according to the information and support the family may request.

SAMPLE REFERRAL FORM



Division for Early Childhood Intervention Services Physician Referral and Feedback

A physician can find a local ECI program at <http://www.dars.state.tx/ecis/searchprogram.asp>. If more than one program serves the family's ZIP code, send the referral to any of them and it will be forwarded to the appropriate program.

Child Information

Child's name: _____ Child's date of birth: _____ Parent or legal guardian's name(s): _____

Mailing address: _____ Telephone number: _____ Language: _____
()

Ethnicity (enter X to select one): Hispanic or Latino Not Hispanic or Latino

Race (select all that apply): American Indian or Alaska Native Asian
 Black or African American Native Hawaiian or Other Pacific Islander White

Physician Information

Physician's name: _____ Telephone number: _____ Fax number: _____
() ()

Address: _____ Contact name and title: _____

Reason for Referral

In the items below, enter X to select the appropriate boxes.

1. Suspected developmental delay in the following areas: Cognitive Motor
 Communication Adaptive/Self-Help Social-Emotional other (specify)

2. Medically diagnosed conditions, if applicable, including ICD-9 code(s)—list all:

3. Sensory Impairment: Auditory Visual

4. Screening results, if applicable: ASQ PEDS

M-CHAT Other (specify): _____

Physician's signature:

Date:

X

Authorization to Release Pertinent Medical Information to ECI

I authorize the physician named above to send to the ECI program any of my child's pertinent medical information that the physician determines would help ECI evaluate my child and assess his or her service needs.

Parent or legal guardian's signature:

Date:

X

For Physician: Before sending referral to ECI, indicate the information you want to receive from the ECI program by checking the appropriate boxes in **Sections 1, 2, and 3** and obtain written parental consent for Section 1. After you obtain parental consent, ECI will send information for only those sections that are marked.

Section 1: Referral Status—If Section 1 is checked, the ECI program will complete and return the form to the physician. ECI must confirm the parent's consent to send this information.

Authorization to Release Referral Status to Physician

- Parent declined evaluation
- Eligible for ECI services—parent accepted services
- Eligible for ECI services—parent declined services
- Not eligible for ECI services
- Unable to establish contact with the parent (consent not required to release this information)

I authorize the ECI program that receives this referral to provide the applicable information about the referral indicated in Section 1 to the physician identified on this form. I understand that before sending this information to the physician, ECI will confirm my consent to provide this information to the physician and give me the opportunity to withdraw my consent.

Parent or legal guardian's signature:

Date:

X

For Physician: Indicate the information you want to receive from the ECI program by checking the boxes below.

Section 2: Eligibility Determination

Please send me a copy of the completed Eligibility Statement forms that show the basis for the determination of eligibility or any other information used to establish eligibility.

Section 3: Request for Additional Information

After the child's Individualized Family Service Plan (IFSP) is developed, please send me the following information:

- Initial IFSP Services Pages showing services the child and family will receive from ECI
- Other

I authorize the ECI program that receives this referral to provide the physician the information requested in Sections 2 and 3 above. I understand that before sending this information to the physician, ECI will confirm my consent to provide any or all of this information to the physician and give me the opportunity to withdraw my consent.

Parent or legal guardian's signature:

Date:

X

For ECI Program: To be completed by ECI provider.

Confirmation to Release Information to Physician

ECI has fully informed the parent or legal guardian of the information to be sent to the child's physician as requested in Sections 2 and 3 above and explained the parent or legal guardian's right to withdraw consent.

Initials of the ECI staff member confirming consent:

Date:

X

END NOTES

¹The Pew Center on the States and the National Association for State Health Policy (NASHP), Medicaid Financing Options for Home Visiting Programs, April 2012.

²HEDIS is a tool used by more than 90 percent of America's health plans to measure performance on important dimensions of care and service. Altogether, HEDIS consists of 80 measures across 5 domains of care. Because so many plans collect HEDIS data, and because the measures are so specifically defined, HEDIS makes it possible to compare the performance of health plans on an "apples-to-apples" basis. Health plans also use HEDIS results themselves to see where they need to focus their improvement efforts.

³Pediatric Core Measure #8 - Developmental Screening. Specification: HEDIS 12: The percentage of children screened for risk of developmental, behavioral, and social delays using a standardized screening tool in the 12 months preceding their first, second, or third birthday. CPT Code 96110 (Developmental testing, with interpretation and report).

⁴In early 2010 the Secretary of the U.S. Department of Health and Human Services identified 24 pediatric core measures on which state CHIP and Medicaid programs could begin voluntary reporting. Since WVCHIP currently has no contracts with managed care plans who might already be reporting some of these measures, it must extract this information to the extent possible from claims data. Most of the data is extracted according to specifications developed for the Health Plan Effectiveness Data and Information Set (HEDIS®). Some core measures were developed by other states and for which they are the steward and were included into the core set by national panels of experts. One such example is the Emergency Department Utilization measure developed by the State of Maine. In this year's report, WVCHIP has expanded to report 14 measures in the national measure set. There are four measures which relate to perinatal health for which we hope to receive data gathered by the WV Department of Health and Human Resources in the coming year to expand further our set of reported measures. This set of measures is expected to be studied and evaluated and will become mandatory reporting for all states' CHIP and Medicaid child health programs in 2013. HEDIS® is a set of standardized health performance measures that identifies only those individuals with a continuous 12 month enrollment period before the treatment or visit data can be included in calculating the measure. This helps to assure that the population measured is comparable from one health plan to another. HEDIS® specifications are annually reviewed and their sponsorship, support, and maintenance is under the aegis of the National Committee of Quality Assurance. HEDIS®-type data are usually those that meet the continuous 12 month enrollment definition for the denominator and which meet part of additional HEDIS® specifications in the numerator.

⁵Annual Report, West Virginia Children's Health Insurance Program, 2012, page 59.

⁶In 2012, the Office of Maternal, Child and Family Health, Health Check Program conducted a quality improvement chart audit of 264 pediatric providers and found that at the 9, 18 -24, 30 month health supervision visits, developmental screening occurred 29 percent, 28 percent and 26 percent of the time respectively.

⁷Laura Ices, Developmental Screening in Primary Care, the Effectiveness of Current Practice and Recommendations for Improvement, the Commonwealth Fund, December 7, 2007.

⁸Cynthia A. Connolly, A History of the Commonwealth Fund's Child Development and Preventive Care Program, The Commonwealth Fund, August 2013, page 9.

⁹Approved tools include Ages and Stages Questionnaire, Battelle Developmental Inventory Screening Tool, Bayley Infant-Neuro-developmental Screen, Brigance Screen II, Child Development Inventory, Child Development Review-Parent Questionnaire, Infant Development Inventory, Parents' Evaluation of Developmental Status. These tools are listed in State Level Measure of Developmental Screening in the First 3 Years of Life prepared by the Child & Adolescent Health Measurement Initiative, October 20, 2010.

¹⁰Maternal, Child, Family Health Survey, Developmental Screening and Referral Survey Results – Summary, July 26, 2013.

¹¹Other tools being used for developmental screening include Parent Evaluation Developmental Status (PEDS) and Child Developmental Review- Parent Questionnaire (CDR-PQ), and "others."

¹²Joan Phillips, Kidnitiative West Virginia, Quality Improvement Partnership Notebook, 2008.

¹³In conversations in May 2013 with medical providers in Morgantown including a genetic specialist there was discussion about the need for earlier and better identification of children with autism spectrum disorders.

¹⁴Carla Plaza, Jill Rosenthal, and Larry Hinkle, The Enduring Influence of the Assuring Better Child Health and Development (ABCD) Initiative, National Academy for State Health Policy, July 2013.

¹⁵Cynthia A. Connolly, page 9.

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