

**A Strategic Framework for Universal Developmental Screening  
for  
The State of Washington**

June 2, 2010

Final Stakeholder Input and Minor Revisions/Additions:

December 15, 2010

Prepared for the Washington State Department of Health, Office of Maternal and Child Health

by

Katherine TeKolste, MD  
Developmental Pediatrician  
University of Washington

## **Table of Contents:**

Executive Summary	5
Background	
What do we know about the developmental progress of children?	12
What is currently happening with developmental screening?	
Primary health care providers	16
How to do better in the primary health care practice	17
North Carolina	17
Oregon	19
The status in primary health care practices in WA State?	20
Are primary health care practices the solution for early identification?	21
Where else is developmental screening done?	23
An Emerging Consensus for Universal Approach to Developmental Screening	25
Early Support for Infants and Toddlers (ESIT) – WA IDEA Part C Program	
Kids Get Care/Children’s Health Initiative	
Kids Matter/ Early Childhood Comprehensive Systems	
Department of Early Learning	
Washington State DOH – LAUNCH and Autism grants....	26
Act Early Summit	
Parents	
Models of Developmental Screening Outside of the Primary Health Care Practice	26
New York – ICHAP/Child Find	27
Connecticut – Help Me Grow	28
Rhode Island’s Pediatric Practice Enhancement Project – Care Coordination	30
Health Information Technology – Database and Screening Tool Access	30
Databases Examples	
Kidsnet – Rhode Island	30
FamilyNet – Oregon	31
Standardized Developmental Screening Tools	
PEDS	32
ASQ™	33
CHADIS	34
Cell Phone Technology	35

Washington State Assets	
Cell Phone Technology	36
Databases	
Newborn Metabolic Screening	36
Newborn Hearing Screening	37
CHILD Profile Immunization Registry	38
Longitudinal Educational Data System	39
Health Information Outreach and Resource Connection for Parents	
WithinReach and ParentHelp123	39
CHILD Profile Health Information Mailings	40
Parent Support and Advocacy Groups	40
Where to Go from Here – A Draft Vision to Respond To:	41
Components	41
Developmental Screening Diagram – Basic	43
-WA state draft	44
Universal reach to parents of our youngest children	46
A means to provide results to providers and to families	47
Community connection to a spectrum of information and services	48
A means of care coordination and linkage to a continuum of services	48
Potential Workgroups	
Screening System	50
Reaching All Populations	50
Care Coordination, Resources and Referrals	52
Data System/Registry	53
Fiscal	53
Outreach/Marketing –General public, parents and providers	54
Evaluation	55
Information Technology	55
Other Considerations	
Autism Screening	55
Maternal Depression Screening	55
Identification of Infants birth to 12 months in need of early intervention	56
Foster Care	57
Multicultural and language issues –growing diversity	57
Partnerships	59
Appendices	
A. A survey of efforts to improve developmental screening in other states	61
B. Risk factors pertaining to referrals of at-risk children – New York State	70

C. Connecticut Help Me Grow – more information	72
D. KIDSNET authorized users	76
E. Child Health Profiles: Enhancement of immunization registries	77
F. CHADIS – Child Health and Development Information System	84
G. Help Me Grow Service Barriers and Gaps (2008 Annual Evaluation Report)	85
H. Some Systems to House a Washington State Screening System	88

## Executive Summary

In Washington State, and across the nation, we face ‘a public health epidemic of children arriving at kindergarten unprepared’. Nationally, over half of the children who enter kindergarten are found to be lagging in physical health, socio-emotional, and/or cognitive development. Physical health and mental health-related issues, alone or in combination, account for **all but 6%** of the children each year who are not school-ready. Efforts to ensure an opportunity for every child to succeed must address the needs of the whole child—including physical and mental health and well-being, as well as cognitive and social-emotional development and skills. Early intervention and other services supporting healthy early childhood development can reduce the number of children with problems that carry long-term consequences. Early identification is critical to providing a connection to needed interventions.

Research has helped us understand what young children need to be healthy and to optimize their development. A child’s growth and development are deeply influenced by the family environment - from prenatal exposures, food choices, early security and attachments, and language exposure to behavioral expectations. Partnering with parents is essential to optimize childhood developmental outcomes and improve readiness for learning. There is a general consensus that providing education and support to parents as their child’s first teacher is vital.

Indeed, parents often express a desire to know more about their children’s development, learning and behavior and how to best support growth in these areas. Parents want information on development and behavior from their child’s health care provider more than any other source. Furthermore, many parents have specific questions about children with special needs. In some cases, child care providers maybe the first adult to express concern to parents about a child’s development. Early childhood service providers also seek information on developmental and behavioral expectations and how to talk with parents about concerns, highlighting the need to connect the health and early learning systems.

Developmental screening is a key strategy to support each child’s development, help decrease the kindergarten preparation gap and assure optimal childhood outcomes. Research has clearly demonstrated that standardized developmental screening tools are needed to identify children with potential delays, and start the process for further assessment when indicated. Whether a child is developing typically for age or demonstrating difficulties, screenings and assessments can also give parents, families, caregivers and others who work with children a better understanding of a child’s strengths and needs.

For children who are **developing typically**, developmental screening serves as a ‘teachable moment’. Parents increase their awareness of developmental expectations and are attuned to new milestone achievements. When a child’s development is **lagging**, but not delayed to the point of eligibility for early intervention services, developmental screening can identify the need for developmental activities, child or family supports, interventions and/or services which may

prevent the need for more intensive interventions at a later time. Indeed, studies have indicated that children with false-positive screening results are a group at high risk who are likely to benefit from programs other than early intervention or special education. Developmental screening and assessment can **identify delays** in children who would benefit from formal IDEA Part C and B Early Intervention services – infant/toddler early intervention and preschool special education, respectively. Early intervention reduces the need for special education and other services later in life.

**Developmental screening is a priority** of the American Academy of Pediatrics (AAP). AAP policy published in 2006 recommends standardized developmental screening tools be routinely administered in the health care setting to all children at 9, 18 and 24/30 months of age and whenever there is parental or provider concern. Based upon parental report, results from the 2007 National Survey of Children's Health indicate the rate of developmental screening in primary health care settings nationally ranges from 10.7% to 47% (mean 19.5%), with Washington State at 25.6%.

With growing emphasis on access to health care for all children in a medical home, developmental screening in the health care setting makes sense. Yet there are many challenges to full implementation, including lack of reimbursement for developmental screening, overall poor payment rates for well-child care within Medicaid, and significant barriers to practice change required to operationalize a new system and maintain that system within the office setting. In addition, many children do not access primary care on a regular basis, including many children at higher risk of developmental problems.

There have been successful efforts to increase developmental screening in Washington State and on a larger scale elsewhere. As health programs and/or AAP chapters have worked with individual practices and clinics to implement primary health care practice-based developmental screening, a high need for **ongoing, outside technical assistance** to the practices has been noted. Additionally, there is a need for **systems for tracking and care coordination** to support referrals resulting from screening, either supported within or provided external to the primary health care setting.

### **Where else is developmental screening done?**

In addition to the primary care setting, there are a number of early childhood programs and settings that incorporate developmental screening. Because the children and families participating in these programs are often those at higher risk for delays and poor outcomes later in life, it is important to assure that they receive these screenings.

Developmental screening is mandated in a number of early childhood programs – e.g. Early Childhood Education and Assistance Programs (ECEAP)/Head Start/Early Head Start Programs, nurse home visiting and Parents as Teachers programs. In 2006-7, Head Start programs

nationally identified 13% of children with concerns on developmental, sensory and behavioral screens as needing further evaluation. Although formal developmental screening is not done in most child care settings, a survey of child care providers in King County Washington identified that 85% of the providers had concerns about development for at least one child in their care but lacked knowledge of child development resources and were not comfortable discussing concerns with parents.

Evidence-based home visiting programs, such as the Nurse-Family Partnership, reach pregnant women, young children, parents and informal caregivers in their homes. Some of these programs provide developmental screening.

Children and youth in foster care placements receive screening, revealing a high number of previously unrecognized developmental and behavioral issues in this population. Of children entering foster care, between 20- 60% have developmental delay or disability and 35-50% demonstrate significant emotional and behavioral health problems.

In addition, IDEA legislation mandates Child Find efforts in all states ‘...to locate, identify, and refer as early as possible all young children with disabilities and their families who are in need of Early Intervention Program (Part C) or Preschool Special Education (Part B/619) services of the Individuals with Disabilities Education Act (IDEA)’.

While these settings may be important sites for developmental screening, in general these screening efforts are not connected with each other and results are typically not shared outside the program. Children may receive similar screenings in multiple settings. And no one is coordinating the results between programs, sharing with the medical home provider or looking at the child and family more holistically over time.

### **After the Screening**

While it is clear that a more systematic approach to screening needs to occur, it is equally important to recognize that screening is only the first step in a bigger process. Someone has to interpret the results, share the results with the parents and help arrange for next steps. There is a need for systematic tracking and care coordination to support referrals resulting from screening. There are very real issues to address relating to information transfer, referral and access to supports and services.

Connecticut has led the nation in providing a single point of entry from screening through assuring connection to all needed services. They adopted a statewide, coordinated system of identification, triage, and referral for children at risk for developmental and behavioral problems. This program, called ‘Help Me Grow’, gives providers a single point of access to all developmental programs and services for children birth to age 5 years through a toll-free referral line.

‘Help Me Grow’ offers families the option to sign up for the ‘Ages and Stages (ASQ™) Child Monitoring Program’. If no developmental concerns are identified as a result of completing the screening tool, parent information on developmental expectations, activities and when to expect the next questionnaire is sent to the family. When concerns are identified, dedicated staff help make connections between families and community-based resources. ‘Help Me Grow’ liaisons link to local communities, contribute information to the resource inventory and support providers by facilitating local networking opportunities.

### **Emerging Consensus for Developmental Screening in Washington State**

In Washington State there has been growing recognition of the needs of young children and their families which has resulted in several systemic efforts to improve outcomes for children. In addition to the American Academy of Pediatrics, several groups in Washington State have recently highlighted the need to act on developmental surveillance and screening.

An emphasis on the importance of health insurance and access to a medical home has led to legislation and implementation of efforts to assure that all children in Washington State receive care in a medical home. The Kids Get Care program, the model currently being used by the Children’s Health Initiative (CHI), works to ensure that children, regardless of insurance status, receive early integrated preventive physical, developmental, mental and oral health services through a medical home.

Early childhood comprehensive systems (ECCS) building efforts have recognized how interrelated the health and early learning efforts are and that these occur within the context of families and communities. The *Kids Matter* (ECCS) framework was developed emphasizing the need for cross-discipline collaboration linking the domains of child health, social-emotional development and mental health, early care and education, and parenting education and support.

The *Plan for the Early Learning System 2010-2020* from the Washington State Department of Early Learning (DEL) includes a strategy to ‘ensure universal developmental and social-emotional/mental health screening that refers children birth through third grade to early intervention and/or special education services when indicated’ to be accomplished in the next five years. The *Washington State Birth to 3 Plan* has also highlighted developmental screening as a priority, including linking to behavioral support services in child care settings for identified children.

The Washington State Department of Health (WA DOH) has made developmental screening a performance measure. WA DOH has received two grants, the LAUNCH Grant and the Autism State Implementation Grant, that include a focus on early identification of special needs – social-emotional/mental health issues and diagnosis of autism spectrum disorders in very early childhood, respectively. Developmental screening is an essential component of achieving the goals of these grants and efforts to enhance community capacity for early screening and services statewide are being identified.

Washington State participated in an *Act Early summit* (a Center for Disease Control, CDC, autism initiative) in February 2010. Universal screening of children was a specific identified outcome – ‘All Washington State children will be screened at 9, 18, 24/30 months and at appropriate intervals for Early Head Start, Head Start, birth to three home visiting programs, foster care, early intervention, and for parent or provider concern.’

Parents continue to support efforts to improve early screening and identification – as voiced in their work on advisory councils such as the Combating Autism Act advisory council, at Conversations with Families events through ESIT, and by attendance at community screening events throughout the state, e.g. local Child Find and Easter Seals autism screening events. During the 4 quarters leading up to June 2010, WithinReach’s Family Health Hotline received over 500 calls from parents looking for services/screenings for their child.

Within all these contexts, the issue of developmental screening and supporting the needs of young children and their families has risen as a top priority.

### **Implementation Tools**

#### **Electronic Screening:**

The readiness of Washington State to move forward with a comprehensive developmental screening and referral system coincides with exciting technological advances which will help to facilitate our goals. First, there is now the ability to access developmental screening tools electronically and complete them online, along with database support. This decreases costs and increases accessibility. Currently there is online access for the Parents’ Evaluation of Developmental Status (PEDS), PEDS-Developmental Milestones (PEDS-DM), the ASQ and ASQ-Social Emotional (ASQ-SE). These are some of the most commonly used standardized developmental screening tools.

In addition the Child Health and Development Interactive System (CHADIS) provides access to these screening tools and others, including the Edinburgh Postnatal Depression Scale and tools used for older children and teens. The PEDS, ASQ and CHADIS systems each have databases with additional features. Which tools, which ages to screen and which systems to use need to be determined, but the possibility of bringing developmental screening to scale is enhanced by their availability.

#### **Database Tools:**

In addition to the screening tools, Washington’s quest for a comprehensive system can benefit from the experience and expertise of other states and communities who have led similar efforts, including those here at home. Washington State has database-specific experience from implementing a newborn metabolic and hearing screening database and the CHILD Profile Immunization Registry.

Rhode Island's Department of Health has developed a child health integrated system, **KIDSNET**, which houses data from several public health programs. KIDSNET online secure data is available to providers on a 'need to know' basis. 'Need to know' providers may include pediatric providers, Head Start, home visiting nurses agencies, WIC, Comprehensive Child Care Service Programs, school nurses, Lead Centers, and Early Intervention sites.

**FamilyNet** is a health data system under development by the Oregon Department of Human Services to integrate public health programs and coordinate services for children and families on the local agency level. It will help public and private providers screen, assess, and coordinate services to children and families; monitor risks, conditions, services, and outcomes over time; and feed a state-level data warehouse for epidemiology, program evaluation, decision support, and research.

### **Creating a Developmental Screening and Referral System in Washington State**

The time is right to create and implement a developmental screening system in Washington State as part of our larger medical home and early learning efforts. We have a unique opportunity to support children and families through a coordinated system which links through the child's medical home, identifies concerns early, assures referrals to services which can reduce the impact of identified concerns and delays, supports children's optimal health and development and ultimately increases each child's readiness for success in school and life.

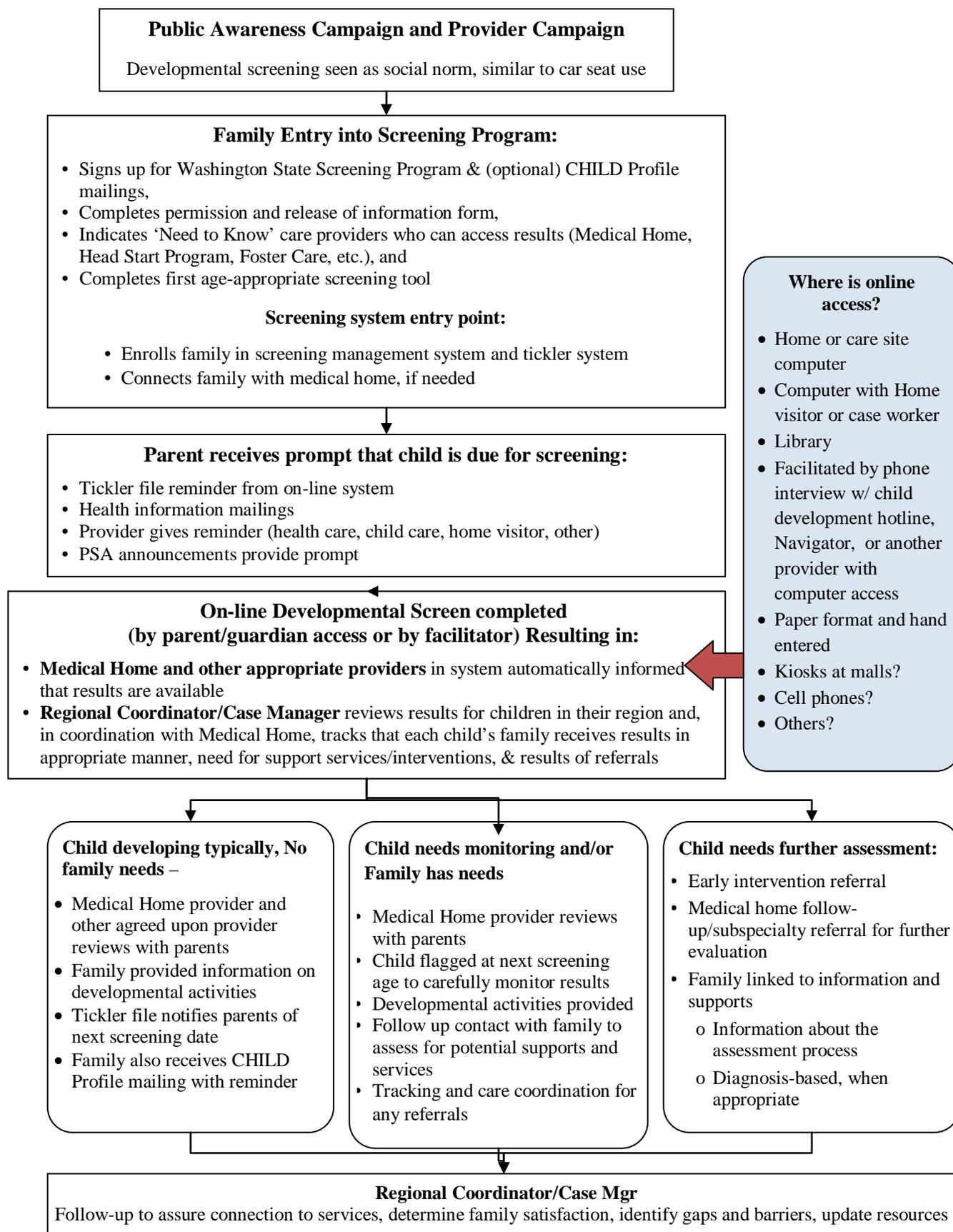
We can capitalize on new technology and new electronic developmental screening resources to better reach families and screen the young children of Washington State. This will better enable us to provide needed education and supports at the earliest possible time. We can support the goals of the AAP and the Washington State Early Learning Plan to identify developmental concerns and to meet the range of needs of the childhood population and their families—those benefiting all, needed by some, and indicated for a few.

A developmental screening system for young children can be built to:

- Support screening with recommended standardized tools
- Provide a secure data base with access for physicians and other health care providers, families, early childhood providers and others with a 'need to know'
- Reduce duplication of screening efforts and link results between providers
- Enhance family understanding and promotion of optimal child development
- Link children and families to a spectrum of services, according to need
- Facilitate resource identification, utilization and community networking

We propose a system with the following features:

## Components for Universal Developmental Screening for Children 0-3 Years in Washington State



## Background:

### What do we know about the developmental progress of children?

In Washington State, and across the nation, we face ‘a public health epidemic of children arriving at kindergarten unprepared’.<sup>1</sup> Nationally, over half of the children who enter kindergarten are found to be lagging in physical health, socio-emotional, and/or cognitive development. Physical health and mental health-related issues, alone or in combination, account for **all but 6%** of the children each year who are not school-ready.<sup>2,3</sup> Research in neuroscience and the developmental and behavioral sciences unequivocally shows that experiences in the first years of life have a direct and enduring impact on children’s future learning, behavior, and health – important determinants of a child’s readiness to succeed in school and life.<sup>4</sup> Efforts to ensure an opportunity for every child to succeed must address the needs of the whole child—i.e., physical and mental health and well-being, as well as intellectual and social-emotional development skills.<sup>5</sup> Early intervention and other services supporting healthy early childhood development can reduce the number of children with problems that carry long-term consequences. Early identification is critical to providing a connection to needed interventions.

A major report from the National Research Council in 2000, *From Neurons to Neighborhoods*, summarized current scientific understanding of early childhood development. Among the key findings:<sup>6</sup>

- Development of the brain is the most intense from birth to age 3 years. In the first few years of life, 700 new neural connections are formed in the brain every second.<sup>7</sup>
- The brain builds itself in response to the child’s experiences. Brain circuits that the child uses in daily life are strengthened. Those that the child doesn’t use fade away.

---

<sup>1</sup> David Willis, MD, president of the Oregon Chapter of the American Academy of Pediatrics (AAP) in ‘Developmental delays surge in Oregon kids and educators say that should mean increased service for them’. Hammond B. *The Oregonian*. March 10, 2010. (accessed 3/29/2010).

[http://www.oregonlive.com/education/index.ssf/2010/03/more\\_little\\_kids\\_in\\_oregon\\_ide.html](http://www.oregonlive.com/education/index.ssf/2010/03/more_little_kids_in_oregon_ide.html)

<sup>2</sup> Wertheimer R, Croan T, Moore KA, Hair EC. Attending kindergarten and already behind: a statistical portrait of vulnerable young children. Washington, DC; Child Trends; 2003.

<sup>3</sup> A Framework for Child Health Services: Supporting the Healthy Development and School Readiness of Connecticut’s Children. Dworkin P, Honigfeld L, Meyers J. Child Health and Development Institute of Connecticut, Farmington, CT ([www.chdi.org](http://www.chdi.org)), March 2009.

<sup>4</sup> Center of the Developing Child at Harvard University (2007). A science-based framework for early childhood policy: Using evidence to improve outcomes in learning, behavior and health for vulnerable children. <http://www.developingchild.harvard.edu> (Accessed 12/14/10).

<sup>5</sup> Washington State Early Learning Plan. September 2010. <http://www.del.wa.gov/publications/elac-gris/docs/ELP.pdf> (Accessed 12/14/10).

<sup>6</sup> National Research Council. (2000). *From Neurons to Neighborhoods: The Science of Early Childhood Development*. J. P. Shonkoff and D. A. Phillips, eds. Washington, D.C.: National Academy Press.

<sup>7</sup> In Brief: The Science of Early Childhood Development. Center on the Developing Child. Harvard University. [www.developingchild.harvard.edu](http://www.developingchild.harvard.edu) (accessed 12/14/10)

- The nurturing a child receives and responsive relationships with parents and caregivers help to build the child's brain structure. Good parent-child relationships are a crucial foundation for the child's learning, behavior and health.
- A child who experiences extreme poverty, abuse, chronic neglect, severe maternal depression, substance abuse or family violence will be in a state of toxic stress that disrupts brain growth.
- Brain circuits stabilize with age. It is possible to build connections and to adapt later, but it is more difficult and expensive.

Researchers have also identified risk factors seen consistently in children who have poor learning and health outcomes, including low income and low parental education. Children with these risk factors start showing poor outcomes in cognition, social skills, behavior and health as early as 9 months of age. By 24 months, the gap is widening between children with these risk factors and children without these risks. The more risk factors present, the bigger the roadblock to a child's optimal development.<sup>8</sup> In a one-time survey conducted in 2004, kindergarten teachers in **Washington** reported that less than half (44%) of children are ready when they enter kindergarten. More startling, they reported that among low-income children, only one out of four is ready on the first day of kindergarten.<sup>9</sup>

Research has clearly demonstrated that standardized developmental screening tools are needed to identify children with potential delays and start the process for further assessment when indicated. Screenings and assessments also give parents, families, caregivers and others who work with children a better understanding of a child's strengths and needs. Developmental screening is a key strategy to support each child's development, help decrease the kindergarten preparation gap and assure optimal childhood outcomes. Substantial resources are expended for the care of individuals with developmental delays and disabilities – medical, educational and community supports are all required. The life-long costs, including medical care and costs related to lost productivity for a individual with intellectual disability have been estimated at over \$1 million (in 2003 dollars).<sup>10</sup>

For children who are **developing typically**, developmental screening serves as a 'teachable moment'. Parents frequently express a desire to know more about their children's development,

---

<sup>8</sup> Washington State Early Learning Plan. (P.5) September 2010. <http://www.del.wa.gov/publications/elac-gris/docs/ELP.pdf> (accessed 12/14/10).

<sup>9</sup> Office of Superintendent of Public Instruction, State of Washington. (November 2005). *Student Readiness for Kindergarten: A Survey of Kindergarten Teachers in Washington State*. Prepared by Dave Pavelcheck, Washington State University Social and Economic Sciences Research Center.

<sup>10</sup> *MMWR*. Jan 30,2004. 53(03):57-59. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5303a4.htm> (accessed 4/10/2010).

learning and behavior and how to best support optimal growth in these areas.<sup>11</sup> With repeated exposure to developmental screening tools, parents become more aware of developmental expectations and are attuned to new milestones in their child's developmental progress.

In Washington state, results from a parent survey after a pilot study of the 18-month Ages and Stages Questionnaire (ASQ™) 2 screener made available through CHILD Profile mailings supported these findings regarding parents and the power of an increase in knowledge: 'It was helpful just to reassure me that my child is developing normally', 'Interesting – I found she has skills I didn't know she had', and 'It is helpful to see benchmarks in children's development. We know what to work on now!'<sup>12</sup> Recent statewide surveys found that 80 percent of parents would like information on activities, events and places in the community designed for families. Approximately two-thirds of parents surveyed would like information about ways to support children's early reading and school readiness skills, ways to help children's social-emotional development, and how to use positive discipline. More than half of parents want information on ways to keep children healthy and to support children's overall development, including social-emotional development and early reading skills. Parents want information and, in particular, trust the information received from health care providers.<sup>13,14</sup>

Many resources are available to direct parents to developmentally-stimulating activities for children, from Washington State's CHILD Profile Health Information mailings to websites and activity sheets associated with developmental screening tools (e.g. the ASQ™). With research showing that early language development and literacy skills are critical to school success, awareness of early literacy resources and programs, such as Reach Out and Read and local library's Children's Story Hour, is another important connection to make for all families.

Developmental screening can also identify the need for interventions and services when a child's development is **lagging but not to the 'tipping point'** of eligibility for IDEA Part C or B services. Screening can identify when behavioral and/or mental health issues threaten to impact learning and, potentially, mental health in later life.<sup>15</sup> Studies have indicated that children with false-positive screening results are at high risk and are likely to benefit from programs other than early intervention or special education.<sup>16</sup> A recent study demonstrated parents who have a

---

<sup>11</sup> Partnering with parents to promote the healthy development of children in Medicaid: Results from a survey assessing quality of preventive and developmental services for young children enrolled in Medicaid in three states. Bethel C, Peck C, Abrams M, Halfon N, Sareen H, Collins KS. The Commonwealth Fund. September 2002, p. 23.

<sup>12</sup> CHILD Profile-linked Developmental Screening Pilot with the Ages and Stages Questionnaire. Snohomish County Public Health Department et al. September, 2004.

[http://medicalhome.org/leadership/region\\_nw.cfm#snohomish](http://medicalhome.org/leadership/region_nw.cfm#snohomish)

<sup>13</sup> Washington State Department of Early Learning (DEL). 2008. *Parent Voices: Executive Summary, Washington State Department of Early Learning Parent Needs Assessment*. June 27. Prepared by SRI International.

<sup>14</sup> Thrive by Five Washington. March 2008. *Report on Opinion Research*.

<sup>15</sup> National Scientific Council on the Developing Child, 2008. And Zero to Three policy statement on Infant Mental Health at [www.zerotothree.org](http://www.zerotothree.org)

<sup>16</sup> Are overreferrals on developmental screening tests really a problem? Glascoe FP. *Arch Pediatr Adolesc Med*. 2001; 155:54-59.

paucity of positive parenting behaviors and negative perceptions of their children are more likely to have children with delays in their development.<sup>17</sup>

In a study of 2000 Census data, Washington Kids Count found that one in 10 Washington children experience multiple risks that heighten the probability that they will suffer social, medical and academic setbacks. These risks include parental unemployment, low income and lack of fluency in English. For Hispanic, African-American and American Indian children, the stakes are even higher, with one in five children experiencing three or more risks.<sup>18</sup>

This aligns with a study from the Centers for Disease Control (CDC) and Kaiser Permanente looking at adverse childhood experiences (ACEs) as risk factors. An ACE score considers ten categories of negative childhood experiences: physical neglect, emotional neglect, recurrent physical abuse, recurrent emotional abuse, contact sexual abuse, substance abuse in the household, incarcerated family member; family member with chronic depression, mental illness, institutionalized or suicidal; domestic violence, and one or no biologic parent in the home. One point is given for each category of trauma experienced before the age of 18 and the ACE score ranges from 0 to 9. Early trauma affects brain areas that affect handling mood, stress, bonding and memory and how the body stores fat. Higher ACE scores are associated with higher rates of smoking, alcoholism, antidepressant prescriptions, promiscuity, sexually-transmitted diseases and financial and/or job related problems in adulthood.<sup>19</sup>

Helpful interventions range from reducing family stress, e.g. food security (hence improving family functioning, parent/child interactions and child nutrition), to developmental interventions (e.g. parenting classes, literacy programs, early learning programs).

Washington statistics suggest we are **significantly under-identifying** children who would benefit from early intervention services for infants and toddlers with disabilities. WithinReach's Family Health Hotline (211 hotline serving all Washington State families) receives many calls from parents looking for services/screenings for their child.<sup>20</sup> Nationally, while the prevalence of delays in young children is at least 10 percent, only 2.52 percent of children between birth and age 3 participated in IDEA Part C Early Intervention (EI) programs in 2007. This means that nearly four of five potentially eligible children did not participate.<sup>21</sup> In Washington State, 1.77% of children birth to three participated in IDEA Part C in 2007 - 458 children 0-12 months,

---

<sup>17</sup> Parenting behaviors, perceptions and psychosocial risk: Impacts on young children's development. Glascoe FP, Leew S. *Pediatrics*. 2010; 125:313-319.

<sup>18</sup> Human Services Policy Center. 2003. *One in Ten Washington Children Experience Multiple Risks That Threaten Their Well-Being*. Seattle, WA: University of Washington.

<sup>19</sup>The Adverse Childhood Experiences (ACE) Study; Bridging the gap between childhood trauma and negative consequences later in life. Felitti VJ, Anda RF. <http://www.acestudy.org/> (accessed 4/10/2010).

<sup>20</sup> Personal communication. Jennifer Covert, WithinReach staff. 6.1.2010.

<sup>21</sup> Developmental screening in primary care: The effectiveness of current practice and recommendations for improvement. Sices L. Commonwealth Fund publication #1082. December 2007. Available online at [www.commonwealthfund.org](http://www.commonwealthfund.org).

1396 children 1 -2 years old (yo), and 2719 children 2-3 yo.<sup>22</sup> Other states' participation rates range from 1.19% to 6.94% (Washington DC, Hawaii respectively). *Developmental screening is a necessary element of identification.*

Developmental screening and assessment can identify **eligible children** who would benefit from formal IDEA Part C and B services – infant/toddler early intervention and preschool special education, respectively. Early intervention reduces the need for special education and other services later in life. In Washington State over 9,500 children received birth-to-three early intervention services from July 1, 2008 to June 30, 2009. In the same period, 4,641 children transitioned out of early intervention services. Of these 4,641 children, 1,201 or 31.4% no longer needed special education services.

### **What is currently happening with developmental screening?**

Developmental screening is currently a priority in a number of sites – primary health care practices, several early childhood programs, including head start and home visiting programs, foster care and Child Find activities mandated by the Individuals with Disabilities Education Act (IDEA). The following is an exploration of the activity occurring in these locations:

#### **Primary Health Care Providers:**

**Developmental screening is a priority** of the American Academy of Pediatrics (AAP). AAP policy recommends routine developmental screening tools be administered to all children at 9, 18 and 24/30 months of age and whenever there is parental or provider concern. The AAP recommends 14 health supervision visits between birth and age 5. Many states have developed initiatives to implement developmental screening in the primary care practice, such as learning collaboratives or 'lunch-and-learns'. Some of these programs are now approved as an American Board of Pediatrics (ABP) Maintenance of Certification (MOC) activity for recertification in pediatrics.

Based upon parental report, results from the National Survey of Children's Health indicate the rate of developmental screening in primary care settings nationally ranges from 10.7% to 47%.<sup>23</sup> Prior surveys of pediatricians indicate during health supervision visits for children birth to 3, 70% did not use any screening instrument or checklist. Physicians have predominantly used average milestone lists or checklists. When screening tools are used, they are frequently not used systematically or with all patients.<sup>24, 25</sup> These results are echoed in a 2007 survey of health

<sup>22</sup> [http://www.ideadata.org/TABLES31ST/AR\\_8-1.htm](http://www.ideadata.org/TABLES31ST/AR_8-1.htm) accessed 3/27/2010.

<sup>23</sup> The National Survey of Children's Health. <http://www.nschdata.org/Content/Default.aspx>

<sup>24</sup> AAP Periodic Survey of Fellows #53. 2002.

care providers in Virginia as they initiated efforts to address improvements in developmental screening in primary care practices.<sup>26</sup>

The rate of developmental screening is likely less in family medicine practices, in part because the percentage of the practice population that falls into the birth to five year age group where developmental screening is most prevalent is relatively small in most family medicine practices. Screening efforts in Oregon (see below) have been more difficult to implement in family medicine practices.<sup>27</sup> At least one study has indicated that family physicians are more likely than pediatricians to take a ‘wait and watch’ approach to developmental concerns.<sup>28</sup>

### **How to do better in the primary health care practice – two examples:**

**North Carolina:** On the 2007 National Survey of Children’s Health, the highest rate of developmental screening in primary care practices (by parent report) was 47% in North Carolina. About 70% of counties in NC are medically underserved.<sup>29</sup> North Carolina piloted screening practices in primary care as part of the Assuring Better Child Development (ABCD) I Program of the Commonwealth Fund (2000-2003). The success of that program led to statewide implementation through the infrastructure of the Community Care of North Carolina (CCNC) networks serving Medicaid populations. Starting in July 2004, North Carolina Medicaid required valid, standardized developmental screening tools used at six ages - 6, 12, 18 or 24 months and at the 3, 4, and 5 year visits.<sup>30</sup> Additionally a validated screening instrument for autism must be performed at 18 and 24 months of age.<sup>31</sup>

An Early Intervention (EI) Specialist or other care coordinator oversees collection of ASQ™ information, makes EI referrals, conducts home visits, assists with parent education and provides resources and referrals for specific needs or concerns. Of interest, North Carolina’s participation rate in EI in 2006 was reported at 2.03%, only modestly better than Washington State’s 1.79%

---

<sup>25</sup> Pediatricians’ reported practices regarding developmental screening: Do guidelines work? Do they help? Sand N, Silverstein M, et al. *Pediatrics*. 116(1):174-179. 2005.

<sup>26</sup> Virginia ABCD Project. (2008). Summary of Findings of 2007 Provider Survey. [http://www.nashp.org/sites/default/files/VA\\_ABCD%20PROJECT\\_Survey2007.pdf](http://www.nashp.org/sites/default/files/VA_ABCD%20PROJECT_Survey2007.pdf)

<sup>27</sup> Personal communication, Anne Stone, Oregon Chapter AAP. 4/2009

<sup>28</sup> How do primary care physicians manage children with possible developmental delays? A national survey with an experimental design. Sices L, Feudtner C et al. *Pediatrics*. 2004; 113:274-282.

<sup>29</sup> LEND abstract – University of North Carolina, Chapel Hill. Accessed 4/9/2010 at: [https://perfdata.hrsa.gov/MCHB/DGISReports/Abstract/AbstractDetails.aspx?cbAbstractSummary=T73MC00030\\_2009\\_NonResearch\\_4&tbKeyword=LEND&rbKeyword=Exact&lbService=IsIB&lbStateRegion=All&rbTimePeriod=1&lbMchbProgram=T73&ddlResultsBy=ProjectTitle&rbSortedBy=ASC](https://perfdata.hrsa.gov/MCHB/DGISReports/Abstract/AbstractDetails.aspx?cbAbstractSummary=T73MC00030_2009_NonResearch_4&tbKeyword=LEND&rbKeyword=Exact&lbService=IsIB&lbStateRegion=All&rbTimePeriod=1&lbMchbProgram=T73&ddlResultsBy=ProjectTitle&rbSortedBy=ASC)

<sup>30</sup> Expanding innovation through networks: The Assuring Better Child Health and Development (ABCD) Project. Earls M. *NC Med J*. 2009; 70(3):253-255.

<sup>31</sup> North Carolina Medicaid Special Bulletin Number 1. Health Check Billing Guide. April 2010. <http://www.ncdhhs.gov/dma/helathcheck/> (accessed 4/11/2010)

despite the higher reported rate of screening in Medicaid practices.<sup>32</sup> In July 2006, North Carolina's early intervention program discontinued serving children at-risk and children with atypical development. However, they now indicate that they have increased the number of children 0-3 years old served in EI to 4.6% (17,606 children eligible from 19,662 referrals) in 2008-9. Thirty-seven percent (37%) of referrals to the program are from physicians. The remaining top five referral sources were parents, hospitals, local public health and neonatal intensive care units.<sup>33</sup>

Currently, North Carolina Medicaid monitors screening in primary care practices by billings for a periodic Health Check screening assessment (a developmental screening CPT code with the EP modifier that must be listed in addition to the preventive medicine Early Periodic Screening, Diagnosis and Treatment (EPSDT) CPT codes). According to this EPSDT claims reporting, 90% of practices in North Carolina perform developmental screening using standardized tools and 85% of Medicaid children between ages 0-5 years are screened. No additional reimbursement beyond the EPSDT preventive medicine visit code reimbursement is provided for this code at the required ages.<sup>34</sup> When the screen is performed at a sick visit or other than the required ages, there is a \$10 compensation.<sup>35</sup>

In 2008, North Carolina Medicaid received 230,000 billings for code 96110 (developmental screening, including maternal depression, social-emotional development and autism screening; may include multiple screens on same child).<sup>36</sup> As of July 1, 2008, North Carolina's early childhood population totaled 742,661 children ages birth through 5 years.<sup>37</sup> In

2004, 32.6% of North Carolina's children were enrolled in Medicaid. If that percentage is stable for the birth to 5 population in 2008, there would be 242,107 children in the 0-5 age group on Medicaid. This suggests that 230,000 Medicaid billings for 96110 would come close to one screen per child per year, an impressive accomplishment. Although we do not know what the

2008 EPSDT preventive visit code  
payment - established patient

North Carolina:

- 99391 (<1 yo) -\$80.33
- 99392 (1-4 yo)- \$80.33.

Washington State

- 99391 - \$54.73
- 99392 - \$62.69

<sup>32</sup> [https://www.ideadata.org/tables30th%5Car\\_7-1.htm](https://www.ideadata.org/tables30th%5Car_7-1.htm) (accessed 5.5.2010)

<sup>33</sup> NC Early Intervention Program 2009-2010 At-A-Glance. [www.ncei.org/ei/publications.html](http://www.ncei.org/ei/publications.html) (accessed 12/14/2010)

<sup>34</sup> NC Medicaid Special Bulletin I. April 2010. P. 39.

[www.dhhs.state.nc.us/dma/bulletin/pdfbulletin/0410specbull.pdf](http://www.dhhs.state.nc.us/dma/bulletin/pdfbulletin/0410specbull.pdf) (Accessed 4/12/2010)

<sup>35</sup> Developmental Screening in Early Childhood Systems. ECCS Conference Call #3, 3/11/2010. Chris Collins, North Carolina.

<sup>36</sup> Expanding innovation through networks: The Assuring Better Child Health and Development (ABCD) Project. Earls M. *NC Med J.* 2009;70(3):253-255.

<sup>37</sup> [http://osbm.state.nc.us/demog/countytotals\\_agegroup\\_2009.html](http://osbm.state.nc.us/demog/countytotals_agegroup_2009.html) and [http://osbm.state.nc.us/demog/countytotals\\_agegroup\\_2008.html](http://osbm.state.nc.us/demog/countytotals_agegroup_2008.html). (accessed 4/11/2010)

screening percentage is for children who are uninsured or privately insured in NC, they appear to be the state closest to achieving ‘universal’ screening in the primary care practice.

**Oregon:** By parental report [2007 National Survey of Children’s Health (NSCH), surveying parents of children 10 to 35 months of age], 13.5% of physicians in Oregon are screening development. The 0-3 year old percentage of children in early intervention services in Oregon was 1.7 % (versus nationally 2.7%).

Since 2008, Oregon has utilized an educational model in primary care practices that is based on Tennessee’s START program (see Appendix A: A Survey of Efforts to Improve Developmental Screening in Other States). Physicians receive reimbursement for screening (code 96110) from Medicaid/CareOregon (\$20 per 96110 coding), local MCO and private payers. Providers in the Portland, Oregon area (Multnomah County) attended a 2 ½ hour training in the evening, including dinner and \$100 per hour for three hours plus mileage reimbursement per physician.

After these efforts, Oregon reports 85% of pediatric practices in the Portland area are performing standardized developmental screening at 9, 18 and 24 months, with a few also screening 3 and 4 year olds. Most are also screening for autism with the MCHAT.<sup>38</sup> By early 2010, the number of children under age 3 receiving early intervention services in Multnomah County has increased by 35%.<sup>39</sup> There are legislative efforts underway to address the downside of increased identification - children birth to three years received about 7 hours a month of early intervention services from teachers and therapists in 2004 and now they receive on average 3 ½ hours per month.

Other regional trainings in Oregon have been more difficult, especially getting the whole practice team together for planning. Family medicine practices and rural practices are a struggle. In the newer areas the training has moved to 3-one hour ‘lunch and learn’ modules.<sup>40</sup> Implementation in the physician offices in the Eugene area (Lane County) is now improving.<sup>41</sup> Lane County is now one of the ‘Help Me Grow’ (see page 29, under Connecticut) replication sites addressing care coordination through their ‘211 Parent Help Line’, a Birth to Three parent support organization. The Oregon START Program has expanded to prioritize care coordination and community linkage support for primary care practices.

According to the Oregon Health Plan’s list of prioritized services (which was revised and became effective on April 1, 2008), pediatric providers can bill for 96110 multiple times at a single visit. However, few providers actually take advantage of this opportunity. An increasing number of Oregon practices are now routinely using the ASQ™ and M-CHAT at 18 and 24 months

<sup>38</sup> Personal communication, Dr. Gillespie, 11/26/2008.

<sup>39</sup> Developmental delays surge in Oregon kids and educators say that should mean increased services for them. Hammond B. *The Oregonian*. March 10, 2010. (accessed on line 3/29/2010)  
[http://www.oregonlive.com/education/index.ssf/2010/03/more\\_little\\_kids\\_in\\_oregon\\_ide.html](http://www.oregonlive.com/education/index.ssf/2010/03/more_little_kids_in_oregon_ide.html)

<sup>40</sup> Personal communication, Anne Stone, April 2009.

<sup>41</sup> Personal communication, Joanna Bogins, April 2010.

(96110 twice). With unreliable private payer reimbursement and a sizeable number of non-insured children, pediatric providers are afraid to send parents a clinic bill of ~\$60 for these two tests – general developmental screening and autism screening.<sup>42</sup>

There is further information on various state efforts to increase developmental screening in primary health care settings in Appendix A. (A comprehensive review is beyond the scope of this document.)

**The Status of Developmental Screening in Primary Health Care Practices in Washington State:** Unlike many states, Washington’s Medicaid program does not currently pay for developmental screening in the primary health care setting. This is a significant, but not insurmountable, barrier to implementation of a practice-based model of screening. By parent report (2007 NSCH), 25.6% of children in Washington State received a developmental screen at their physician’s office.<sup>43</sup>

In 2004 and 2005, two learning collaboratives in Washington State (Kids Get Care/Children’s Health Initiative) focused on implementation of developmental screening in the primary care practice. This resulted in some of the 17 participating practices effectively implementing office-based screening. In December 2009, a survey was sent to these practices to assess screening efforts in the seventeen clinics 4 to 5 years later. Five of the 17 practices responded to the survey (return rate 30%). One practice was screening for autism with the MCHAT at 18, 24 and 36 months; no other standardized screens were being done. The remaining four practices all screened with the ASQ™ and ranged from 4 to 10 prioritized ages for screening up to 60 months of age. E.g. all four practices screened children at 6 months, 12 months and 24 months of age; but some practices also screened at 9 months (2 practices), 15 months (1 practice), 18 months (3 practices), 36 months (3 practices), 48 months (3 practices), and 60 months (1 practice).

One family medicine practice participating in a Medical Home Learning Collaborative in 2008 focused on implementing developmental screening but was unable to achieve that goal, in part due to low pediatric patient volume and staffing changes at the practice site. Through Washington State Medical Home Leadership Network activities, we recognize there are other practices in our state that have implemented developmental screening without having participated in a learning collaborative, e.g. Peace Health (formerly Madrona Pediatrics) in Bellingham, Child and Adolescent Clinic in Longview. In these two locations, assistance in follow-up to screening and/or in scoring is provided by a CSHCN nurse and the local neurodevelopmental center, respectively. Other practices have expressed interest in implementing screening, e.g. NeighborCare Clinic, Adams County practices.

---

<sup>42</sup> ABCD Discussion Forum. Kevin Marks, MD. Accessed 1/12/2010.

<sup>43</sup> National Survey of Children’s Health. 2007.

<http://www.nschdata.org/DataQuery/DataQueryResultsAllStates.aspx?validq=1>

A survey of primary care providers in the Yakima area of Washington State identified a need to improve developmental screening practices in that community. The physician advisory group at Yakima's Children's Village indicated some physicians are currently working 11½-hour days and are too busy to do screening; in fact, they don't even feel they can make a meeting to discuss screening. In informal conversations with Children Village's developmental pediatrician, some local primary care providers have indicated interest in screening performed outside of the practice setting and linked to the medical home. They feel an 'outside' screening system would better account for the movement of a family/child between community providers. A hospitalist in the advisory group even indicated that the hospitalists have time with patients and would be able to work on getting developmental screens on children in their care. Yakima physicians are concerned, however, that families whose children are screened in the mobile Child Find program in the Yakima Valley (Kidscreen) often consider this service as fulfilling the need for a well child check.<sup>44</sup> A recent AAP CATCH grant is funding planning efforts around improving developmental screening in the Yakima area.

### **Are primary health care practices the solution for screening for early identification?**

Even if the reimbursement and other issues hindering primary care practice implementation of developmental screening were resolved, there would still be significant gaps in screening if primary health care sites are used as the source to achieve screening for all children (universal screening). Many children do not access primary care on a regular basis, if at all. A study of 81 health plans found that only 31 % of Medicaid enrollees had more than six health supervision visits by age 15 months, compared with 53% of children with private insurance. Fifty percent of Medicaid enrollees had yearly check-ups between ages 3 and 6, compared with 55 percent of those enrolled in private insurance.<sup>45</sup> 'Even with private insurance, only slightly more than half of children received the recommended number of preventive care visits. The rates of adherence were even lower among children covered by Medicaid, who are actually at greater risk for developmental problems due to family poverty.'<sup>46</sup> In 2009, Washington State Medicaid plans improved over this national data with 57% of Medicaid-enrolled children receiving six or more health supervision visits by 15 months of age and 60% of children with annual check-ups between ages 3 and 6 years. Over 10% of the Medicaid-enrolled children had three or fewer health supervision visits in the first 15 months of life and just over 1% had no visits at all.<sup>47</sup>

---

<sup>44</sup> Personal communication, Dr. Diane Liebe, February 2010.

<sup>45</sup> Quality of care for children in commercial and Medicaid managed care. Thompson JW, Ryan KW et al. *JAMA*. 2003. 290(11):1486-93.

<sup>46</sup> Developmental screening in primary care: The effectiveness of current practice and recommendations for improvement. Sices L. Commonwealth Fund publication #1082. December 2007. Available online at [www.commonwealthfund.org](http://www.commonwealthfund.org).

<sup>47</sup> 2009 Performance Measure Comparative Analysis Report. Accumentra Health. November 2009.

In Connecticut, home to the ‘Help Me Grow’ program (see page 28), physicians choose varying options to accomplish developmental screening. Some practices choose to screen on site. Some use a combination of on-site and ‘Help Me Grow’, while others prefer to link to ‘Help Me Grow’ for all their screening.<sup>48</sup> There is reimbursement for screening from the Connecticut Medicaid program (Husky) and many insurance plans. One element of the ‘Help Me Grow’ program in Connecticut is developmental surveillance and screening training and technical assistance (TA) for primary care practices/providers,

As states have worked to implement primary care practice based developmental screening, a high need for **ongoing, outside technical assistance** to the practices has been noted. Dr. Blythe Buerger, working with the early childhood efforts in Rhode Island, indicates they could use ten more full time technical assistance positions to help primary care practices implement and maintain screening efforts with the ASQ™, ASQ™-SE, and a maternal depression screen.<sup>49</sup> The ‘Help Me Grow’ project manager indicates, for system continuity, the program has to have an ongoing relationship with the primary care provider’s office and TA needs to be constantly available, usually as ‘academic detailing’.<sup>50</sup> In one clinic in Washington State, a care coordinator, who is funded by an outside grantee to provide services and assistance to uninsured children and oversee developmental screenings and other services, indicates screening is a team effort involving the front desk, medical assistants, providers and parents. Even then, this effort is only sustained by publically posting screening rates for the site’s providers, offering acknowledgement and prizes to individual providers with outstanding results, and providing lunches to teams who excel on a quarterly basis.<sup>51</sup>

The **Developmental Surveillance and Screening Policy Implementation Project (D-PIP)**, a study of practice-based screening implementation in 17 pediatric practices in 15 states, found that while screening rates rose to 85% at the AAP recommended ages, screening in the presence of concerns remained low. Only 61% of those with delays suspected by screening were sent for further testing and therapy. Practices struggled to determine results of referrals and, when results were tracked, they found many families did not complete recommended referrals.<sup>52</sup> There is a need for systems for tracking and care coordination, either supported within or provided external to the primary health care setting.

## Where Else is Developmental Screening Done?

---

<sup>48</sup> Personal communication, Joanna Bogin, 4/7/2010

<sup>49</sup> Developmental Screening in Early Childhood Systems. ECCS Conference call #3. 3/11/2010.

<sup>50</sup> Personal communication, Joanna Bogin, 4/7/2010

<sup>51</sup> Personal communication, D Bryson, 2/11/2009.

<sup>52</sup> Implementing Developmental Screening and Referrals: Lessons learned from a national project. King TM et al. Pediatrics. 2010. 125(2):350-360.

Developmental screening is mandated in a number of early childhood programs – e.g. foster care, Early Childhood Education and Assistance Programs (ECEAP)/Head Start/Early Head Start Programs, nurse home visiting and Parents as Teachers programs. In addition, IDEA Parts B and C mandate Child Find, defined by federal Office of Special Education Programs as a “continuous process of public awareness activities, screening and evaluation designed to *locate, identify, and refer as early as possible* all young children with disabilities and their families who are in need of Early Intervention Program (Part C) or Preschool Special Education (Part B/619) services of the Individuals with Disabilities Education Act (IDEA)” efforts in all states. Parenting telephone lines, child information mailings and community screenings are all access points for connection to screening in these early intervention programs.

In 2006-2007, **Head Start** programs nationally completed 941,484 developmental, sensory and behavioral screens with 124,654 children (13%) identified as needing a follow-up assessment or formal evaluation.<sup>53</sup>

Studies have demonstrated that between 20% and 60% of children entering **foster care** have developmental delay or disability. Additionally, 35% to 50% of these children have significant emotional and behavioral health problems.<sup>54</sup> It is possible to achieve a high rate of ASQ™ completion in a medical home for children in foster care. The rate of detection of developmental problems with the screening is comparable to rates reported in studies of the foster care population.<sup>55</sup> In Washington State foster care, the Child Health and Education Track (CHET) is a comprehensive program that begins when a child enters out-of-home placement until exiting out-of-home care and includes developmental screening. Screening is performed in the first 30 days of out-of-home placement for any child expected to remain in out-of-home care for more than 30 days. There is no requirement to repeat screening at a later date. The ASQ™ and the ASQ™-SE are used for children ages 3 months to 5 years.

**Evidence-based home visiting** is a voluntary early childhood strategy that can enhance parenting, *and* promote the optimal growth and development of young children. These programs are focused, individualized and culturally-competent services intended to reach pregnant women, young children, parents and informal caregivers in their homes. Four evidence-based home visiting programs are in use in Washington: Nurse-Family Partnership, Parents as Teachers, Parent-Child Home Program, and Early Head Start. The total capacity of the four programs is enough to serve only 2 percent of the estimated eligible families who would choose to

---

<sup>53</sup> Partnering to Address Mental Health Concerns in Early Education and Child Care. AAP Webinar. Barry Marx, MD, FAAP, Senior Medical Advisor, Office of Head Start. 3/23/2009. Can be accessed at <http://www.aap.org/mentalhealth/mh9et.html>  
[www.aap.org/mentalhealth/docs/Partnering%20Webinar%20MASTER%20Recording.ppt](http://www.aap.org/mentalhealth/docs/Partnering%20Webinar%20MASTER%20Recording.ppt)

<sup>54</sup> Comprehensive assessments for children entering foster care: A national perspective. Leslie LK, Hurlburt MS, et al. *Pediatrics*. 2003; 112(1):134-142.

<sup>55</sup> Improved detection of developmental delays among young children in foster care. Jee SH, Szilagyi M, et al. *Pediatrics*. 125(2):282-289.

participate. Some additional evidence-based home visiting is funded by the Council for Children and Families. In addition, Thrive by Five Washington is providing a range of home visiting programs, including evidence-based home visiting in two demonstration projects. These programs support parents, reduce the risk of child maltreatment and some provide developmental screening. Often the visitor and the parent complete the screening questionnaire together and use the interaction as a time of ‘teachable moments’ and celebrating milestones.

Although there is not currently a mandate for linking to developmental screening from **child care settings**, this is a potential venue. Child care providers indicate they have concerns about development for some children in their care but lack knowledge of child development resources and are uncomfortable discussing concerns with parents. A consultant from the Kids Get Care Program in King County Washington worked with a group of family child care providers recruited by Child Care Resources. In focus groups conducted in 2004, 85% of participating providers indicated having had concerns about the development of at least one child in their care. After learning about community resources, as well as receiving training on and subsequently utilizing a ‘Red Flags’ list, providers felt positive about using such an approach. They indicated this information gave them credibility and specifics to share with parents about developmental concerns and linking to resources.<sup>56</sup>

Nearly 30% of children under age 6 years are in *center-based childcare* (including preschool). Five percent (5%) of children receive care in a *family-based child care* program in a family home with 12 or fewer children. Only 7% of the youngest children (under 18 months) attend a center-based child care program. Center-based care provision increases to more than half of children ages 3 through 5 years. Fifteen percent (15%) of children under age 6 years are in *informal care* arrangements, such as relative, friend or nanny care either in the family home or the caregiver’s home.<sup>57</sup>

However, half of children in Washington State younger than age 6 who have not yet entered kindergarten receive care *only* from a parent or guardian. Children under 18 months of age are more likely to be in parental or informal child care arrangements. Sixty-eight percent (68%) of children in this age group are cared for by their parent(s), whereas about one third of children ages 3 to 5 years are in parental care.<sup>58</sup>

As part of Washington State’s efforts on the Assuring Better Child Development (ABCD I) grant, 2001 recommendations from the State Developmental Screening Committee suggested that despite efforts at the primary health care setting and other community sites such as Head

---

<sup>56</sup> Child Care Provider Screening Tool Survey. Child Care Resources. September 30, 2004.

<sup>57</sup> Parent Voices: A statewide look. Washington State Department of Early Learning Parent Needs Assessment: Phone Survey. June 27, 2008, p 39.

[http://www.del.wa.gov/publications/research/docs/WA\\_DEL\\_PNA\\_SurveyReport.pdf](http://www.del.wa.gov/publications/research/docs/WA_DEL_PNA_SurveyReport.pdf)

<sup>58</sup> Ibid.

Start, a not-insignificant number of children are still likely to be missed by these screening approaches. The committee recommended exploring the feasibility of a statewide system for linking families to developmental screening.

### **An Emerging Consensus for Universal Approach to Developmental Screening:**

In Washington State there has been growing recognition of the needs of young children and their families which has resulted in several systemic efforts to improve outcomes for children. Improving the identification of children birth to three with special needs has long been a priority of the **Early Support for Infants and Toddlers** [ESIT -formerly the Infant Toddler Early Intervention Program (ITEIP)], Washington State's IDEA Part C Program. This program is especially working to improve identification of infants from birth to age 12 months.

An emphasis on the importance of health insurance and access to a medical home has led to legislation and implementation of efforts to assure that all children in Washington State receive care in a medical home. The **Kids Get Care** program, the model currently being used by the **Children's Health Initiative** (CHI), works to ensure that children, regardless of insurance status, receive early integrated preventive physical, developmental, mental and oral health services through a medical home. The program works on a wide range of preventive and primary care health outcomes including immunizations, numbers of well child visits at all ages, screening and treatment for maternal depression and children's mental health, and referrals for dental, mental health and developmental services.

**Early childhood comprehensive systems** (ECCS) building efforts have recognized how interrelated the health and early learning efforts are - *and* that all occur within the context of families and communities. The **Kids Matter** (ECCS) framework was developed emphasizing the need for cross-discipline collaboration linking the domains of child health, social-emotional development and mental health, early care and education, and parenting education and support.

The focus on early learning led to the creation of the **Department of Early Learning** (DEL, a Governor's cabinet level department) in 2006. In 2010, ITEIP moved to DEL, and was renamed 'Early Support for Infants and Toddlers', underscoring the importance of thinking about children with special needs within the larger context of supporting young children and families.

In 2009-10, the drafting of a state Early Learning Plan has continued to move Washington forward in systemic collaborative efforts to enhance early childhood outcomes and to set the stage for success in school and life. Within this plan, within the state legislature, and among those involved in health and early learning is a growing recognition of the need to specifically and systematically plan for and address the needs of young children and their families.

The current *Washington State Early Learning Plan* includes a strategy to ‘ensure universal developmental and social-emotional/mental health screening that refers children birth through third grade to early intervention and/or special education services when indicated’ to be accomplished in the next five years. The *Washington State Birth to 3 Plan* has also highlighted developmental screening as a priority, including discussions on linking to behavioral support services for identified children in child care settings. Developmental screening is part of the seven priority policy recommendations presented to the Washington State Legislature in December 2010.

The **Washington State Department of Health** (WA DOH) has received two grants, the LAUNCH Grant and the Autism State Implementation Grant, that include a focus on early identification of special needs – social-emotional/mental health issues and diagnosis of autism spectrum disorders in very early childhood, respectively. Developmental screening is an essential component of achieving the goals of these grants and strategies to enhance community capacity for early screening and services statewide are being identified.

Washington State participated in an **Act Early Summit** in February 2010. Universal screening of children was a specific identified outcome – ‘All Washington State children will be screened at 9, 18, 24/30 months and at appropriate intervals for Early Head Start, Head Start, birth to three home visiting programs, foster care, early intervention, and for parent or provider concern.’

**Parents** continue to support efforts to improve early screening and identification – as voiced in their work on advisory councils such as the Combating Autism Act advisory council, at Conversations with Families events through ITEIP/ESIT, and by attendance at community screening events such as Child Find events throughout the state and Easter Seals autism screening events. During the four quarters leading up to June 2010, WithinReach’s Family Health Hotline received over 500 calls from parents looking for services/screenings for their child. Of the 508 calls, 313 referrals were made to the lead Family Resource Coordinator (FRC) who accesses screenings, evaluations and resources for the IDEA Part C Program (ESIT).

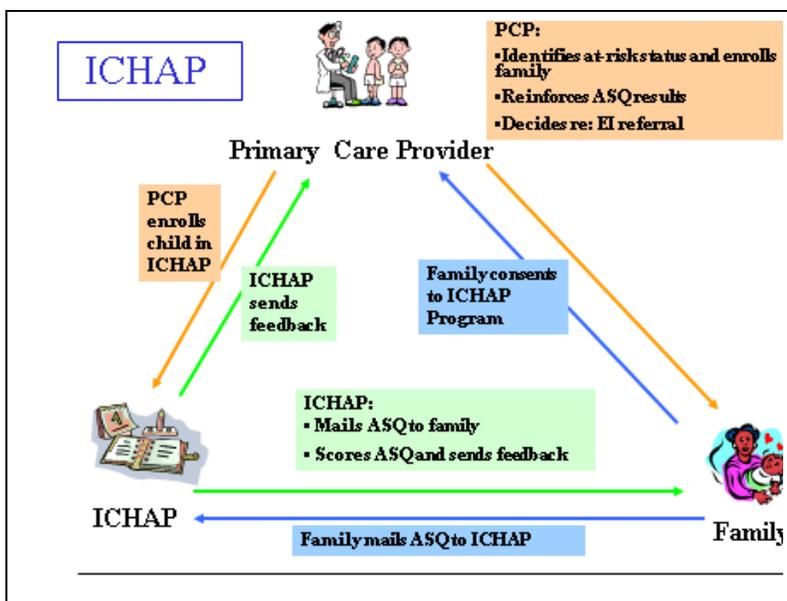
Within all these contexts, the issue of developmental screening and supporting the needs of young children and their families has risen as a top priority.

### **Models of Developmental Screening Outside of the Primary Health Care Practice:**

There have been successful partnerships to implement more ‘universal’ developmental screening and/or more streamlined referral processes in various settings in Washington State and nationally. Public health approaches have been shown to be effective at increasing rates of early detection. Increasingly, states have initiatives within early childhood services to improve screening and connection to services.

**New York:** New York City (NYC) initiated the Infant Child Health Assessment Program (ICHAP) in the early 1990's to screen children identified as 'at risk'. An at risk child is considered to be any child who was born prematurely, has been exposed to environmental lead, has a growth or metabolic disorder, history of maternal alcohol or substance abuse, suspected hearing or vision impairment, illness or trauma, congenital

infections, lack of prenatal or well baby care, parental developmental disabilities or mental illness, parenting concerns, family history of child abuse or neglect, homelessness or any concerns about the child's developmental skills.



Families were enrolled in the program by risk factors. The NYC program linked with the primary care office – the office signs the family up for the program, receives the results of the standardized screening and reinforces the need for follow-up referral for further evaluation or continued screening. "...the family sees the ASQ™ program as an integral component of their child's primary care." The program worked, in part, because of the *personal* parts of the program, including the primary care provider connection and consistent follow-up by a specific public health program staff person with whom the family is familiar.

The ICHAP program felt that the ASQ™ approach worked satisfactorily with families lacking a high school education, with concerns about literacy, and with children with multiple risk factors for delay. The program provided a much-needed safety net for at-risk children and alleviated part of the burden on the health care system to provide an ever-increasing number of services in an increasingly time-constrained health care visit. The program was well received by participating health care providers and significantly improved the provision of developmental surveillance and screening in the primary care setting in NYC.

The NYC ICHAP program is now Child Find of the NY State Early Intervention Program. The program provides monitoring to children who are 'at-risk' for developmental delay but who do not qualify for Early Intervention services. (See Appendix B) Nurses work with the family and their health care provider to monitor a child's skills by using developmental screenings as part of their regular health care follow-up through 2 years of age. They will also provide home visits, health education and referrals to other community agencies, as needed.

**Connecticut:** Connecticut has adopted a statewide, coordinated system of identification, triage, and referral for children at risk for developmental and behavioral problems. The system, called ‘Help Me Grow’, gives providers a single point of access to all developmental programs and services for children birth to age 5 years through a toll-free referral line called the Child Development Infoline.

Since July 2002, ‘Help Me Grow’ has offered families the option to sign up for the ‘Ages and Stages (ASQ™) Child Monitoring Program’ to screen the developmental progress of children four months to five years of age. Families learn about the ASQ™ from several sources: health care providers, the Birth to Three program and from Help Me Grow contacts.

Parents complete an enrollment/consent form. The consent form includes permission to send the ASQ™ results to the child’s health care provider (see Appendix C). Families receive the ASQ™ by mail at specified intervals. Once they complete the questionnaire and mail it back, the ‘Help Me Grow’ program scores it. If no developmental concerns are identified, an activity sheet that outlines the next stage of development and what to expect until the next questionnaire arrives is mailed to the parents. The provider can then document the findings in the child’s chart and this information can guide surveillance at subsequent office visits and well child encounters.

Community development liaisons also provide information and training for pediatricians and other health care providers on how to encourage parent use of the ASQ™ developmental screening. One tool for this is the Help Me Grow ‘Ages and Stages Child Development Kits’ for the 4-month well child visit which helps to promote efforts to provide universal developmental screening beginning at the earliest age possible. Using the starter kit, the 4-month ASQ™ is completed with the family at the well-child visit and entered into the Help Me Grow system. The family is then signed up for ongoing monitoring.<sup>59</sup>

The ‘Help Me Grow’ program has five components, the remaining four of which can be explored more in Appendix C.

- Child Health and Development Institute training module in Educating Practices in the Community (EPIC) – ensures primary care providers are trained in effective developmental surveillance and screening
- Child Development Infoline (CDI) - a specialized call center (through United Way 211) which serves as the ‘Help Me Grow’ access point and links young children and families to:
  - Existing services and supports
  - ASQ™ monitoring system
- Resource Inventory – information on community-based programs statewide which is maintained by United Way 211 Information Department

---

<sup>59</sup> Help Me Grow: 2008 Annual Evaluation Report. Hughes M, Damboise MC. Center for Social Research, University of Hartford. March 1, 2009. P. 6.

- Community Liaisons (from the Children’s Trust Fund) – serving as a link between local communities and the call center. Providing:
  - Information about local resources for the Resource Inventory
  - Support to providers by facilitating local networking opportunities
  - Help with local needs assessment
- Annual Outcome Evaluation – documenting who calls ‘Help Me Grow’ and the nature of those calls, the effectiveness of matching family needs with program services, and program effectiveness relative to annual goals and state criteria for results-based accountability.

### **Connecticut ‘Help Me Grow’ Replications:**

A number of communities nationally are working to transfer elements of what Connecticut has created and learned to their area. The communities’ approaches are each unique and at varying stages of implementation. The sites are:

- California – ‘Help Me Grow’ Orange County - one of the first replications, funded in part by Rob Reiner’s efforts
- Iowa – 1<sup>st</sup> Five initiative
- Oregon (Lane County) - Parent Help Line 211, Success by Six, Lane County EC Cares EI
- South Carolina – Promoting Resources in Developmental Education (PRIDE) program
- New York (Erie and Niagara Counties) – Community Health Foundation of Western and Central New York and Early Childhood Connections Program
- Kentucky (greater Louisville area) – MetroUnited Success by Six project
- Colorado - in planning phase (4/7/2010 personal communication)
- Utah (Utah County) – unofficial replication site

In December 2010, one of the next round of replication grants from ‘Help Me Grow’ was awarded to Washington State.

### **Rhode Island’s Pediatric Practice Enhancement Project (PPEP) – Care Coordination<sup>60</sup>**

PPEP is a Medical Home initiative of the Rhode Island Department of Health (RI DOH). PPEP places and supports specially trained parent consultants in pediatric primary and specialty care practices that serve large numbers of children with special health care needs and their families. Parent consultants are trained by the Rhode Island Parent Information Network. Parent consultants help physicians provide comprehensive medical homes by linking families with

---

<sup>60</sup> Engaging Parents as Partners to Support Early Child Health and Development. Ahsan N, Rosenthal J. NASHP State Health Briefing. May 2010. Accessible at <http://nashp.org/node/2039>.

community resources, helping providers and families get specialty services and identify systems barriers to coordinated care.

When a provider learns or suspects a child and family has needs beyond the medical scope of the practice, the family is referred to the parent consultant. The parent consultant talks with the family regarding the families concerns and develops a plan to address the needs. These needs may include resource identification, community referrals for social, developmental or mental health services, links with the educational system, eligibility or application assistance for health insurance, nutrition, housing services, and peer-to-peer support. Parent consultants call to confirm appointments are made and that the family knows what to expect when they arrive for the service. Parent consultants also educate practice staff about community and state programs and services.

Parent consultants complete project paperwork, which is entered into a data system developed and maintained by the RI DOH. Each PEPP site receives quarterly reports from the RI DOH, giving physicians and staff information as to how many of their families have been served, major issues and concerns, and whether problems were resolved.

### **Health Information Technology – Databases and Screening Tool Access:**

If a ‘universal’ approach to developmental screening is to be implemented, one issue is how to house the information obtained so that the various parties with a ‘Need to Know’ can access the information in a timely manner. Some states have worked to establish a database that can house similar information. In addition, there are increasing options from proprietary concerns associated with standardized developmental screening tools which include electronic database with online access. Access to screening tools can also be provided by mail, consumer hotlines and perhaps cell phones. Information on a couple of examples and options follows:

#### **KIDSNET (Rhode Island): [www.health.ri.gov/family/kidsnet](http://www.health.ri.gov/family/kidsnet)**

KIDSNET is designed to support families and providers with health and related services. While other states have linked child health data, few states use this data to promote service linkages. To facilitate care coordination, Rhode Island law permits qualified health care professionals to share health data without patient consent.<sup>61</sup> The data system is the property of the Rhode Island Department of Health. The information in the system is carefully protected and a number of confidentiality practices are in place.

---

<sup>61</sup> Improving Care Coordination, Case Management , and Linkages to Services for Young Children: Opportunities for States. Johnson K, Rosenthal J. National Academy for State Health Policy. April 2009.

Children are enrolled in two ways: 1) at the time of birth for children born in Rhode Island, and 2) for children born in another state, at the time they become patients of a healthcare provider or program participating in KIDSNET. Information about KIDSNET is sent to families upon enrollment in the program.

KIDSNET links health data from pediatric providers and 10 public health programs including newborn screening, immunization services, Part C Early Intervention, the Supplemental Nutrition Program for Women, Infants, and Children (WIC), home visiting and birth defect surveillance. It provides access to the linked health information to families, doctors, school nurses, health plans, Head Start, home visiting nurses agencies, WIC, Comprehensive Child Care Service Programs, school nurses, Lead Centers, and Early Intervention. KIDSNET data is available on a 'need to know' basis. (For a full list of KIDSNET authorized users, go to Appendix D).

KIDSNET provides the immunization schedule for each child in the system. A new public-facing site offers information for parents, providers, and other users, answers to frequently asked questions, confidentiality policies and program highlights. Each child's information is accessible to parents or legal guardians and participating primary care providers will produce printed copies of data for parents and guardians upon request. (For more information see Appendix E under Model Programs)

### **FamilyNet (Oregon):**

FamilyNet is a health data system under development by the Oregon Department of Human Services (DHS) to integrate public health programs and coordinate services for children and families on the local agency level. FamilyNet will help public and private providers screen, assess, and coordinate services to children and families; monitor risks, conditions, services, and outcomes over time; and feed a state-level data warehouse for epidemiology, program evaluation, decision support, and research. This system will support coordination of services and evaluation of the service delivery system while ensuring individual and family confidentiality and data security.

The Client Master module contains demographics and contact information (addresses, family links, telephone numbers, guardian's name) and links the other modules to each other. A module for the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and the Immunization Record Information System (IRIS) for public-sector immunizations has been in use throughout Oregon since 2003.

Current development includes enhancing the WIC module, providing IRIS immunization status for WIC clients directly from IRIS, and completing a project to exchange data between the Oregon Immunization ALERT Registry and IRIS. Most immunizations in Oregon are given in

the private sector. Linking ALERT data with other FamilyNet data would give public and private health-care providers a complete picture of the immunization status of their patients.

FamilyNet goals include:

- Avoiding redundant data entry by collecting data shared among programs only once.
- Providing timely access to data for state and local health departments and their close partners.
- Increasing accountability for state and federal program conditions, including program and fiscal assurances.
- Reducing fragmentation of data and health care services available to the public by providing a method to coordinate services among health and social service programs.

### **Standardized Developmental Screening Tools:**

The AAP and others (e.g. Oregon, North Carolina, Illinois and a number of other states) have a list of recommended developmental screening tools. In a preponderance of state AAP chapters and other organizations deciding on screening tools, the ASQ™ screener has been the screening tool of choice for general developmental screening. Many sites are also using the PEDS™. A number of states recommend screening tools for other conditions, such as autism and maternal depression.

### **Electronic Access for Screening:**

At this time there is online access for the Parents Evaluation of Developmental Status (PEDS™), PEDS-Developmental Milestones (PEDS-DM™), the ASQ™ and ASQ -SE™, some of the most commonly used standardized developmental screening tests.

### **PEDS™ -**

Professional use of PEDS™ Online requires a license. All licenses are assigned with a unique username and password and allow the professional user to administer PEDS™ online for a specific number of times. PEDS™/PEDS:DM™ items, apart from scanning completed forms, may not be included in electronic records, except under a completed and signed license agreement involving research protocols, and/or and electronic interface with the PEDS Online site. It is illegal to independently create electronic scoring algorithms for PEDS™ and the PEDS:DM™.

Options for completing the PEDS™ Response Form include having parents go online and use the *Patient Portal* (see below) to type in their concerns or using paper-pencil administration. Parents can complete the PEDS™ screen at home prior to an appointment, via computer kiosks in the waiting/exam rooms, or by having a staff person administer PEDS™ by interview while typing in parents' comments. When using paper-pencil administration, scannable Acrobat files in multiple languages are available, although staff need to type in parents' comments (in English only). Results can be routed to the provider ready for the child's visit.

The *Patient Portal* can be accessed either by a direct link on a provider's website or providing parents the direct URL to the portal. Either way, parents will need a licensed subscribing provider's login and password information. The advantage of posting the link on a provider's website is that the login will be pre-populated and the family will need only a password. Upon completing the test the parent is directed to contact their provider for review of the results. Parents are not shown the scored results. Notification of a completed developmental screen is sent by e-mail to the subscriber indicating that a screen has been submitted for '*Patient\_Name*'. Different logon information is required to open the subscriber's *administration page* to access the results.

[PEDS Online](#) provides automated scoring, generates a summary report for families, and produces referral letters, as needed, for sharing with other providers. The site can optionally be used with an electronic record system. Outputs can be customized including resource links, letterhead, and summary/referral letter content. PEDS™ Online also provides an interactive version of the Modified Checklist of Autism in Toddlers (MCHAT). PEDS:DM™ is expected to be online soon (in Spanish and English).

In addition, anyone can complete a PEDS™ screen on line at [www.forepath.org](http://www.forepath.org) for a payment of \$9.95. This price includes the MCHAT autism screener for children between 18 months and 4 years of age.

## ASQ™

Brookes Publishing has electronic versions of the ASQ™ -3 and ASQ™ -SE available through *ASQ™ Family Access*. *ASQ™ Family Access* allows a program to set up a secure website where parents can complete questionnaires. The website can be customized for an individual program. Parents can complete the online questionnaire anytime, anywhere. This eliminates mailing costs and parents losing/forgetting to bring forms back. Questionnaire selection is automated, including correction for prematurity. They are automatically scored and entered into the system and appear at the site-user with the next login. It also records and saves comments written on the questionnaires. The questionnaires can also be completed on paper at home; during home visits by nurses, social workers, or program staff; in waiting areas; or in educational

centers. ASQ™ -3 can be adapted to a variety of settings, including primary care clinics, child care settings, and teen parenting programs.

Subscription to ASQ™ *Family Access* must be accompanied by subscription to an online data management system, either ASQ™ *Enterprise* (for multiple sites, ‘as many as you need’) or ASQ™ *Pro* (for single sites). For multisite programs, the site administrator would register and then others at the site can access it by individual logins. These systems allow one to organize a screening and monitoring program, as well as create and manage child and program records. The system tracks screening results, management decisions and timing for next screening. Results can be analyzed by program and by child. Ages and Stages Learning Activities, activities to encourage a child’s developmental progress, are included. These systems also are able to generate parent results letters. There is capacity to upload your own templates – e.g. a consent form.

ASQ *Hub*™ is an administrative subscription that links ASQ *Enterprise*™ and ASQ *Pro*™ accounts. This system allows the overarching organization to manage the screening program. There are one time linking fees for each account and an annual subscription fee for each of these online tools – *Family Access*, *Enterprise*, *Pro* and *Hub*. In addition, there is a sliding scale per screen fee which starts at \$0.50/screen if < 5,000 and falls to \$0.25/screen for over 100,000 screens.

More information on the ASQ™ online options is available at <http://agesandstages.com> and <http://agesandstages.com/videtour.html>

### **CHADIS – The Child Health and Development Interactive System**

CHADIS is a web-based screening, diagnostic and management system that administers and scores online questionnaires available from Total Child Health, Incorporated (TCH). A for-profit Limited Liability corporation, TCH incorporated for the specific purpose of promoting the usage of CHADIS in Pediatric care and licensing the use of CHADIS.

CHADIS includes standardized screening tools across a broad age range and diagnostic concerns. In the birth to three age range, CHADIS supports the ASQ™, the Infant Development Inventory, Modified Checklist for Autism in Toddlers (M-CHAT), PEDS™ with interface in both English and Spanish for many of these questionnaires. In addition, the Edinburgh Postnatal Depression Scale, Adverse Childhood Experiences (ACE), and a number of other screeners are included (see Appendix F).

Anticipatory guidance materials and information chosen based on diagnosis and questionnaire results are included, adjusted for 5<sup>th</sup> to 8<sup>th</sup> grade reading level. The system supports some communication links, with parental permission, to teachers and other professionals.

CHADIS is sold in a core package that includes all the CHADIS questionnaires, an electronic textbook (22 chapters on mental health, health risk and developmental issues), and an electronic resource database of handouts and community resource lists. Pricing in January 2010 was on a sliding scale with a minimum of \$695 per physician for groups of more than 8 physicians.

### **Cell Phone Technology:**

Increasingly cell phone technology is accessible to families of all cultures and being utilized to send and receive information. Mobile technologies present an interesting opportunity to provide probes on child developmental progress because they are interactive, are often with the user when they are away from home and provide many capabilities for presenting data. Mobile phone technology can help parents from diverse backgrounds to record, review, and share their child's developmental milestones. The heaviest usage of mobile phones is among the African-American and Hispanic populations and, in particular, among Generation Y, the generation currently having young children.<sup>62</sup> Thus, mobile phones are an ideal solution for reaching young parents, especially from ethnically diverse and often underserved populations.

Because families from underserved populations may not be able to afford expensive data plans or the latest mobile technology devices, there is a need to have the application function on a mobile using the most basic data plans available, including pre-paid service. For families with data plans on their mobile phones, their data network could be used to transmit information. Other methods (e.g. simple telephony using recorded and played back messages or Simple Messaging Service (SMS) protocol) can be used by families without a data network service.

A variation of this was introduced in late 2009 as an educational program of the National Healthy Mothers, Healthy Babies Coalition (HMHB). Text4baby is a free mobile information service designed to promote healthy birth outcomes among underserved populations. Text4baby provides pregnant women with information they need to give their babies the best possible start in life. Women sign up for the service by texting BABY to 511411 (or BEBE for Spanish). They then receive free SMS text messages each week, timed to their due date or baby's date of birth. The messages focus on a variety of topics critical to maternal and child health: birth defects prevention, immunization, nutrition, seasonal flu, mental health, oral health, and safe sleep among others. Text4baby messages also connect women to early prenatal care as well as a variety of existing resources available to them.<sup>63</sup>

---

<sup>62</sup> Cell phone usage highest among African-American and Hispanic consumers according to Telephia; Generation Y use their mobile devices more than any other age group. Telephia Customer Value Metrics. 2005. (Now Nielsen Mobile, Inc) [http://www.videoaccessalliance.org/resources/docs/telephia\\_release.pdf](http://www.videoaccessalliance.org/resources/docs/telephia_release.pdf)

<sup>63</sup> Text4baby Executive Summary. [http://pathoftheblueeye.com/multimedia/community\\_resources/Text\\_4\\_Baby\\_exec\\_summary.pdf](http://pathoftheblueeye.com/multimedia/community_resources/Text_4_Baby_exec_summary.pdf) (accessed 4/15/2010).

## **Washington State Assets: A partial list!**

### **Cell Phone Technology:**

Researchers at the University of Washington are trying to identify ways that mobile and social computing technology can help parents to record, review, share and track their child's developmental milestones. They are working to explore and understand the tensions and opportunities for technology to support the health of young children while involving parents and professionals across diverse and underserved populations. Their research seeks ways to build feasible and effective technologies that motivate and encourage record-keeping for parents.

### **Washington State Database Examples:**

#### **Newborn Screening:**

**Metabolic Disorders** - Newborn metabolic screening in Washington State involves population-based screening of all newborns carefully coordinated with providers of birthing, primary and specialty care services. The metabolic screen targets preventable or treatable diseases that, if undetected, would result in catastrophic outcomes. The screening also identifies 1) mild forms of some disorders that still require treatment or close monitoring, and 2) some disorders (e.g. hemoglobinopathies) that have important implications for future reproductive options for infants and their parents. Currently, the Washington State Newborn Screening program screens for 24 disorders.

In 2007, there were almost 86,000 births in Washington state and an additional 3,000<sup>+</sup> births at military facilities in the state. Data on infants born at Madigan Army Medical Center, Oak Harbor Naval Hospital and Bremerton Naval Hospital is not in the system, as these military hospitals do not participate in Washington State's Newborn Screening Program.

The Newborn Screening Program is a self-supporting program. Operational costs for the metabolic screening program are covered through a fee charged for each infant through the hospital of birth. In 2007, this charge was \$60.90 for each child (not per specimen) which is typically covered by insurance and other third party payers.<sup>64</sup> Diagnostic testing involves additional costs. Significant savings are realized by avoiding costs of lifetime treatment for disabling metabolic conditions. An additional \$3.50 per birth is collected to support specialty clinic care for infants diagnosed through newborn screening (e.g. PKU Clinic).

The program is a collaboration between the Washington State Newborn Screening Program, health care facilities (hospitals, local health departments, clinics), health care providers (pediatricians, family practice physicians, nurse practitioners, midwives), and families of

---

<sup>64</sup> Annual Report. Newborn Screening 2007, with preliminary data for 2008. Washington State DOH, Epidemiology, Health Statistics and Public Health Laboratories. October 2009. Available at <http://www.doh.wa.gov/ehsphi/phl/newborn/pubs/BOHRReport.pdf>

newborns. Privacy policies for the Newborn Screening Program are available at <http://www.doh.wa.gov/ehspl/phl/newborn/privacy.htm> .

**Newborn Hearing Screening:** In 2000, the WA DOH, in cooperation with the Centers for Disease Control and Prevention (CDC), initiated efforts to develop a statewide Early Hearing Loss Detection, Diagnosis and Intervention (EHDDI) Program, including a tracking and surveillance system. In 2002 the tracking system was initiated at 5 pilot hospitals. A tracking and surveillance system was **linked to the metabolic screening system**. The system follows infants from hearing screening through diagnostic evaluation. The tracking and surveillance system helps to ensure that all babies are screened for hearing loss prior to one month of age, those that are referred receive diagnostic audiological evaluation by 3 months of age, and those that are diagnosed with hearing loss receive early intervention by 6 months of age. In addition, infants with any one of four risk factors for late-onset or progressive hearing loss are tracked.

The EHDDI program follows all infants born at non-military birthing hospitals in Washington to ensure they are screened for hearing loss and receive further testing if needed. Hospitals and clinics send the EHDDI program newborn hearing screening results on revised Newborn Screening cards. The WA DOH sends hospitals monthly reports with screening statistics. Some hospitals find these reports to be sufficient for data management purposes. Each hospital, regardless of size, is encouraged to keep its own record of hearing screenings, be it a log sheet, book, or electronic record, to manage daily screening needs. If an infant is referred to an audiologist for a diagnostic evaluation, the EHDDI program requests that the audiology clinic report risk factor information, diagnostic results, and if the infant was referred to early intervention services. Most diagnostic information from audiology clinics is submitted through a secure web application. Some clinics fax results to the EHDDI program.

Of note, only 72% of infants who do not pass their hearing screens receive the recommended audiologic evaluations. An Attorney General's opinion states that DOH does not have the authority to contact parents regarding their babies' newborn hearing screening results and recommended follow-up since hearing screening is voluntary. This places the responsibility of notification and follow-up on health care providers. Further work is needed to identify ways to ensure that at-risk infants receive audiologic evaluations and that the diagnostic outcomes are reported to DOH.

The DOH EHDDI program and the follow-up services were predominately funded (until August 2008) by federal grants from the Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC). Additional funding was from general state funds. Maintaining the program requires identifying ongoing funding to support the program. (Not sure of the current funding status.)

### **CHILD Profile Immunization Registry:**

The CHILD Profile Registry is linked with the public portion of birth certificates through Washington State's Center for Health Statistics. The Washington State Birth Certificate System has information about each baby born in Washington State. Similar information is collected for mothers who live in Washington but have a baby in another state or country. Thus, the Birth Certificate System contains records on all births occurring in the state and nearly all births to residents of the state.

The CHILD Profile Immunization Registry is a tool for a child's health care provider to access patient immunization information in a shared, secure database. Health plans and local public health jurisdictions can get population-based immunization information to help with reporting. Schools, Head Start and ECEAP Programs can also apply for registry access. To help providers manage their immunization services, the Registry includes:

- Immunization histories
- Recommendations and forecasts of immunizations needed
- Recall/Reminder lists, mailing labels or postcards for patients who are due or who have missed immunizations
- Vaccine usage reports
- Data for practice-specific immunization assessment reports
- Tracking of children eligible for state-supplied vaccine

If a child changes health care providers, the new provider may access the CHILD Profile Immunization Registry to review the child's record. This ensures that the child's health information continues to be updated in one central location.

Access is available to providers who sign an information sharing agreement that assures confidentiality, privacy, and security of the Registry. Authorized users can:

- Add and edit patient records.
- Review vaccination records, adding or editing current and historical immunizations.
- Maintain facility-specific records on vaccinators, physicians, and lot numbers.
- Record required information for each VIS (Vaccine Information Statement)<sup>65</sup> given.
- Access the tools to support a reminder/recall system.
- Create CoCASA (Comprehensive Clinic Assessment Software Application) reports.

---

<sup>65</sup> **Vaccine Information Statements** (VISs) are information sheets produced by the Centers for Disease Control and Prevention (CDC) that explain to vaccine recipients, their parents, or their legal representatives both the benefits and risks of a vaccine. Federal law requires that VISs be handed out whenever (before each dose) certain vaccinations are given.

## **Department of Education Grant - Longitudinal Education Data System: An Opportunity?**

On May 21, 2010, it was announced that Washington State has been awarded a \$17.3 million grant to help design and build a statewide longitudinal education data system. The Office of Financial Management's Education Research and Data Center will lead this effort. Washington State will be able to "follow" students from pre-kindergarten through college to adult employment to know how they are doing and what can be done to better support them throughout their educational experience. The three-year grant will combine the K-12 data system, managed by the Office of Superintendent of Public Instruction, with pre-kindergarten data, post-secondary data and workforce data to create a comprehensive, unified and efficient P-20 data system. DEL will receive \$3.3 million over three years to help design and build a data system that will align DEL data across programs (licensing, ECEAP, professional development, QRIS, subsidies, etc.) rather than the current storage in various systems.

The Office of the Superintendent of Instruction (OSPI) will serve as the fiscal agent for the grant and the Education Research and Data Center (ERDC) will manage the execution of the grant activities in collaboration with OSPI, the Legislative Evaluation and Accountability Program and other partner agencies. This unique arrangement highlights the close collaboration of agencies across state government dedicated to improving the state's education system. The ERDC was created by the 2007 Washington state Legislature. Its purpose is, in part, to "[conduct] analyses of early learning, K-12, and higher education programs and education issues across the P-20 system." The ERDC is located in the Office of Financial Management (OFM), the Governor's Budget Office.

## **Health Information Outreach and Resource Connection for Parents:**

### **WithinReach and Parent Help 123.org**

WithinReach works to ensure optimal health for all families in Washington by connecting them to programs, resources and information they need to build healthy families. The program is committed to serving all Washington State families and removing barriers of language, socio-economics, and access. WithinReach conducts outreach to families, service providers, community centers, and employers to reach families. Families can call, go on-line, or meet with outreach staff in their communities. WithinReach has a long-standing public-private partnership with the Washington State Department of Health and the Department of Social and Health Services.

WithinReach helps over 200,000 Washington State families per year. The program offers a simple, family-centered path to help through the phone (WithinReach toll-free hotlines) or on the web (ParentHelp123.org). Highly trained specialists can help families access services in any language using interpreter services. Bi-lingual specialists are available to help Spanish-speaking

families. Both programs help Washington State families apply for health and food programs and locate resources in their local communities. The website has health information for pregnant women, parents of new babies, and families with children.

The executive director of WithinReach indicates technology can be used to send alerts to local physicians and program coordinators when follow-up needs to happen. This innovation has been developed by WithinReach for the Assuring Better Childhood Dentistry (ABCD) Program in partnership with the Washington Dental Service Foundation.<sup>66</sup>

### **CHILD Profile Health Information mailings**

CHILD Profile, sponsored by the Washington State Department of Health is Washington's Health Promotion system, designed to help ensure all children get the preventive care they need. The Health Promotion system consists of materials sent at age-specific intervals to 86% of all parents of children from birth to age six who live in Washington State. These materials contain comprehensive health information about parenting, child health, early learning and safety, with the goal of helping parents make informed decisions about their children's health, development and safety. All materials are translated into Spanish. Information is included in these mailings indicating how to get assistance when concerns about a child's development are present.

As mentioned above, a 2003 pilot project in Snohomish County utilized the CHILD Profile Health Information Mailings to provide options for an 18-month ASQ™ screening by either direct mailing or return postcard request. The results of that pilot were very promising in increasing identification of children eligible for early intervention as well as other needs. Issues raised by parents in the open-ended questions on the ASQ™ primarily dealt with childhood eating patterns, nutrition, age-appropriate behaviors and discipline. Staff created a file of materials on these topics and mailed information to the concerned families. In addition, telephone contact to discuss concerns was made with most of these families.

### **Parent Support and Advocacy Groups such as Parent to Parent, Father's Network, Opening Doors for Multicultural Families, Autism Resource Center**

We are fortunate to have a number of advocacy, resource and support groups throughout the state with active and informed parents. Many of these parents and organizations have worked on the issues of developmental screening and care coordination. Many have also been involved in advisory councils and systems work. Some have participated in creating grants to expand services for children, e.g. care coordination. There is great potential for collaborative efforts with parent partners in a universal developmental screening system.

---

<sup>66</sup> Personal Communication. Patty Hayes, RN, MN, Executive Director, WithinReach. 5.24.2010.

### Where to go from here – A Draft Vision to respond to:

We are currently at a unique juncture to support efforts to achieve universal access to screening for young children and their families in Washington State. Private and public health partners are interested in working toward policies and programs that help assure children receive appropriate screening, assessment and services. Partners include the Washington Chapter of the AAP, Washington State Department of Health, Department of Early Learning, Thrive by Five, Washington State’s IDEA Part C Program, WithinReach, Early Childhood Comprehensive Systems, and many others (see pages 59-60). Recent advances in health information technology (HIT) and availability of electronic screening tools and data systems support make this effort quite feasible.

### Components:

We need a strategic statewide effort to facilitate collaboration and reduce duplication across sectors resulting in a system of screening that is accessible to all children in Washington State and links with a spectrum of services for families and young children. This will require a system with:

- Universal reach to parents of our youngest children,
- A means to administer, score and track screens,
- A means to provide results to providers and to families,
- Community awareness of and connection to a spectrum of information and services as dictated by screening results, and
- A means of care coordination to link children to a continuum of health services and other needed community services and track resulting referrals.

This system should build on the framework outlined in work done in Connecticut by Dr. Paul Dworkin and others which connects to services by level of need:

- *Universal Services* – for all children and families to support optimal development and early identification of concerns
- *Selected Services* – including developmental, medical and mental health services which are available to all children, but likely to be accessed by some
- *Indicated Services* – services provided to those children with identified difficulties meeting eligibility guidelines, such as IDEA Part C intervention<sup>67</sup>

---

<sup>67</sup> A Framework for Child Health Services: Supporting the Healthy Development and School Readiness of Connecticut’s Children. Dworkin P, Honigfeld L, Meyers J. Child Health and Development Institute of Connecticut, Farmington, CT (<http://www.chdi.org/admin/uploads/1238295334a292abb7c7aa.pdf>), March 2009.

This aligns well with the concepts in the Washington State Early Learning Plan from the Department of Early Learning – strategies that benefit ‘all, some and few’.

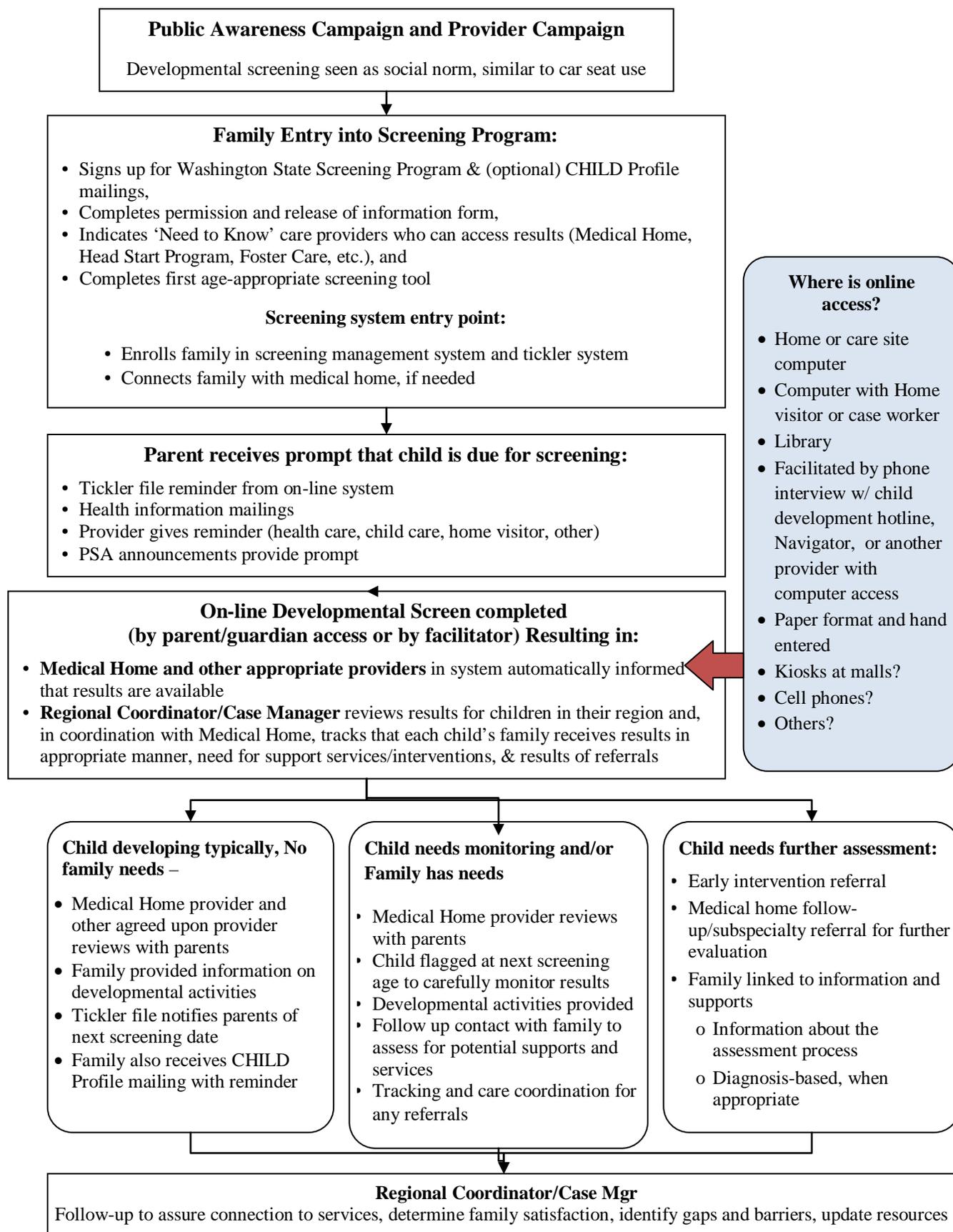
The system we build in Washington State will be unique to the population, geography, policies, infrastructure, funding and partnerships in our state. It should capitalize on knowledge obtained from all partners, attend to the diversity of our state’s population, and integrate current efforts such as those supported by the CATCH Grant in Yakima, Department of Health Project LAUNCH grant and Autism grant.

What follows is a first draft of a vision of how to create a system in Washington State for ‘universal’ screening and linkage to appropriate services across the spectrum of need, in concert with the Early Learning Plan’s focus strategies for ‘all, some and few’.

The diagram that follows outlines the basic elements and flow of events envisioned for a screening system in Washington State. The next diagram proposes one view of where we might house and how we might accomplish these system elements. These two diagrams are followed by further discussion of each of the steps. Then there is information on a number of special issues to attend to, such as meeting the priority of earlier identification (targeting the first 12 months of life) of children in need of early intervention services and multicultural issues. This is followed by suggested workgroups to address some of the important issues and decisions needed to take this vision to reality.

It is the hope that through the cooperative efforts of the Developmental Screening Partnership Group, topical workgroups and other contributors, we can review, respond to and refine this vision into a workable system and create a roadmap to accomplish this vision in the next five years. As you read the following information, please reflect on the overall vision, where else these elements might be housed, what else might be used to accomplish this vision, and what is missing – i.e. is each goal appropriate and how would *you* operationalize such a system?

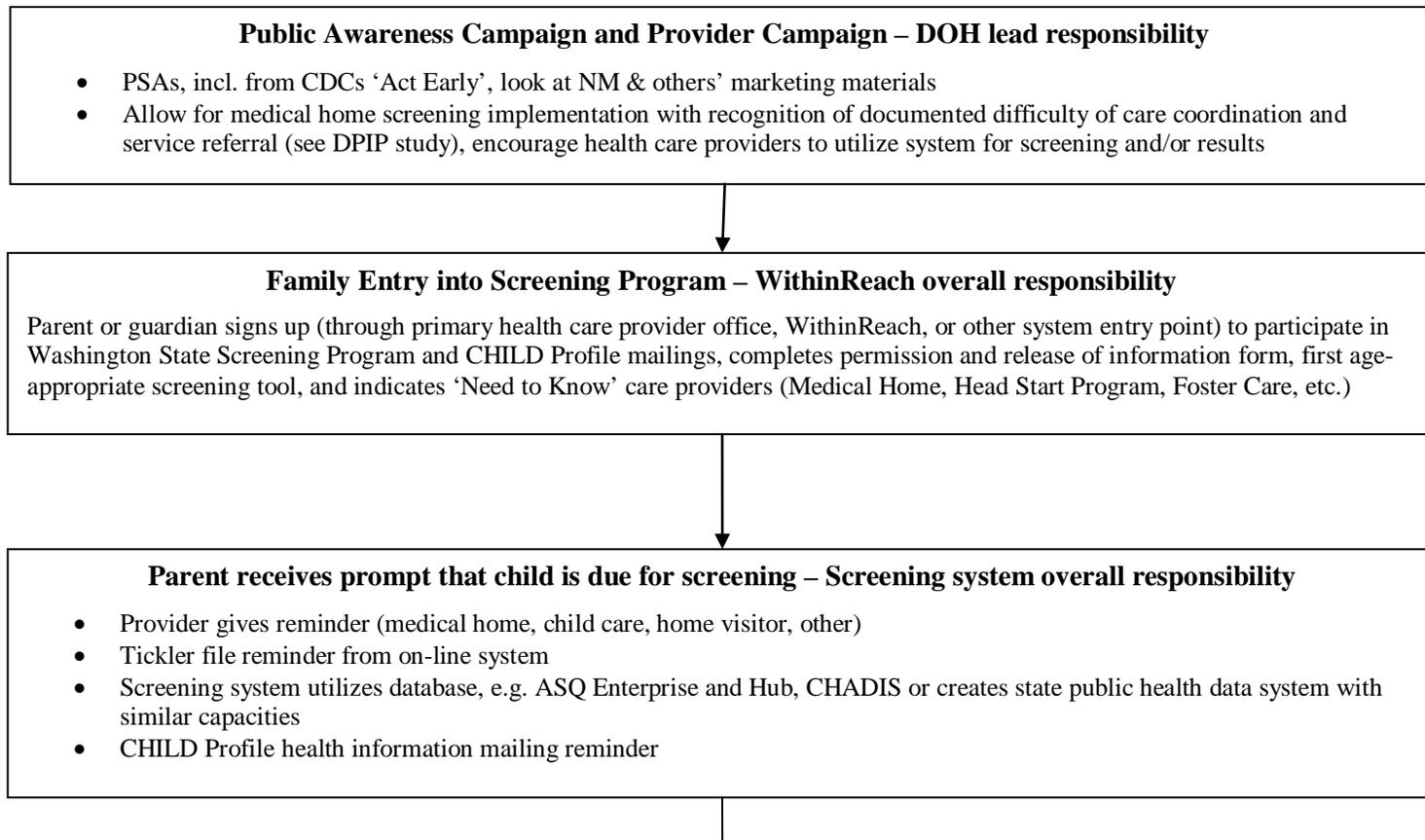
## Components for Universal Developmental Screening for Children 0-3 Years in Washington State

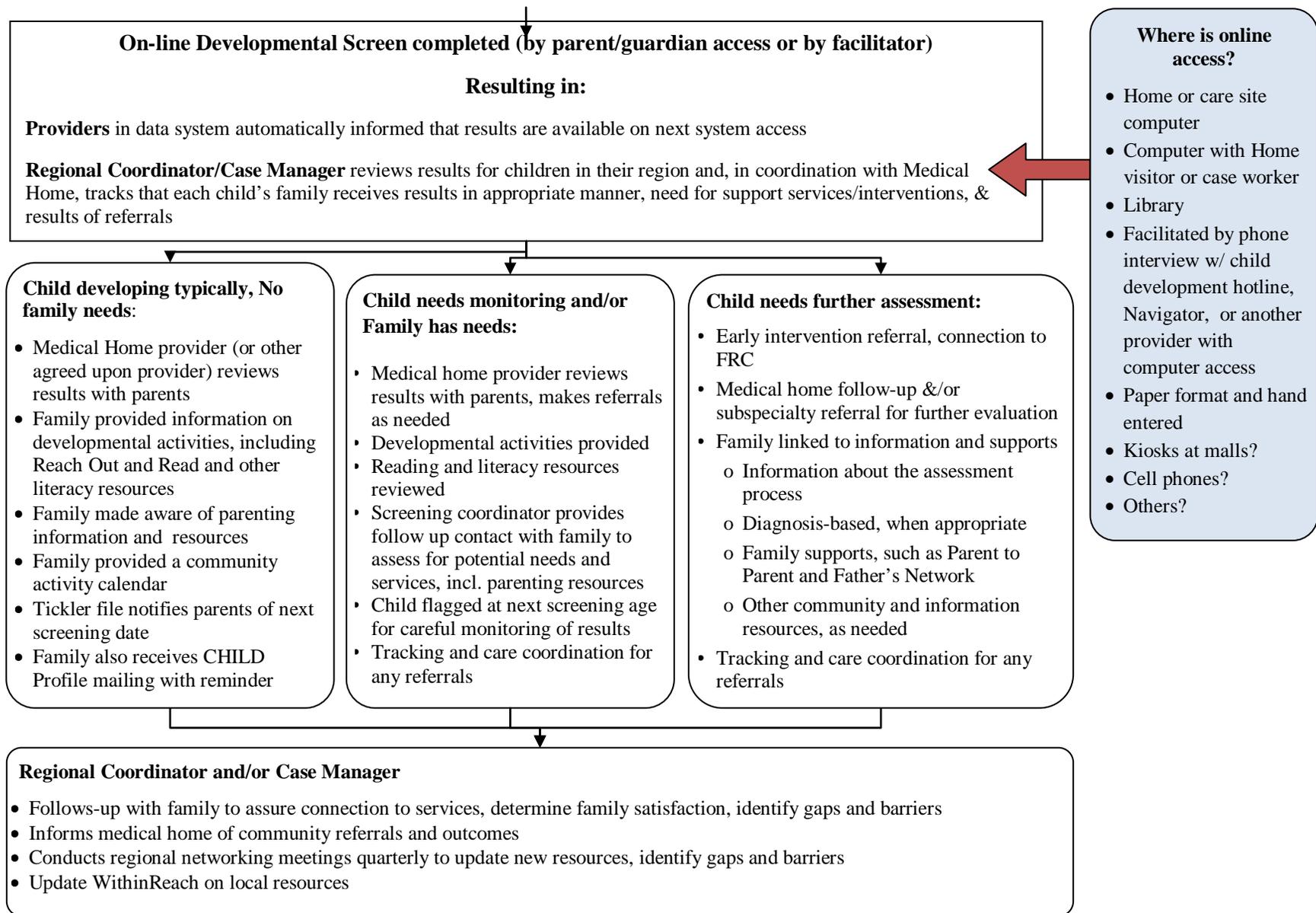


**Universal Developmental Screening for Children 0-3 Years in Washington State –  
A Draft System**

**Oversight:**

- **State Level - Washington State Department of Health**
- **Hotline Resource for System Entry – WithinReach**
- **Community Level – Screening Personnel in ?LHJ or ?As determined by LICC or DOH e.g. Neurodevelopmental Center [Program and Care Coordinator(s)]**





## **Universal reach to parents of our youngest children:**

With outreach and marketing efforts, parents and community members will expect all Washington State children to be screened for developmental progress at selected ages and at other ages when there are concerns. Parents will know of the availability of developmental screening in Washington State. There will be ‘no wrong door’ as anyone who interacts with young children will know how to advise parents to link to developmental screening.

Service providers (primary health care/medical home, early childhood providers) will emphasize the importance of developmental screening and connect parents to standardized developmental screening. Parents without health insurance and/or a primary health care provider will be linked to insurance information and to a medical home that can advise parents of results of screening, monitor developmental progress and refer when needed, as well as provide ongoing health care.

Steps to achieve universal reach to parents:

1. Determine where to house the screening system– oversight agency, local liaisons
2. Create a screening system to provide standardized developmental screens to children
  - a. Identify standardized screening tool(s) and requirements for use in the system and schedule of use. Look at the needs of various providers and programs (see also information in Other Considerations (page 55):
    - i. Review general developmental screening and autism screening recommendations from the AAP (9, 18 and 24/30 mo with several tools recommended; 18 and 24 mo with MCHAT respectively)
    - ii. Should there be an ‘at risk’ category for enhanced screening, e.g. for premature infants, ongoing screening of children in foster care
    - iii. Early Head Start/Head Start requirements– e.g. 2 mo for infant of mother followed through pregnancy
    - iv. Foster care needs screening within 30 days of out-of-home placement
    - v. LAUNCH efforts looking at social-emotional screening
    - vi. ESIT program would like to increase identification in 0-12 month age group
    - vii. Autism State Implementation Grant prioritizes early identification of autism and entry into services - some states are using the ASQ™ -SE for autism screening
    - viii. Monitor research on ASQ™-3 for utility as autism and social-emotional screener
  - b. Create (or subscribe to) a database and address privacy issues
    - i. Examine database components and options, including costs – e.g. build a public health database, expand on the CHILD Profile Immunization registry, utilize ASQ™ and Brookes Publishing Company’s database subscriptions, CHADIS system
    - ii. Address privacy, password protections and section protections

- c. Determine and establish enrollment and permission granting requirements and process
  - d. Determine and establish access point to screening for families
    - i. Address connecting with hard-to-reach families: undocumented status, literacy issues, cultural and language issues, other
    - ii. Establish need to/how to document legitimacy of an individual accessing screening for their child (has anyone tried to ‘scam’ a screening program?)
    - iii. Provide for multiple methods to complete standardized screening tool – on line, interview, hard copies, cell phone, other; examples:
      - 1. *ASQ™ Family Access* or CHADIS for on line questionnaire completion web-based from any computer
      - 2. *WithinReach* telephone line – could fill out for family by telephone interview, especially for those with interpreter needs, literacy issues
      - 3. Public health nurses, home visitors, navigators, cultural brokers and others – could use on line access or paper form with later data entry
      - 4. ?Kiosks at mall ?other
  - e. Determine and establish a method for recording, scoring and tracking screening results and referrals
  - f. Determine tickler system for ‘next needed screen and screening date’ for each child participant
3. Determine staffing needs for the entire system (training, technical assistance, screening, referral, care coordination, community resource liaison and tracking) and hire staff
  4. Create an outreach/marketing campaign to parents, providers and the community
  5. Provide ongoing technical assistance to providers to assure implementation and maintenance of developmental screening, and linking with the statewide system

**A means to provide results to providers and families (Essential link to the Medical Home):**

1. Determine and establish linkage to results and tracking by providers on a ‘need-to-know’ basis
  - a. Address privacy, password protections and section protections
  - b. Providers in different settings (health care, child care, early intervention, etc.) will trust the results of the standardized screening tool and have access to the results, as appropriate
2. Results will be provided to the family (review Help Me Grow and other models)
  - a. Determine how to provide results to the family
    - i. Primary - From the medical home
    - ii. Other:
      1. From the referring program
      2. Through a local coordinator or case manager

- b. Work with primary health care providers, families and other partners to evaluate the feedback methods and continue to adjust as necessary
- c. Address the concerns that screening (if not accessed at the medical home well child visit) not be viewed as a substitute for a well child visit, as has occurred in some community Child Find efforts

**Community awareness of and connection to a spectrum of information and services as dictated by screening results:**

1. Providers will know and take the next steps indicated depending on screening results (see flow diagram on page 43).
2. Determine need for services
  - a. Families and the general community will know about the parent resource telephone line as a resource for information and services
  - b. Parents will have opportunity to discuss and indicate child and family information and/or service needs when receiving screening results
  - c. Health care providers will pursue or refer for indicated medical evaluations based on screening results
  - d. All providers will be aware of the screening system role in linking children and their families to needed information and community services and either provide families with contact information to the resource line or assist in making the connection
  - e. Screening system local care coordinator will monitor screening results and, with the medical home, track disposition of children whose screens indicate concerns or need for further monitoring
3. The child and family will be referred to services as indicated and the care coordinator will follow-up on service connection

**A means of care coordination and linkage to a continuum of health services and other needed community services and track resulting referrals (Essential link to Medical Home)**

Care coordination within the medical home and between early childhood providers and the community cannot be overemphasized. The D-PIP (Developmental Surveillance and Screening Policy Implementation Project (see page 22) project documented that a system for referral and connection to community resources is a need for primary health care providers in diverse settings<sup>68</sup>. The challenges of care coordination for children at risk of developmental delay have

---

<sup>68</sup> Implementing developmental screening and referrals: Lessons learned from a national project. King TM, Tandon SD, et al. *Pediatrics*. 2010; 125:350-360.

been further outlined by the work of the National Committee on Quality Assurance (NCQA).<sup>69</sup> Statewide parenting and resource lines have proven to be efficient in identifying needs and triaging to appropriate services. They are an effective single point of access to community resources.<sup>70</sup>

Steps to take:

1. Local care coordinators will be part of the screening system and will support families and health care providers in accessing needed health care services, community programs and services.
2. Care coordinators will follow-up on referrals to ensure connection, satisfaction, and to identify gaps and barriers in service provision. (see Appendix G)
3. Care coordinators will conduct local outreach/communication to connect early childhood personnel and update local resources and pass information to the state level for updating on websites and the statewide resource line databank.

Recommended reading –

**Help Me Grow, [How to Develop a Statewide System to Link Families with Community](#)**

**[Resources: A Manual Based on Connecticut's "Help Me Grow" Initiative.](#)**  
by Paul Dworkin, M.D.



**Iowa's 1<sup>st</sup> Five Program**

- Executive Summary:

<http://www.state.ia.us/earlychildhood/docs/1stFiveReport2008.pdf>

- Full report:

[http://www.commonwealthfund.org/us\\_reports/Silow-Carroll\\_1stFiveinitiative\\_1176\\_ib.pdf?section=4039](http://www.commonwealthfund.org/us_reports/Silow-Carroll_1stFiveinitiative_1176_ib.pdf?section=4039)

<sup>69</sup> Measuring Care Coordination for Children at Risk of Developmental Delay: Challenges and Opportunities. French JB, Scholle SH. NCQA. November 2010.

<sup>70</sup> How to develop a statewide system to link families with community resources: A manual based on Connecticut's 'Help Me Grow' Initiative. Dworkin P, Bogin J et al. The Commonwealth Fund. 2006.

## Potential Workgroups:

### 1. Screening System -

Suggested tasks: Determine detailed outline of system. A data system/registry will be addressed by a separate workgroup. However, a decision on what standardized screening tool(s) to use will impact the data system/registry options and should be communicated to that workgroup at the earliest possible time. Outreach/marketing to community, families and providers will also be addressed by another workgroup.

Use of a standardized developmental screening tool has been generally assumed as part of implementation. However, initially a look at the Iowa use of a Red Flags approach for ages other than AAP recommended screening ages would be of interest.

The workgroup will need to identify where the system will be housed and an oversight agency. (See Appendix H) What will be done locally and what at the state level? How will it be staffed? This information should be provided to the fiscal workgroup.

Some additional issues to address: family identifiers for enrollment and access to the screening, permission and release of information, how to provide results to families, who are ‘need-to-know’ providers who can access screening results in the database/registry, what are the essential links to and needs of the medical home that the system must address.

Consider if there is a need for legal review – especially privacy and consent issues.

### 2. Reaching All Populations

Who are our populations in the state which might need extra effort to reach with screenings? Where are they? Help Me Grow identifies the following as ‘hard to reach’:

- Difficult or unable to contact by phone;
- Have multiple/complex needs;
- Have unpredictable living circumstances;
- Experience difficulty “navigating” service system due to a language or cultural barrier;
- Experience difficulty navigating service system due to issues related to literacy/education

#### **From the Help Me Grow Annual Report 2008– Summary of findings on reaching “hard to reach” families**

There are many difficulties with linking hard to reach families and children to needed services in communities with high poverty rates. However, this pilot project served as a

good foundational model. Face-to-face care coordination was more immediate and effective when working with hard-to-reach families. The initial presenting issues were often not the most important, rather through observations in the home, a more comprehensive assessment of needs was possible. Based on what was learned during the short period that the project was implemented (approximately 6 months of services for 51 families, 99 children), the issue is not so much a lack of services, but more one of comprehensive coordination among services. In addition, by providing families with accurate information on programs and very concrete support that addresses specific needs, families are more motivated (empowered) to access services on their own. Moreover, many families, including those with limited education, were available and receptive to learning about their child's development, and in fact, took pleasure in completing The Ages and Stages Questionnaire.

The Parent HelpLine of Lane County OR brochure indicates: 'Schedule a time to talk about the specific needs of YOUR family; appointments may be at your home, a park or other public setting.'

Some issues to consider include:

- Language and literacy issues
- Non-citizens: Births in Washington State, 2006 – 86,858; 47.1% to women with Medicaid-paid maternity care (40,873 births) with 21% (8,682) Medicaid deliveries to Non-Citizens.
- Immigrant populations
  - Mixteco-speaking immigrants, mostly to Othello, Quincy and Mattawa. Othello, with a population of about 5,800, is home to the state's highest concentration of Mixtecos. As many as 800 people from the highlands of southern Mexico live here -- often in cold, cramped duplexes and mobile homes outside of the city's quiet downtown.
  - Russian
  - Somali
  - Ethiopian
  - And many more
- Hispanic Infants: Despite healthy births and lower infant mortality among most immigrant Hispanic women, risk factors linked to maternal and home practices contribute to slower infant cognitive development by late infancy. These factors include: lower maternal education, weaker cognitive facilitation during interactions tasks and larger family size (more children per resident adult). The pattern of more robust births by immigrant mothers seems to weaken for later-generation Hispanic mothers. Hispanic mothers (compared to white mothers) scored lower in their knowledge of child development, demonstrated lower levels of praise and encouragement for their infant during problem-solving tasks, less warm affect and

less responsiveness to the infant when in distress. ‘These social dynamics resemble the home environments of other low-income populations, along with the subsequent deterioration of health indicators.’<sup>71,72,73,74</sup>

**Anticipate need for initial workgroup and then an ongoing advisory council on hard to reach populations**

### 3. Care Coordination, Resources and Referrals

Review models in other states and programs (e.g. Smart Start coordinators in 23 counties in North Carolina working in collaboration with Community Care of North Carolina network case managers; Help Me Grow and the replications of this program). Determine how to meet the needs and demands around care coordination, resource awareness and making and tracking referrals.

Review the role for local health jurisdictions, e.g. utilizing the CSHCN Coordinators; Home Visiting Nurses, Neurodevelopmental Centers and other early intervention providers, major health centers, and Interagency Coordinating Councils, among others.

The workgroup should examine:

- Who provides care coordination and what support is needed for that service?
- How to coordinate with the medical home?
- Who is responsible for keeping the resource list for the statewide database and what is the role of local community resource hotlines or others?
- Where is the resource database housed?
- How are resource updates provided? Look at the role of:
  - CSHCN Regional Meetings buttressed by each community meeting/emailing quarterly
  - Early Support for Infants and Toddlers (formerly ITEIP) Family Resource Coordinators role in referral, service linkage and tracking
  - OSPI Child Find
- How do we track gaps and barriers in services?
- What outcomes do we need to track for care coordination, resources and referrals?

<sup>71</sup> Maternal practices that influence Hispanic infants’ health and cognitive growth. Fuller B, Bein E et al. *Pediatrics*. 125(2):e324-e332, February 2010.

<sup>72</sup> Cabrera N, Shannon J et al. Parental interactions with Latino infants: Variation by country of origin and English proficiency. *Child Dev*. 2006; 77(5):1190-1207.

<sup>73</sup> Landale N, Oropesa R et al. Immigration and infant health: Birth outcomes of immigrant and native women. In: Hernandez D, ed. *Children of Immigrants: Health Adjustment and Public Assistance*. Washington, DC: National Academy Press; 2006:244-285.

<sup>74</sup> McLoyd V. Socioeconomic disadvantage and child development. *Am Psychol*. 1998; 53(2):185-204.

#### 4. Data system/Registry

A registry will be created or identified, for example using CHADIS or Brookes Publishing ASQ™ HUB or building on current Washington State systems such as the CHILD Profile immunization registry or the Newborn Hearing Screening system.

Determine components of data system/registry, where to house the data system/registry or whether to utilize an already existing data system/registry. Address privacy concerns, access for ‘need-to-know’ providers and access for families.

The workgroup should examine:

- Privacy and access issues.
- Parental consent incorporated into the system.
- Protected access to information for providers on a ‘Need-to-Know’ basis - Physicians, physician office staff, child care providers, head start programs and other early childhood programs, home visitors, school personnel, CSHCN Coordinators and a limited number of other providers for those children in their care.
  - How parent-identified providers will be apprised of the availability of results of newly-completed developmental screens? How will parent-identified providers know when the medical home (or other agreed upon provider) has reviewed the screening results with the family?
- Can the database system adapt to the addition of other screenings (e.g. maternal depression, autism, etc.)?
- How do we build the actual system?
  - Do we use Brookes and license it all with them with annual fees– need consultation with regional representative Paul Kelly, [pkelly@brooksepublishing.com](mailto:pkelly@brooksepublishing.com) User friendly for each accessing site – e.g. Head Start, Foster Care, Primary Care Office/Medical Home
  - Do we use CHADIS?
  - Is there another option already available?
  - Or do we build our own system building on either the immunization registry, the newborn hearing screening registry or a broader HIT system such as Oregon’s *FamilyNet* or Rhode Island’s *KIDSNET* (See webinar ‘Using Data Integration and Information Technology to Improve Care Coordination for Young Children’)
  - How to enter information and how to access information

#### 5. Fiscal

Cost out the screening system – cost of developmental screens, facilities, personnel, and other components necessary to implement the system. Look at funding mechanisms, partnerships and sustainability.

Cost depends in part on how many screens need to be done to realize the goal that all children will be screened at intervals as recommended by the AAP and other early childhood programs – (EHS- as enter the program, HS - ; foster care – within 30 days of out-of-home placement; AAP – all children at 9, 18 and 24/30 months and whenever there are concerns (parent or provider)). The number of births in Washington State in 2006 was 86,858 of which 47.1% to women with Medicaid-paid maternity care (40,873 births). The workgroup should:

- Align with screening subcommittee on standardized developmental screening tool choice
- Examine the cost of implementing the chosen tool
  - Screening tool purchase and annual fees; per screening charges
  - Decision on ages required to be screening and estimates of number of children needing screens at other ages in order to know number of screens
- Examine other screening tool use
  - Are there other screenings needed as part of the statewide system?
- Support reimbursement for medical home provider screening, interpretation and follow-up of results with families, E.g Follow up of concerning screening results, re-administration of screener when necessary, additional screenings such as maternal depression screening, autism screening, social-emotional/behavioral screenings and reimbursement for follow-up screening and/or assessment, e.g. domain-specific screening, such as Social-emotional screen, behavioral screen, speech and language screen.

## 6. Outreach /Marketing

We would like to establish developmental screening as a community expectation similar to car seats for young children. In addition, we must address community, family and provider awareness and encourage buy-in to a statewide screening access system. A critical mass of users will be necessary to operationalize the system. This workgroup should address how to raise awareness of the need for screening, the elements of the system itself and move providers and families toward acceptance and utilization of the system. Determine methodology for outreach education to medical home providers, early childhood providers, families, general public and others on developmental screening, system and database/registry access and use, resource linkage. Need for series of informational presentations, tutorials and assistance.

Review marketing efforts from other states – New Mexico, New York brochures, technical assistance efforts in Rhode Island, Iowa.

## 7. Evaluation

How do we know we are achieving our goals? Determine outcome measures and evaluation components and how to implement program evaluation.

## 8. Information Technology as an Overarching Issue

Technologies and applications continue to change and emerge. We need to address these issues in several of the workgroups. In addition, we need to continue to track changing interfaces, from computers to cell phones and beyond, especially monitoring opportunities to interface with families with young children who should be screened.

### Other Considerations:

#### **Autism Screening**

Currently administering the MCHAT at 18 and 24 months is the AAP recommendation for autism screening. Many states are using the ASQ™-SE for autism screening. There is emerging evidence that autism screening should continue after age 2 years.<sup>75</sup> To effectively reduce significant over-identification, the MCHAT Follow-up Interview should be administered. This is time consuming and done in only a few settings. If the ASQ™-3 is shown to be adept at identifying children with early signs of autism, we will be able to move to one screener.

#### **Maternal Depression Screening and Mental Health/Behavior Issues in the Child**

Should maternal depression screening be included as part of our developmental screening program for early ages? Should there be an automatic depression screener link ifor infants ages 6-8 months. Should we screen prenatally? Should our state have a specific intervention and child monitoring program for infants in the presence of maternal depression? Other issues to consider may include screening for: family risk, paternal depression and post-adoption depression.<sup>76,77</sup>

Many states are currently screening for maternal depression. A number are using the Edinburgh depression screener. For states serving at risk children, this can help identify children 0-12 months who would benefit from services and closer monitoring. Should the ASQ™-SE also be used? Or will the ASQ™-3 screener accurately for mental health/behavioral issues in young children?

---

<sup>75</sup> A Prospective Study of the Emergence of Early Behavioral Signs of Autism. Ozonoff S et. Al. *J Amer Acad Child Adol Psychiatr.* 49(3)256-266; March 2010.

<sup>76</sup> Post-Adoption Depression. Payne JL, Fields ES, et al. *Arch Women's Ment Health.* 13(2):147-151. Apr 2010.

<sup>77</sup> Post-adoption Depression among Adoptive Mothers. Senecky Y, Agassi H, et al. *J Affect Disord.* 115(1-2):62-68, May 2009.

**Identification of Infants 0-12 Months Eligible for Early Intervention Services:** (Note: Washington State does not serve ‘at-risk’ children, only children eligible by diagnosis or because of documented delay of 25% in one or more areas of development.)

- **Preemies** – is there a subset that should be followed routinely? In one study<sup>78</sup>, a group of 1,427 caregivers and children in the U.S. attending their 12- or 24-month well-child visits with regular screening for developmental delays by pediatricians completed the Ages & Stages Questionnaire® (ASQ™). The study examined the number of lower-risk, pre-term (most who were born between 34 and 37 weeks gestational age) children versus the number of term children who were referred to an early-intervention agency. Higher-risk premature infants already involved with an early-intervention agency or previously identified with a delay were excluded. The data shows the selected pre-term children were approximately two times more likely to be eligible for early intervention programs than term children, but that many of these children are being missed due to insufficient standardized screening at well-child visits. In addition, the study shows that an unacceptably high percentage of children who are identified as potentially delayed (and likely to benefit from early intervention), are not accessing services due to lack of follow-up between parents and early intervention programs.
- **Do we need to learn to count differently?** There is a count discrepancy between determining age by age at time of enrollment rather than by the age on the December 1 headcount.<sup>79</sup>
- **Are we counting the 0-12 month children** seen in other therapy settings? How do we link to all pediatric therapy providers to determine who is receiving services already?
- **Should we serve other populations identified in IDEA reauthorization** – domestic violence, homeless, low literacy groups, substance-exposed infants?
  - Does the Adverse Childhood Events (ACEs) score identify at-risk populations who would benefit from services to prevent life span and lifecourse/intergenerational poorer adult outcomes?
  - More than three children in the home, multiple moves, limited English and parental depression have been identified as psychosocial risk factors for fewer positive parenting behaviors and negative perceptions of children. Families with fewer positive parenting behaviors and negative perceptions of children were associated with child performance nearly 2 SDs below the mean on Brigance screens.<sup>80</sup>

---

<sup>78</sup> Lowering Developmental Screening Thresholds and Raising Quality Improvement in Pre-term Children. Marks K, Hix-Small H, et al. *Pediatrics*, 123(6) 1516-1523, June 2009. DOI: [10.1542/10.1542/peds.2008-2051](https://doi.org/10.1542/10.1542/peds.2008-2051)

<sup>79</sup> ‘Method for Counting the Number of Children Served in the IDEA Part C Early Intervention Program May Be Underestimating State Efforts’, Dunst CJ, Fromewich J, Hamby DW. *Snapshots*, I(3) At [www.tracecenter.info/products.php](http://www.tracecenter.info/products.php)

<sup>80</sup> Glascoe FP, Leew S. Parenting Behaviors, Perceptions, and Psychosocial Risk: Impacts on Young Children’s Development. *Pediatrics*. 2010; 125(2):313-319.

- **Foster Care**

How well are we doing with the CHET screening system? In a study of systematic screening using the ASQ™ the detection of potential developmental delay doubled among children in foster care (58% vs baseline 29%) for both boys (64% vs 35%) and girls (50% vs 22%) in each age group – infancy (4-12 months of age, 38% vs 18%), toddler (13-36 months of age, 89% vs 41%) and preschooler (37-61 months of age, 82% vs 43%). While potential delays were identified in all areas of development, there was a dramatic increase in the detection of delays in problem-solving, personal-social and fine motor domains. 48% of children had delays in more than one domain. Potential development delays in the infant group were spread evenly across the domains – communication, gross motor, fine motor, problem solving and personal social (slightly higher).<sup>81</sup>

### **Multicultural and Language Issues – Growing Diversity, Disparities:**

Washington’s population also is becoming more diverse. In 2000, all people of color viewed together represented one in five people in Washington. By 2030, one in three Washington residents will be a person of color. The largest growing groups are the Asian/Pacific Islander and the Hispanic populations. But the most rapidly growing racial group is the category called “two or more races,” which is projected to increase by 160 percent. The non-Hispanic white population tends to be quite a bit older than other racial and ethnic groups. This is because births and immigration of young adults play a large part in the growth of many racial and ethnic communities. The number of children (0 to 17 years) is expected to increase by 29 percent between 2000 and 2030. Approximately 81 percent of that increase will be among children of color (Office of Financial Management, 2006).

There is evidence that autism diagnosis, in particular, is diagnosed at older ages in Hispanic, African-American and immigrant children than in White children.<sup>82,83</sup>

**Language.** Eight percent of public school K-12 students in 2008-09 were English language learners and were in transitional bilingual programs (OSPI, 2009). The percentage of English language learner students has more than doubled since 1990, but has hovered between 8 percent and 9 percent since 2004. More than half of these students are in kindergarten through third grade. In 22 of the state’s 295 school districts, English language learners are a quarter or more of

---

<sup>81</sup> Jee SH, Szilagyi M et al. Improved detection of developmental delays among young children in foster care. *Pediatrics*. 2010; 125(2):282-289.

<sup>82</sup> Underdiagnosis and referral bias of autism in ethnic minorities. Begeer S, El Bouk S, et al. *J Autism Devel Disord*. 39:142-148, 2009.

<sup>83</sup> Effect of Ethnicity, Bilingualism and Other Demographic Characteristics at Age at Diagnosis of Autism Spectrum Disorder. Valicenti-McDermott M, Hottinger K, et al. Poster presented at Pediatric Academic Society meeting. Vancouver, BC. May 2, 2010. [http://www.abstracts2view.com/pas/view.php?nu=PAS10L1\\_2653](http://www.abstracts2view.com/pas/view.php?nu=PAS10L1_2653) (Accessed 5.30.2010)

the student population. The English language learner students speak a total of 204 different languages. Spanish is the primary language of two-thirds of English language learners. The other top languages are Russian, Vietnamese, Ukrainian, Somali, Korean and Tagalog. English language learners are not distributed evenly across the state, however. The largest concentrations are in the Puget Sound area (37 percent of the English language learners), the Yakima Valley (15 percent), the northwestern part of the state (14 percent), and the Tri-Cities (13 percent). In the western part of the state, more language groups are represented, with districts serving speakers of 20 or more languages. In the central and eastern regions, the majority of the English language learners speak Spanish (OSPI, 2008).

### **English as a Second Language**

Telephone interpretation and delivery of ASQ™ by interview may work very well. In a prospective, randomized trial of the relative efficacy of interpreter modalities in an urban pediatric emergency department comparing efficacy of telephonic and in-person medical interpretation to visits with verified bilingual physicians, ‘Both telephonic and in-person interpretation resulted in similar concordance in understanding of discharge diagnosis compared with bilingual providers.’<sup>84</sup> Interpreters who have worked with immigrant populations indicate phone interpretation is an inappropriate method to deliver concerns, diagnosis, next steps and/or planning information.<sup>85</sup>

### **Subpopulation differences by language:** (DEL, 2008 Parent Phone Survey)

More Spanish-speaking families than English-speaking families trust and want information “a lot” from:

- Their faith or religious community
- Parenting classes
- Home visits
- Materials that come in the mail
- Television or radio
- A toll-free advice line.

Fewer Spanish-speaking families than English-speaking families trust and want information from their health care providers and the Internet.

---

<sup>84</sup> Interpreters: Telephonic, in-person interpretation and bilingual providers. Crossman KL, Wiener E, et al. *Pediatrics*. March 2010. 125(3):e631-e638.

<sup>85</sup> Personal communication. Susanne Martin-Herz. May 27, 2010.

## **Partnerships:**

- *Washington Chapter of the American Academy of Pediatrics*
- *Washington State Department of Health*
  - *Local Health Jurisdictions*
  - *Children with Special Health Care Needs Program*
    - *CSHCN Coordinators*
    - *Parent to Parent*
    - *Father's Network*
  - *CHILD Profile*
  - *WIC*
  - *LAUNCH Grant – in year 2 of 5 year grant.*
    - *Grants in 5 states and 1 tribe;*
    - *Five areas of focus*
      - *Developmental screening*
      - *Home visiting*
      - *Parenting*
      - *Mental health consultation*
      - *Behavioral health in the primary care setting*
    - *Also workforce development and creating a definition of 'child wellness'*
  - *Autism State Implementation Grant*
  - *Early Childhood Comprehensive Systems (ECCS) Grant*
    - *Five required components: health, social-emotional development, early care and education, and parent and family support*
    - *Developmental Screening is identified as strategic priority*
- *Department of Early Learning (State Early Learning Plan)*
  - *Early Support for Infants and Toddlers (formerly ITEIP)*
  - *Head Start, Early Head Start/ECEAP*
  - *Child care*

- *Other*
- *Department of Social and Health Services*
  - *Washington State Medicaid, including foster care health program*
  - *Substance and Alcohol Abuse*
  - *Mental health*
  - *Children's Administration*
- *Thrive by Five – lead partner in State Early Learning Plan*
- *WithinReach*
- *OSPI – lead partner in State Early Learning Plan*
- *University of Washington,*
- *Parent Support Groups*
  - *Family to Family Health Information Centers*
  - *Parents as Teachers*
  - *Opening Doors for Multicultural Families*
  - *Other*
- *NEED: Washington Chapter of the American Academy of Family Physicians*

## Appendix A: A Survey of Efforts to Improve Developmental Screening in Other States

### **Primary Care Physician Training: Screening Tools and Referral Training (START) Program - Tennessee –(Similar programs in Illinois, Ohio, Oregon and other states):**

The Tennessee Chapter of the American Academy of Pediatrics (TNAAP) has a free training program for practices called **Screening Tools And Referral Training (START)**. START is an educational program developed by TNAAP to help pediatric care providers - including pediatricians, family physicians, nurse practitioners, nurses, and others - learn skills and strategies to implement routine developmental screening using standardized screening tools as part of their health care procedures.

TNAAP offers START training throughout the state to educate physicians, allied health care providers, and office staff about developmental and behavioral screening tools, referral procedures, and office workflow, and coding for payment for screening that can be easily incorporated into a practice routine. This training program is funded through a grant from the Bureau of TennCare and is an extension of the EPSDT project. This training is approved for 3.0 CME credits from the American Academy of Pediatrics and 2.5 CME credits from the American Academy of Family Physicians. Nurses can earn 2.67 contact hours from the Tennessee Nursing Association (TNA).

#### Training :

**Part I** covers the science of developmental/behavioral screening using standardized screening tools and how developmental and behavioral screening enhances surveillance for the physician.

**Part II** examines standardized developmental and behavioral screening tools that can easily be incorporated into the child health visit. Participants get hands-on experience scoring and interpreting developmental and behavioral tools, as well as a tool for detecting autism spectrum and one for detecting post-partum depression in new moms. Part II also covers coding for payment when standardized screening tools are used.

**Part III** provides strategies for implementing screening procedures during the child health visit. Participants have the opportunity to work as a team to determine developmental/behavioral screening protocol, select the screening tools they would like to use, determine at which well child visits they would like to use them, and develop an action plan for their practice to begin to implement the protocol as soon as possible. Part III also provides information and strategies that practices may use to access appropriate referral resources in their community.

#### Goals:

- Increase early identification of children with developmental delays or behavioral problems using standardized screening tools without adding significantly more time to the office visit.
- Better understand how to refer children for services to your community
- Learn how to code for reimbursement of these services.

### Outcomes:

- Recognize the value of both clinical surveillance and standardized developmental and behavioral screening tools.
- Recognize why using standardized developmental and behavioral screening tools benefits the child, the family, and the physician.
- Understand the importance of early intervention and how it improves outcomes of children with developmental delays or behavioral problems.
- Select appropriate screening tools best suited for your practice.
- Know how to administer and score selected screening tools correctly.
- Know how to make timely referrals to appropriate community resources for children whose results indicate developmental, behavioral, or emotional problems.
- Be able to implement efficient office procedures for screening and referrals.
- Know how to code for these services.

### New Mexico: <sup>86</sup>

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 Initiative<sup>11</sup> (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*.<sup>12</sup> 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

---

<sup>86</sup> Developmental Screening in Early Childhood Systems: Summary Report. AAP, HCCA and CCHP.  
<http://www.healthychildcare.org/pdf/DSECSreport.pdf>

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)<sup>13</sup> 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.

**North Carolina: 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 program, Community Care of North Carolina (CCNC).<sup>14</sup> 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%).

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 professional 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.

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%.

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 valuation 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*. 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.

**Rhode Island: 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)* 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<sup>19, 20</sup>, 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/risk
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.

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.

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.

## **Oklahoma**

The **Oklahoma** University Child Study Center's State Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs supports implementation of a medical home in primary care practices by providing a practice improvement facilitator to help primary care providers as they implement medical home concepts. Much of this work focuses on establishing evidence-based screening and referral procedures.

Through a toll-free phone line and website, the Oklahoma Area-wide Services Information System (OASIS) provides information, referral and assistance to Oklahomans, including families with young children with disabilities and special health care needs. The service maintains a large resource directory that includes available community services around the state and is accessible to providers as well as families.

### **Oklahoma Web-Based Portal:**

The Assuring Better Child Health and Development (ABCD) III project team in Oklahoma is rolling out a secure, web-based referral portal to facilitate information sharing between primary care and community service providers, maintain a historical record for each child, and provide a mechanism to remind providers if follow-up for a child is not yet completed.<sup>87</sup>

---

<sup>87</sup>Linking Children to Services: Building on Community Assets to Pilot Test Improvement Strategies. (p.12). Hanlon C. National Academy for State Health Policy. December 2010.

## Appendix B - Risk Factors Pertaining to Referrals of At-Risk Children – New York State

10 NYCRR 69-4.3(f) provides that referrals of children at risk of having a disability shall be made based on the following medical/biological risk factors:

1. Medical/biological neonatal risk criteria, including:
  - birth weight less than 1501 grams
  - gestational age less than 33 weeks
  - central nervous system insult or abnormality (including neonatal seizures, intracranial hemorrhage, need for ventilator support for more than 48 hours, birth trauma)
  - congenital malformations
  - asphyxia (Apgar score of three or less at five minutes)
  - abnormalities in muscle tone, such as hyper- or hypotonicity
  - hyperbilirubinemia (> 20mg/dl)
  - hypoglycemia (serum glucose under 20 mg/dl)
  - growth deficiency/nutritional problems (*e.g.*, small for gestational age; significant feeding problem)
  - presence of Inborn Metabolic Disorder (IMD)
  - perinatally- or congenitally-transmitted infection (*e.g.*, HIV, hepatitis B, syphilis)
  - 10 or more days hospitalization in a Neonatal Intensive Care Unit (NICU)
  - maternal prenatal alcohol abuse
  - maternal prenatal abuse of illicit substances
  - prenatal exposure to therapeutic drugs with known potential developmental implications (*e.g.*, psychotropic medications, anticonvulsant, antineoplastic)
  - maternal PKU
  - suspected hearing impairment (*e.g.*, familial history of hearing impairment or loss; suspicion based on gross screening measures)
  - suspected vision impairment (suspicion based on gross screening measures)
2. Medical/biological post-neonatal and early childhood risk criteria, including:
  - parental or caregiver concern about developmental status
  - serious illness or traumatic injury with implications for central nervous system development and requiring hospitalization in a pediatric intensive care unit for ten or more days
  - elevated venous blood lead levels (above 19 mcg/dl)
  - growth deficiency/nutritional problems (*e.g.*, significant organic or inorganic failure-to-thrive, significant iron-deficiency anemia)

- chronicity of serous otitis media (continuous for a minimum of three months) HIV infection

10 NYCRR 69-4.3(g) provides that the following risk criteria may be considered by the primary referral source in the decision to make a referral:

1. no prenatal care
2. parental developmental disability or diagnosed serious and persistent mental illness
3. parental substance abuse, including alcohol or illicit drug abuse
4. no well child care by 6 months of age or significant delay in immunizations; and/or
5. other risk criteria as identified by the primary referral source

### **Diagnosed Physical and Mental Conditions with a High Probability of Resulting in Developmental Delay<sup>79</sup>**

Diagnosed physical and mental conditions with a high probability of resulting in developmental delay found at 10 NYCRR §69-4.1(3)(e) of the New York State Department of Health EIP regulations:

- Chromosomal abnormalities associated with developmental delay (*e.g.*, Down syndrome);
- Syndromes and conditions associated with delays in development (*e.g.*, fetal alcohol syndrome);
- Neuromuscular disorder (*e.g.*, any disorder known to affect the central nervous system, including cerebral palsy, spina bifida, microcephaly or macrocephaly);
- Clinical evidence of central nervous system (CNS) abnormality following bacterial/viral infection of the brain or head/spinal trauma;
- Hearing impairment (a diagnosed hearing loss that cannot be corrected with treatment or surgery);
- Visual impairment (a diagnosed visual impairment that cannot be corrected with treatment (including glasses or contact lenses) or surgery);
- Diagnosed psychiatric conditions, such as reactive attachment disorder of infancy and early childhood (symptoms include persistent failure to initiate or respond to primary caregivers; fearfulness and hypervigilance that does not respond to comforting by caregivers; absence of visual tracking); and
- Emotional/behavioral disorder (the infant or toddler exhibits atypical emotional or behavioral conditions, such as delay or abnormality in achieving expected emotional milestones such as pleasurable interest in adults and peers; ability to communicate emotional needs; self-injurious/persistent stereotypical behaviors).

<sup>79</sup> For additional information, consult Early Intervention Guidance Memorandum 1999-2 on Reporting of Children's Eligibility Status Based on Diagnosed Conditions with a High Probability of Developmental Delay

## **Appendix C: Connecticut – Help Me Grow**

Supported by Children’s Trust Fund [www.take5parenting.com](http://www.take5parenting.com) , Department of Mental Retardation, Department of Public Health, Department of Education and United Way of Connecticut.

Help Me Grow is a universal system that provides a cost-effective, efficient and user-friendly mechanism for identifying children from birth to age eight for developmental or behavioral problems and connecting them to appropriate community resources in a timely manner. There are five components:

1. Child Health and Development Institute training module in Educating Practices in the Community (EPIC) ([www.chdi.org](http://www.chdi.org)) – ensures PCP are trained in effective developmental surveillance and screening
2. Child Development Infoline (CDI) ([www.ctunitedway.org/cdi.html](http://www.ctunitedway.org/cdi.html)) – a specialized call center of United Way 211 which serves as the Help Me Grow access point – Free and confidential telephone access point linking young children and families to existing services and supports AND offers participating in ASQ™ screenings via a tracking system that helps PARENTS and CHILD HEALTH PROVIDERS monitor a child’s development
3. Resource Information, an inventory of community-based programs – maintained by United Way 211 Information Department
4. Community Liaisons from the Children’s Trust Fund – link between local communities and the call center.
  - a. Contribute information about local resources to the Resource Inventory
  - b. Support providers by facilitating local networking opportunities
  - c. Help with local needs assessment (?)
5. Annual Outcome Evaluation (Conducted by Center for Social Research, University of Hartford [www.centerforsocialresearch.org](http://www.centerforsocialresearch.org)) – who calls Help Me Grow, the nature of the calls, the effectiveness of matching family needs with program services, program effectiveness in meeting annual goals and state criteria for results-based accountability

Help Me Grow is a program of the Connecticut Children's Trust fund working in collaboration with: The United Way of Connecticut/ Infoline, (the state's telephone information and referral service), the Connecticut Birth to Three System (through the Department of Mental Retardation) and the state's Department of Education Preschool Special Education Program. Through this collaboration we have developed a statewide network designed to help families and providers access appropriate services for young children (birth to 5) who are at risk for developmental, health or behavioral problems. The components of the program include: a statewide toll free telephone number for accessing needed care (Child Development Infoline); partnerships with community-based agencies throughout the state; and child development community liaisons that serve as a conduit between the community-based services and the telephone access point. Child

development community liaisons conduct regional Networking Breakfasts that bring together community-based agencies to share information and brainstorm solutions to challenging issues using case specific presentations.

The Help Me Grow training component is targeted at child health providers in the State of Connecticut to support the practice of developmental surveillance. Grand rounds presentations are delivered through hospital-based pediatric departments and large pediatric clinics across the state. Help Me Grow trainers visit community-based pediatric practices and present a Child Development Resource kit that contains: materials on Help Me Grow, the administration guide and protocols for the PEDS (Pediatric Evaluation of Developmental Status) and the Denver II (developmental screening instrument). A referral to Help Me Grow is appropriate when a provider needs to link the family to programs in the community or has requests for further evaluation. Workshops on developmental surveillance will also be presented to child care providers and parents.

In addition, the Ages and Stages Child Monitoring System is offered to any family that requests participation. Questionnaires are sent out to parents every few months to check their child's development. If there is a question about development the parent is connected to the appropriate referral source.

The evaluation component includes a data collection system that identifies gaps in services and barriers to obtaining appropriate services. In addition detailed data is being collected on the time it takes to find an appropriate service, follow up calls and hard to reach families. This information is being generated to help legislators understand the need for systems change issues involving prevention and the need for supporting services and resources for young children.

In summary, Help Me Grow is a unique program that assists families and providers in identifying developmental concerns, finding appropriate resources and helping families connect with programs and services. The training of child health, child care providers and parents on developmental surveillance is a critical component of Help Me Grow. Training and evaluation of the program are the keys to bringing about substantive systems change.

### Sign Up to Get Your Ages & Stages Questionnaire! <sup>88</sup>

The Ages and Stages Questionnaires are easy-to-use tools for families to check on the development of their young children, ages birth through 5 years. By completing this tool with your child, you are taking the first step in making sure he or she is on track to be successful in school! Thanks for your participation.

\* Required

Child's Name (First & Last):

Your Name (First & Last):

Relationship to Child:

Child's Sex:

Child's Date of Birth:  ex: mm/dd/yyyy

If baby was born three or more weeks prematurely, please give the number of weeks premature.:

numbers only

Phone Number :

Mailing Address:

City:

State:

What County do you live in?:

ZIP:  ex: 12345, 12345-1234

E-Mail Address:

How did you hear about this opportunity?:

Please indicate your language preference:

English

Español

<sup>88</sup> From - Metro United Way 2-1-1 serves Louisville area - three counties in Indiana (Clark, Floyd, and Harrison) through a partnership with Indiana 2-1-1 and nine in Kentucky (Bullitt, Carroll, Jefferson, Henry, Nelson, Oldham, Shelby, Spencer and Trimble). Anyone can dial 2-1-1, speak to a trained counselor and receive information on the

Metro United Way:

[http://www.metro united way.org/index.cfm?fuseaction=home.viewPage&vpage\\_id=EADFD25D-05D7-3E22-BB6EF4C455923628](http://www.metro united way.org/index.cfm?fuseaction=home.viewPage&vpage_id=EADFD25D-05D7-3E22-BB6EF4C455923628)

Families also have the option sign up to participate in a child developmental monitoring program using the Ages and Stages questionnaires.

Education is key to improving our community, an essential building block that leads to a better life for all. On June 12th, Metro United Way introduced an exciting new tool: Ages and Stages Questionnaires are user-friendly school-readiness screening tools for parents of children ages birth through 5.

### **Ages and Stages Questionnaires**

Every concerned parent wants to know whether or not his or her child is developing at a rate that will let them enter kindergarten prepared to learn. Metro United Way is offering a screening tool that will help parents and caregivers discover what facets of their child's development might benefit from additional attention.

The Ages and Stages Questionnaire gives parents the opportunity to check on their child's developmental growth between the ages of 4 months and 5 years. You can [sign up to receive an Ages and Stages Questionnaire online](#), or call Metro United Way 2-1-1 to request the age-appropriate tool be sent to you, then complete the survey on your own.

This simple tool will help parents and caregivers discover how they can be even more effective in preparing their young children for school. If the screening tool suggests serious developmental lags then information on where a parent can turn for further assessment and assistance will be provided.

The Ages and Stages Questionnaire is part of an overall Help Me Grow system being studied by Metro United Way. Louisville was recently selected as one of only five sites across the nation to receive technical assistance from the Connecticut Children's Medical Center's Help Me Grow National Replication Team to review the system that has had great success in Connecticut. Their program concentrates on identifying children who have developmental delays and getting them early assistance. With funding from The Commonwealth Fund, Dr. Dworkin and his team will be working with a group of interested child development professionals to consider what is applicable to Greater Louisville.

Later, by aggregating Ages and Stages Questionnaire results, Metro United Way will be able to report on the state of readiness of our school children for the first time.

## **Appendix D - KIDSNET AUTHORIZED USERS**

- **PRIMARY CARE PRACTICES**
- **NON PRIMARY CARE PRACTICES** – School-based health centers, Residential schools, Specialty clinics (e.g. allergy and asthma, GI specialty clinic, Neurodevelopmental program), Urgent care and walk-in care centers, Immunization clinic
- **DEPARTMENT OF HEALTH and DEPARTMENT OF HUMAN SERVICES PROGRAMS**
  - Birth Defects
  - Data & Evaluation Early Intervention Family Health Information Line Family Outreach Program
  - Immunization
  - KIDSNETLead ScreeningPerinatal Hepatitis B Program
  - Universal Newborn Screening
  - Hearing
  - Developmental Risk
  - Blood Spot
  - Vaccinate Before You Graduate, VBYG
  - Vital Records
  - WIC
- **RI CONTRACTED AGENCIES**
  - RI Hearing Assessment Program
  - VNS – Family Outreach Program
  - VNA Care New England – Newborn Screening Programs
- **PEDIATRIC AUDIOLOGISTS**
- **PEDIATRIC GYN PROVIDERS**
- **COMMUNITY AGENCIES**
  - Comprehensive Child Care Services Program: (CCCSP)
  - Early Intervention Programs
  - Headstarts
  - Lead Centers
  - WIC Local Agencies
- **MANAGED CARE ORGANIZATIONS**
- **SCHOOLS**
  - Public and Charter Schools
  - Private Schools
  - State Schools- RI School for the Deaf
  - Schools for Children w/Disabilities

## **Appendix E: Child Health Profiles (CHP) – Enhancement of immunization registries and linkage with other health records.**

**From:** Review: Progress along developmental tracks for electronic health records implementation in the United States. Hollar DW. *Health Research Policy and Systems*. 2009; 7(3): 1-12. (<http://www.health-policy-systems.com/content/7/1/3> )

**Abstract:** The development and implementation of electronic health records (EHR) have occurred slowly in the United States. To date, these approaches have, for the most part, followed four developmental tracks: (a) **Enhancement of immunization registries and linkage with other health records to produce Child Health Profiles (CHP)**, (b) Regional Health Information Organization (RHIO) demonstration projects to link together patient medical records, (c) Insurance company projects linked to ICD-9 codes and patient records for cost-benefit assessments, and (d) Consortia of HER developers collaborating to model systems requirements and standards for data linkage. Until recently, these separate efforts have been conducted in the very silos that they had intended to eliminate, and there is still considerable debate concerning health professionals access to as well as commitment to using EHR if these systems are provided. This paper will describe these four developmental tracks, patient rights and the legal environment for EHR, international comparisons, and future projections for EHR expansion across health networks in the United States.

**Full Article:** (References available at the website link above.)

Substantial progress has been made in the linkage of children's electronic health records, especially given the long-term medical and public health focus on improved children's health during the 20<sup>th</sup> century. Between 1992–2004, the Robert Wood Johnson (RWJ) Foundation funded the Public Health Informatics Institute (PHII; Decatur, Georgia) with over \$30 million (U.S.) to improve electronic systems for storing and transmitting immunization records between public health departments and health care providers at state and national levels. This funding continued with efforts to link these immunization records to other health registries, thereby creating an electronic Child Health Profile (CHP) [9]. Projects were further supported by simultaneous funding of state public health departments by the U.S. Health Resources Services Administration (HRSA, a division of the U.S. Department of Health and Human Services) [9,10].

### **CHP Need**

A specific focus of the CHP projects involved children with special health care needs (CSHCN), operationally defined by the HRSA Maternal and Child Health Bureau as being "those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health care-related services of a type and amount beyond that required by children generally" [[11-13,11], p. 138]. These children include children with genetic or metabolic conditions, birth defects, and other disabilities.

CSHCN represent approximately 12.8% of American children, and roughly 20% of American households with children include a CSHCN [12,13]. Furthermore, 9.73% of CSHCN experienced delayed or forgone care, with such lapses in healthcare being significantly associated with race (i.e., highest for Hispanics), age (i.e., being an adolescent CSHCN), region (i.e., living in the American South or West), having severe functional limitations, being at or near the federal poverty level, and having no medical insurance [13]. Additionally, the two most frequently cited reasons for delayed care were financial problems (including transportation issues) and provider non-accessibility, both of which were significant across the same pattern of associations for general delayed/foregone care [13]. Financial and transportation issues are also of particular note since they are listed barriers to be addressed in the federal *Healthy People 2010* [14] objectives for improved American healthcare.

The value of data linkage for NBS into a CHP for CSHCN that can be followed up by health services providers is forcefully argued by Hinman et al. [9], who estimated the annual number of missed cases of classical phenylketonuria (n = 10) and congenital hypothyroidism (n = 52), out of 4,058,814 U.S. births [15,16]. They based these estimates upon the number of children screened for these conditions, numbers of true and false positive cases, and number of cases that were lost to follow-up testing and potential treatment [9]. The lifelong medical, psychological, quality of life, educational, and financial impacts of each missed phenylketonuria case on the patient, their family, and society are substantial [17].

Furthermore, Desposito et al. [18] found that 31% of surveyed pediatricians reported receipt of NBS-positive results more than 10 days after testing was completed, and 28% of respondents fallaciously viewed no results as indicating a negative screen not requiring follow-up, thus potentially complicating the lack of urgent care that might be needed by some of these newborn infants.

Therefore, the combined PHII, RWJ, and HRSA effort to create electronic child health profiles directly responded to the American Academy of Pediatrics Newborn Screening (NBS) Task Force recommendations that child health delivery required an adequate systems infrastructure that links the NBS heel-stick program (for identifying genetic or metabolic conditions in newborns) with birth registration, immunization, newborn hearing screening, and the Women, Infants, and Children (WIC) support programs [10,19]. The electronic Child Health Profile would enable rapid identification of conditions in CSHCN that lead to swift follow-up services for confirmed conditions.

### **CHP Results**

HRSA awarded seven states (i.e., Arizona, Colorado, Iowa, Massachusetts, Missouri, Rhode Island, and Wisconsin) with the first HRSA SPRANS State Development Grants for Newborn Screening Efforts and Infrastructure Development [10]. Fifteen more states were funded for such exploratory programs in 2000–2001, and of these 22 states, 16 states would receive further

funding to actually implement Child Health Profiles [9,10]. Rhode Island, Missouri, Oregon, and Colorado were successful at early data linkage projects that created functioning CHPs. Other states, such as Tennessee with its TN-CHP program, utilized unique public health-university-advocacy group partnerships that specialized in data for children with genetic/metabolic conditions [20].

By 2001, the PHII and HRSA state immunization programs had yielded highly successful results, with many states showing dramatic improvements in the numbers of newborn infants receiving at least one immunization and the numbers of children receiving the recommended array of childhood preventative vaccinations [21,22]. Nationally, 89.4% of children aged 19–35 months had received polio vaccinations, 76.3% had received varicella vaccinations, and 73.7% had received the 4:3:1:3:3 series of DTP (Diphtheria, Tetanus, Pertussis), poliovirus, measles, Haemophilus influenzae b, and Hepatitis B immunizations [21].

Nevertheless, a focus on newborn screening (NBS) continued because of expanded technological capacities (i.e., the invention of tandem mass spectrometry, TMS) for evaluating dozens of genetic and metabolic conditions [23]. During early 2005, only seven states were screening every newborn child for more than seven genetic or metabolic conditions. However, by late 2006, 25 states were screening more than 20 conditions using TMS [24]. Traditional genetic and metabolic conditions tested since the 1970's had included phenylketonuria, galactosemia, congenital hypothyroidism, and hemoglobinopathies (e.g., Sickle Cell Anemia, Thalassemia). TMS enables blood serum measures of levels and ratios of the 20 biological amino acids and other biochemicals, thus expanding the measurement array to over 50 conditions. Unfortunately, the incidence of many of these conditions is unknown, and many conditions have no known treatment [24].

Therefore, the state CHP programs were highly successful at increasing childhood immunizations. Nevertheless, NBS and TMS were creating an exponential data explosion. State CHP projects were successful at linking together many children's health records, but they encountered logistical issues with the datasets. These problems included varying computer language formats for databases, inconsistent child and family identifiers for data linkage, and political (e.g., "data silo") resistance. Problems varied from state to state, but all states faced data linkage barriers.

### **Model CHP Programs**

One of the most successful CHP programs has been Rhode Island, which currently has over 150,000 children in its Kidsnet database, with approximately 14,000 new births each year, nine different linked databases, and a majority of health care systems and private physicians utilizing the linked data [25]. Rhode Island has carefully implemented its program since 1997 and currently serves as the national model for an electronic Child Health Profile.

Including Rhode Island, 12 of the 22 HRSA/PHII-RWJ funded state projects were actively integrating child health records by 2004, six other states were still in the planning stages, and four states were no longer planning because of a lack of political and financial support from their state governments [26]. Thirteen states had linked NBS and dried blood spot data, nine states had these two databases linked with vital registration, five states had these three databases plus an immunization registry, and nine states had no immunization registry included at all [26]. The reporting state programs cited organizational constraints (13 states), a difficult external political environment (ten states), financial resources (11 states), data sharing agreements (nine states), and data duplication (six states) as major challenges to their projects [26].

Based upon Rhode Island's success, public health leaders there and PHII identified central features of successful electronic health records [27]. Nineteen core principles of EHR include: making information available to parents, families, providers, and programs; involving these stakeholders in the system design; maintaining security and confidentiality of individual patient data; ensuring timeliness of data availability using appropriate technologies; using computerized audit trails of who accesses data; making the system simple to use and adaptable to changing technology; making the system cost effective; and most importantly, preventing use of the data for punitive or discriminatory purposes. Patient/parental control of the data is a unique component of the Child Health Profile approach, although this latter goal may not be achievable in an NHII given the strong involvement of for-profit service providers and insurance companies, an issue that will be addressed below. PHII [27] also identified 22 core functions of EHR, many of these functions mirroring the 19 principles, but specifically advocating the establishment of a record for each newborn within 2 weeks but ideally within 24 hours of birth (a critical point for potentially life-threatening genetic or metabolic conditions such as classical galactosemia [28-30], establishing unique identifiers for each patient in the database; retrieving and processing immunization and hearing data within one month of service and NBS dried blood spot within 24–48 hours; allowing provider data entry at patient visit and tracking of individual case progress as well as immunization updates throughout the treatment process; and using national standards for electronic data exchange [27]. Furthermore, PHII operationally defined the purpose of the electronic Child Health Profile "to facilitate assessment and prompt provision of appropriate services to ensure an optimal healthy start for all children and improve the health of children" [[27], p. S54].

D'Alessandro and Dosa [31] reiterated the child and family orientation of the Child Health Profile that is the centerpiece of the Rhode Island Kidsnet and PHII programs. The current international healthcare movement from traditional medical to bio-psychosocial philosophical service delivery models is easily extended into the new information technology facet of healthcare delivery, where patient empowerment is a central theme [31].

## Prospects for CHP

An electronic Child Health Profile can be used to improve developmental tracking and service provision to CSHCN and their families. It can serve as an integrating healthcare tool for improving individual access to *the medical home*. It can also allow primary providers to monitor patient improvements and treatments over time regardless of the location of service provision [32]. The integration of service delivery can strengthen patient and family access to medical homes, thereby improving patient safety and services received [33,34].

A 1998–2000 survey of families with CSHCN, conducted by Family Partners/Family Voices and Brandeis University, found that families were receptive to the idea of having their child's records in an electronic Child Health Profile, although there were concerns over data security, confidentiality of records, and authorized access to the records [35]. One parent said she was fortunate her daughter with a metabolic condition was born in a European country where the health laboratory operated continuously, unlike their U.S. home in a "predominantly rural state" [[35], p. S26]. While American NBS programs with Tandem Mass Spectrometry (TMS) are beginning to operate around the clock, states differ with respect to newborn screening tests offered, and no state has 100% systems integration for follow-up. Even so, Hinman et al. [9,27] argued for the rapid integration of systems to increase follow-up services. They also argued that the data quality does not have to be perfect, meaning that the occurrence of more false positives will not harm the process of providing improved healthcare [27]. Nevertheless, some experts have questioned the potential psychological harm done to families of false positive children in NBS [36,37]. Given the exponential increase in the amount of information being gleaned from TMS and newborn screening [37,38], some researchers have suggested that reporting of presumptive positives from TMS proceed more cautiously than at present [37].

Wild and Fehrenbach [39] and Wild et al. [40] highlighted best practices for the use of children's health information in two CHP development products designed to guide programs that are implementing linked electronic records: *Integration of newborn screening and genetic service systems with other maternal & child health systems: a tool for assessment and planning*, and the accompanying *Tool for Assessment and Planning*, both available from <http://www.phii.org> [webcite](#).

Besides providing rapid follow-up services to child well-being and establishing a medical home, the aggregate data obtained from the Child Health Profile or EHR include regional and national assessments of health care delivery to mothers and children [41-43], the importance of which includes addressing regional variations in the prevalence of conditions and diseases as well as addressing the problem of health disparities based upon race, socioeconomic differences, and urban/rural availability of service providers. The logistical and technical problems encountered by the various state projects described are reiterated in the more comprehensive regional demonstration projects described below. Additionally, service providers, particularly private physicians in rural areas, experience variations in the level of access to information technology,

willingness to learn and invest in such technology, and availability of information technology experts to maintain the technology [44].

### ... Contextual Environment of EHR – Patient Rights/Advocacy and Legal Issues

In the United States, the legal aspects of sharing data center about two American laws: (a) the Family Educational Rights and Privacy Act (FERPA; Buckley Amendment Title IX of the Higher Education Amendments of 1972; 20 U.S.C. §1232g, 34 CFR 99), and (b) the Health Insurance Portability and Accountability Act (HIPAA; 1996 Amendment Part 7 to Title I of the Employee Retirement Income Security Act of 1974; 42 U.S.C. 1320d-1320d-8, Public Law 104–191, sections 262 and 264).

#### **HIPAA**

Most public and professional attention has been placed upon the HIPAA, which prohibits health care entities and individuals working for those entities from disclosing any health-related information about a patient without authorization from the patient or patient's legal representative. HIPAA further prohibits discrimination against patients by insurers for pre-existing conditions if the patient has been insured for at least 18 months. Consequently, patient's are given a HIPAA explanatory form and a waiver form for their signature prior to receipt of clinical services, thus allowing the clinical provider to bill the patient's insurance company and, in the process, transmit the patient's health information for the insurer to decide upon the claim and insurance benefit coverage for the patient. HIPAA applies to any type of individual protected health information (PHI), written, verbal, or electronic, and it stipulates stiff legal and financial penalties for violators.

#### **FERPA**

Similarly, FERPA was established to protect the confidentiality of children's educational records, wherein a child's parent or legal guardian must authorize any release of the child's school records if any agency or individual requests those records; at the age of 18 and beyond, the individual must provide authorization. Since there is overlap between health and education records in many public health databases (e.g., cognitive development, school immunization records), there has been much discussion on the subject of which law takes priority. The general consensus indicates that FERPA overrules HIPAA, in that individuals or their guardians/legal representatives must consent to the sharing of PHI, including health and educational records when both types of information are present. Such consent directly impacts large-scale electronic health records networks at the state level (e.g., Rhode Island) and with the massive RHIOs (e.g., Regenstrief, Volunteer e-Health). Many of these programs are using legally-binding inter-institutional data sharing agreements to allow authorized providers at participating institutions to access data. Furthermore, data security systems include audit trails to monitor any excessive or unauthorized accessions to individual patient records.

## **Rights and Legal Issues**

The legal environment of electronic health information has complicated the development of EHR. Rosenbaum et al. [78] describes major health legal issues, specifically addressing the ownership of health information, disclosure of PHI, extent and power of involvement of health insurers, private civil litigation and access to PHI, access to PHI by the government and law enforcement agencies, and basic research access to patient records. Their study compiled interpretations of a broad-based government, academic, health, business, and other private sector experts on EHR and the law. Overall, they agreed that HIPAA generally is designed to prevent abuses of patient confidentiality and discrimination, although certain areas of disagreement exist with respect to HIPAA overruling less stringent state standards for protecting PHI. Additionally, the ownership of EHR (e.g., patient, hospital, insurance companies) remains a major unresolved issue [78]. Rosenbaum et al. [78] provided various models of centralized and decentralized data sharing agreement models, including Regenstrief as a decentralized model. The Robert Wood Johnson Foundation [[58], pp. 98–100] provides a summary of the confusion surrounding HIPAA and states' use of EHR, misunderstandings that have needlessly limited states' implementation of EHR.

## **Appendix F – CHADIS – The Child Health and Development Information System**

<http://www.chadis.com/>

CHADIS is a web-based screening, diagnostic and management system that administers and analyzes pre-visit, online questionnaires completed by parents, teens or teachers and provides Clinicians with instant access to valuable clinical data and resources. Through its process, CHADIS improves the diagnosis and management of health, emotional and behavioral issues, helping Clinicians address parents' concerns about their child's development while streamlining other routines of Pediatric care.

There is increased recognition within the Pediatric community that early diagnosis and treatment of health, developmental and behavioral issues in children and adolescents is extremely beneficial in successfully dealing with them. Many organizations, including the American Academy of Pediatrics, now recommend using pre-visit screening tools to assist with early identification.

CHADIS was designed with both the practice and families in mind by two highly-respected, experienced Pediatricians working with a team of technical, research and support specialists. The program was devised to be easy to utilize in day-to-day operations of a practice while achieving the ultimate goal of helping Clinicians provide better care and support to patients and families.

How does CHADIS work?

1. Parents complete questionnaires anywhere Internet access is available and can even utilize Web-based, multiple language platforms
2. CHADIS collects all the answers, then scores and tabulates them in an user-friendly electronic worksheet for the Clinician to review
3. CHADIS develops provisional diagnoses and Clinical decision-support management information based on the screened responses
4. CHADIS selects informational handouts and community resources specific to child and family needs from our Resource database of over 16,000 Local and National listings
5. CHADIS captures additional comments and information from the Clinician at the office visit
6. CHADIS stores all the data from the questionnaires and the visit for future reference and the tracking of patient care over time

## Appendix G: Help Me Grow Services Barriers and Gaps (2008 Annual Evaluation Report)

During the past year, program staff, under guidance from *Help Me Grow's* Continuous Quality Improvement (CQI) team and using feedback from evaluation of *Help Me Grow*, established a systematic process for identifying and tracking gaps and barriers to connecting families to services. These data are now being collected; that is, for each issue (and/or request for service) that is assessed at intake, care coordinators document any barrier or gap in service they identify as they research potential programs or services for individual families. This documentation occurs no matter the final outcome (i.e., whether families are connected to a service or not). For example, care coordinators typically help families who are confronted with gaps or barriers to services (one common barrier is when a family confronts a language and/or cultural barrier at the agency or program where they are seeking services). Often care coordinators are eventually able to connect families to services (as already noted, 80% of service needs were addressed for the 2007-2008 year); however, this is because care coordinators either (1) persistently follow through with an agency; (2) move their efforts to other agencies and programs that provide similar services, or (3) modify their efforts and find the next best possible program.

· **Barriers-** The following barriers to services have been identified by the care coordinators and have been included in the database:

- Agency has not returned call in a timely manner. Use when family has called an agency but has not gotten a return call.
- Can't afford service. Use when family can't afford to pay the fee charged for the needed service.
- Child care issue. Use when a child care issue is preventing access to services, including when family can't find child care for sibling(s) of child in need of services.
- Does not live in geographic area covered. Use when family does not live in the geographic area served by the agency.
- Does not meet age criteria. Use when a child is either too old or young for the services offered.
- Hours of operation. Use when the hours of operation are not compatible to family's schedule.
- Immigration status. Use when family is not eligible for services due to their immigration status or fear of being reported to NIS.
- Intake/application process too difficult. Use when family was unable to go through the intake/application because the process is too difficult to understand or follow.

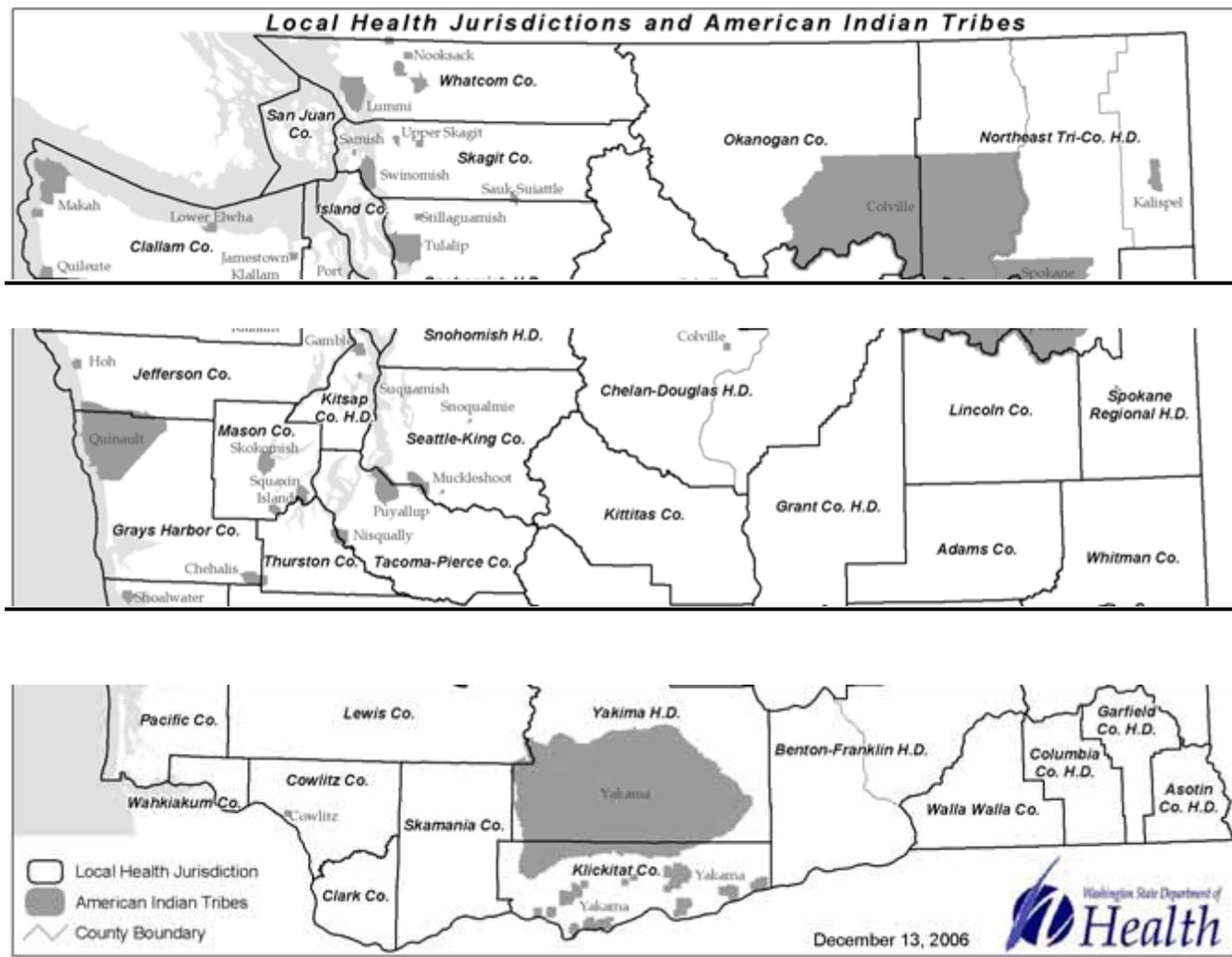
- Lack of diagnosis or DX. Use when child is not eligible for services due to lack of a diagnoses or diagnosed condition.
  - Lack of medical coverage. Use when child does not have medical coverage (insurance) to cover the cost of the care sought.
  - Language/cultural barrier. Use when family confronts a language and/or cultural barrier at the agency/program where they are seeking services.
  - Long waiting list. Use when family is put on a waiting list of 2 weeks or longer.
  - Confused/overwhelmed client. Use when client is confused or overwhelmed due to being a low functioning adult and/or dealing with household stressors including, but not limited to, physical, mental and/or environmental issues, which limits the ability to understand or follow through on applying for or obtaining services.
  - No transportation. Use when family lacks the ability to travel to the agency/program either due to lack of personal and/or public transportation options.
  - Over income. Use when family's income is higher than the program's income eligibility criteria.
  - Phone automation problems. Use when the family's experience with the agency/program's automated phone system prevents them from accessing services.
  - Program/agency too far away. Use when family is geographically too far away from the program/agency to obtain services.
  - Resource exhausted (also below income). Use when the agency/program has exhausted resources such as respite care funds, and as a result stop providing the service.
  - Other. Use when no other code is appropriate.
- **Gaps-** The following systems-based gaps in services are being tracked by the care coordinators:
- Before and after school programs
  - Before and after school programs for child with special needs
  - Child care services
  - Child care services for child with special needs
  - In home services
  - Insurance coverage

- Nursing services
- Parent education services
- Respite services
- Other: when no other code is appropriate

At the end of the program year, data on barriers and gaps in services will be analyzed to determine if there are identifiable patterns for particular service needs. In addition barriers and gaps in services will be analyzed for different geographic locations and for different town groups in Connecticut (i.e., Wealthy, Suburban, Rural, Urban Periphery, and Urban Core) to determine if there are identifiable patterns based on geographic locations or differences in income and rates of poverty. These analyses will be summarized in a briefing report and presented for review by all interested stakeholders.

## Appendix H – Some Systems with Potential to House Washington State 0-3 Screening System

### Local Health Jurisdictions:



### Neurodevelopmental Centers:

1. Birth to Three Developmental Center Federal Way, Washington 98023
2. Boyer Children's Clinic, Seattle 98112
3. Children's Therapy Center, Kent, 98030
4. Good Samaritan Hospital Children's Therapy Unit Puyallup 98372
5. Holly Ridge Center, Inc Bremerton 98312
6. Kindering Center, Bellevue 98008
7. Mary Bridge Children's Health Center Neurodevelopmental Program, Tacoma 98514
8. Progress Center, Longview 98632
9. Providence Everett Medical Center, Providence Children's Center, Everett 98206
10. Skagit Preschool and Resource Center (SPARC), Mount Vernon 98273
11. Skagit Valley Hospital Children's Therapy Center, Mount Vernon 98274
12. Spokane Guilds' School and Neuromuscular Center, Spokane 99205

13. St. Joseph Hospital Children's Neurodevelopmental Program, Bellingham 98225
14. Valley Medical Center Children's Therapy Services, Renton 98055
15. Yakima Valley Memorial Hospital Children's Village. Yakima 980902

**ASSOCIATED TERTIARY CENTERS** - DOH does not contract for services with these associated tertiary centers.

1. Center on Human Development and Disability, Clinical Training Unit, High Risk Infant Follow-up, Seattle 98195
2. Seattle Children's Hospital Neurodevelopmental Program, Seattle 98105
3. Madigan Army Medical Center Developmental Pediatric Clinic, Tacoma 98431

**Early Support for Infants and Toddlers - ESIT (Formerly ITEIP) Service providers –**

1. The Neurodevelopmental Centers listed above, and
2. Go through the Local Interagency Coordinating Councils?

**Major Health Centers**

