Monitoring the Development and Health of Young Children

The focus of this year’s Northwest Bulletin is developmental screening. The topic is timely. The Affordable Care Act expands preventive care, including developmental screening, for individuals across the lifespan. Assuring the collection and use of valid screening information to improve systems of care is fundamental to public health. Screening is an aspect of “assessment.” Assessment, along with policy development and assurance, are the three core functions of public health.

Annually, MCH (Title V) agencies in all 59 states and jurisdictions in the United States report on 18 national performance measures. A new set of national performance measures is being considered right now as part of the transformation of the Title V Block Grant program and final decisions will be made in the next few months. One new measure under consideration is the percentage of infants and young children who have been screened for progress in multiple domains of development, including communication and social-personal behaviors.

This issue focuses on developmental screening of young children. The editorial by David Willis, MD, FAAP, describes the current status of children in the United States in general measures of well-being, why developmental screening is important, and the growing momentum for a national early childhood agenda. He observes that while we have built a foundation of developmental screening, much work needs to be done to assure sufficient resources to respond early and competently through assessment, diagnosis, and intervention to ameliorate developmental problems. The feature article by Katherine Tekolste, MD, overviews current screening tools and recommendations for developmental screening, and highlights regional and national screening initiatives. The article by Wendy Davis, PhD, describes why maternal mental health is an important part of universal developmental screening. An article by Paula Kobos, MN, RN, on text messaging offers an intriguing idea of how to reach parents who might be “hesitant” about developmental screening. An article by Amanda Crawmer, a mother of two boys with autism spectrum disorder, describes her experiences with obtaining intervention services. The state reports illustrate many accomplishments related to developmental screening in the Region X, including improved early identification of developmental delays and maternal depression in Alaska, Idaho’s Infant Toddler Program, Oregon’s efforts to align health care and early learning policies, and Washington’s Universal Developmental Screening Partnership.
Updates

This is the 30th anniversary of the Maternal and Child Public Health Leadership Training Program at the University of Washington. The program has been continuously funded with a grant from the Maternal and Child Health Bureau since 1984. The first issue of the Northwest Bulletin was published in 1987. It included a legislative report from Washington State, regional news and events, a literature review, and a guest editorial.

Since then, the Northwest Bulletin has expanded to articles and state reports focused around a specific topic per issue, and changed to an on-line publication. But we have the same goal with this issue as we did back then: to “serve as a forum for sharing information on local and regional activities.” Next year our program will compete for a five-year renewal of its funding. This competition gives us the opportunity to implement new ideas, and we are asking ourselves: what do we want the Northwest Bulletin to look like in 2020? If you have ideas, send us an email at shattuck@u.washington.edu.

Reader Information

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Developmental Screening: Assuring the Future Well-Being and Competitiveness of Our Children

David W. Willis

We should all be celebrating the progress we are making in early childhood, not only that the editorial board of *Northwest Bulletin* has decided to focus this edition on state-of-the-art practices of developmental screening, but more importantly, that we are witnessing an expanding public discourse and a growing public expectation of assuring the future well-being and competitiveness of our children. Universal, standardized, and sequential developmental screening seems to be taking hold across the nation, not only in medical homes, but also in early childhood programs. This is due to the cumulative successes of decades of efforts by pediatricians, maternal child health leaders, public health advocates, early educators, parents, teachers, and early childhood advocates. We should celebrate the progress we have made with universal screening, but there is still so much more to be done, and more urgently.

Current Status of the United States in General Measures of Child Well-Being

The first UNICEF overview of child well-being indicators of 20 economically advanced nations was published in 2007 with internationally comparable data for the years 2001-2003. The United States ranked #20 of 20, tying with the United Kingdom for bottom ranking. Measurements of well-being included material well-being, health, education, and behaviors, using indicators such as infant mortality, educational achievement, obesity, teenage fertility, smoking, alcohol use, fighting, bullying, and reported life satisfaction.

Last year, a second report was released with data from 2009-2010. The United States ranked #26 of 29 developed countries. (1) Strikingly, this report suggests how little progress has been made in the United States in general measures of child well-being over the last decade. Poor well-being in childhood results in loss of potential and earning capacity later in life, and our nation loses the human capital it needs to stay competitive in a competitive world.
Importance of Developmental Screening

Recent national surveys (2011-2012) indicate that as many as one in four children through the age of five years are at moderate or high risk for developmental, behavioral, or social delays. (2) Young children who live in low-income families are even more likely to have a developmental delay. (3) Twenty-five percent of children live in families below the federal poverty level (4) and only 48% of these children (compared to 75% of those who live in families with moderate to high incomes) are ready for school at age five. (5)

Advances in developmental neuroscience make it clear how Adverse Childhood Experiences (ACE) impact development early and have long lasting impacts on a lifetime of health, mental well-being, and achievement. (6-8) According to Christopher Blodgett, PhD, (personal communication, 2013) the effects of adverse childhood experiences have a cumulative negative impact on behavior and educational readiness that can be seen as early as Head Start preschool.

The challenges to the optimal development of human potential run deep across all our communities. (9-11) According to Clyde Hertzman, PhD, (personal communication, 2012) disadvantaged children and their neighborhoods have, on average, poorer outcomes, yet the most vulnerable children are in the populous middle class. Hence the call for developmental monitoring, surveillance, and screening must be for all children in all communities with, of course, careful attention to those children in poor and vulnerable populations.

Growing Momentum for a National Early Childhood Agenda

On January 2013, President Obama announced his Early Learning Agenda during the second Inaugural Address and articulated a vision for improving educational achievement for our next generation of children by substantial growth in the investments in home visiting and quality early learning environments. Embedded in this national address is the recognition that healthy, stimulating, and safe relationships, and quality early learning environments are the foundation for education readiness and our future work force. (12) New federal investments in evidence-based home visiting—Race to the Top-Early Learning Challenge grants, Early Head Start Childcare Partnerships, and the continued support for Head Start—recognize the importance of supports for the early years as investments for the future.

Birth to 5: Watch Me Thrive!

Building on this growing momentum for a national early childhood agenda is the recent release of Birth to 5: Watch Me Thrive! This unprecedented, united federal effort for young children and families celebrates developmental milestones and promotes universal screening. It also encourages the early identification of development delays, timely referrals, and enhanced developmental supports for all children, families, and communities. The hope of this initiative is for all communities and early childhood providers to join with parents to ensure the developmental health of all children, with developmental screening being only one part of a broader early childhood agenda of family supports, parenting education, community building, and early education for all.

The MCH leadership is making an intentional effort to align public and private activities around development screening by encouraging a focus on the life course, population- and community-based efforts to mitigate the impact of toxic stress on development, and the alignment of early childhood systems to improve rates of developmental screening.

MCH 3.0

With the alignment of public and private efforts to broaden, integrate, and measure progress of these developmental health activities, this is likewise an exciting time within the early childhood community, public health, and maternal and child health (MCH). The Maternal and Child Health Bureau has articulated its vision for MCH 3.0, which includes efforts to incorporate development screening within its proposed Title V performance measures. The MCH leadership is making an intentional effort to align public and private
activities around development screening by encouraging a focus on the life course, population- and community-based efforts to mitigate the impact of toxic stress on development, and the alignment of early childhood systems to improve rates of developmental screening.

Conclusion

We have much to celebrate. Our breakthroughs in building a foundation of developmental screening for all children—to monitor and assure developmental health—brings intentionality to the next breakthrough in our work—to assure that NO child falls off the developmental growth curve appropriate for that child. This focus on preventing the loss of developmental capacity will increasingly drive our population focus on assessing developmental and psychosocial risks, managing those risks in secondary prevention efforts, and targeting evidence-based interventions to achieve healthier developmental trajectories. Developmental screening has come of age, but the next step—to prevent a failed developmental screen—is more challenging. This must become our next vision and then achievement.

David W. Willis, MD, FAAP, joined the Maternal Child Health Bureau, U.S. Health Resources and Services Administration, in July 2012 as its director of the Division of Home Visiting and Early Childhood Services. Programs under his leadership include: Maternal, Infant, and Early Childhood Home Visiting Program; Early Childhood Comprehensive Systems Grants Program; Building Bridges among Health and Early Childhood Systems, Healthy Childcare America; and National Resource Center Grant Program. Board certified in behavioral and developmental pediatrics, he was a clinician for 30 years and long-standing early childhood leader and advocate in Oregon State. Dr. Willis was a previous Harris Mid-Career Fellow with ZERO TO THREE, past President of the Oregon Pediatric Society, Executive Committee member of the American Academy of Pediatrics’ Section on Early Education and Child Care, and first Chair of the American Academy of Pediatrics’ Board’s Early Brain and Child Development Strategic Initiative.

REFERENCES:

12. President Obama’s Second Inaugural Address, January 21, 2013. Available at www.whitehouse.gov/the-press-office/2013/01/21/inaugural-address-president-barack-obama
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s many as one in four children birth to the age of five years are at
moderate or high risk for developmental, behavioral, and social delays.
(1) For children birth to the age of two years, recent data suggests
the incidence is as high as 13%. (2) The incidence of autism is currently
estimated at 1 in 68 children. (3) Yet only 10% to 25% of those eligible for
early intervention services are enrolled. (2, 4) Approximately 5% of children
receive preschool special education. (5) Some populations are at higher risk
of developmental and behavioral problems, including young children in foster
care and in families with low-income or homelessness. (6, 7, 8, 9)

Failure to identify and address developmental problems in the early years
imposes significant costs to the health, education, and child welfare and justice
systems. Early treatment improves outcomes. Intervention prior to kindergar-
ten results in improved academic performance (decreased special education,
increased high school graduation rates), social skills (adult independent living,
decreased delinquency and crime), and economic benefits (increased adult
employment).

The savings for these outcomes are substan-
tial, ranging from $1,400 to $240,000 per child.
For every $1 spent on early intervention, the
return to society ranges from $1.26 to $17.07.
(10) Healthy People 2010 identified developmen-
tal disabilities as one of the six most important
health concerns in the United States. Healthy
People 2020 objectives include increasing the
screening of young children for developmental
delays and autism. (11)

Screening Recommendations

Prevention and amelioration of developmental
problems rely upon the use of accurate screening
tools and connection to therapeutic interventions
and other needed resources. A screening tool
does not provide a diagnosis of developmental
problems: it can indicate that a child is on track
or, with the presence of concerns, in need of
further assessment.
The American Academy of Pediatrics recommends general developmental screening at 9, 18, and 30/24 months of age (30 months is preferred), autism screening at 18 and 24 months of age, and screening whenever there is provider or parent/caregiver concern.

Nationally, 30.8% of parents of children, aged 10 months to 5 years, report completing a standardized developmental screening tool at a health care visit. In Region X states, the percentages are Alaska, 32.6%; Idaho, 25.0%, Oregon, 34.4%, and Washington 29.9%. (12)

In 2009, the American Academy of Pediatrics’ Healthy Child Care America hosted a meeting of academic, government, health, and education professionals from across the nation to strategize ways to “...promote high-quality developmental screening in the context of the medical home.” One recommendation from this meeting is that developmental promotion and screening occur both in health care settings and within the network of community-based services and early childhood systems. (13)

Developmental screening is currently required in a number of early childhood programs, including foster care, home visiting, Head Start, Early Head Start, and Early Childhood Education and Assistance Programs (ECEAP). In 2006-2007, Head Start programs nationally screened 941,484 children for developmental, sensory, and behavioral problems and identified 124,654 children (13%) as needing a follow-up assessment or formal evaluation. (14) Laurel Leslie, et al., found that 20% to 60% of children entering foster care have a developmental delay or disability. (8)

The Child Find Mandate included within the Individuals with Disabilities Education Act (IDEA) Part B requires 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.”

Although there is not currently a mandate for monitoring development in child care settings, child care providers have indicated 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. In focus groups of child care providers conducted in 2004 in King County, Washington, 85% of participating providers indicated having had concerns about the development of at least one child in their care. Washington State has added developmental screening to the Early Achievers’ Quality Rating and Improvement System (QRIS), with some child care providers linking to or administering standardized screenings.

Screening Tools

A full list of parent-completed and observer-administered standardized screening tools is available at http://pediatrics.aappublications.org/content/118/1/405/T1.expansion.html. Developmental screening tools should be broad in scope, sampling all domains including language, fine and gross motor skills, and cognitive and social-emotional development. Screening tools are also available for specific concerns, such as autism spectrum disorders.

According to the Washington State Department of Health, the state significantly under-identifies children who would qualify for Part C Early Intervention Services. Washington State is not alone! We are working to create a coordinated system of screening, referral, and follow-up with connections to needed supports and services. Our partners in this work include physicians and other health care providers, early childhood providers, parents, foundations (e.g., Thrive by Five’s Love, Talk, Play campaign), parenting groups and organizations (e.g., Parent Trust, Parent 2 Parent), community hot-lines (e.g., WithinReach), and community and governmental health agencies. Potential partners include children’s museums and libraries.
Screening tools should be standardized on a nationally representative sample and correctly identify ≥70% to 80% of children with a delay (sensitivity) and ≥70% to 80% of children without a delay (specificity). (15)

Parent-completed tools are relatively inexpensive, easy to complete, and engage families as active observers and partners in promoting child development. Parents’ reports of concerns are highly predictive of problems in language, fine-motor skills, and cognitive and social-emotional development.

Two parent-completed general developmental screening tools—the Ages and Stages Questionnaire (ASQ-3™) and the Parents’ Evaluation of Developmental Status (PEDS™)—are gaining wide application across sectors. (See table for a list of on-line access to ASQ-3™ by state in this region.) The Survey of Wellbeing of Young Children (SWYC) is a new public domain screening tool that shows promise in screening for development, autism, and family risk for children through the age of 60 months.

Recommended screening tools for autism in young children include the Modified Checklist for Autism in Toddlers (M-CHAT™) and the ASQ-Social Emotional (ASQ-SE™). The newly revised Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT–R/F™) has been shown to identify autism at an early age (two years earlier than the current national mean age of diagnosis). Almost all children with a positive two-stage M-CHAT-R/F screening had autism spectrum disorder or other delays; only 5.4% were judged to be normally developing. (16) In addition, the Communication and Symbolic Behavior Scales Developmental Profile (CSBS-DP™) Infant-Toddler Checklist can be of use in screening for autism. (17)

Examples of Screening Initiatives

To date, quite a bit of work has been done to enhance developmental screening in pediatric health care settings and community health clinics in a number of states, primarily by providing training and technical assistance to incorporate screening into daily practice. With initial support from the Assuring Better Child Development (ABCD) Screening Academy, the Oregon Pediatric Improvement Partnership has been a leader in significantly improving standardized developmental screening and referrals in primary health care practices in Oregon.

Communities have partnered with WIC programs to implement developmental screening. In Washington State, Lincoln County Public Health Department has partnered with WIC offices to provide developmental screening to participating families through WithinReach. Children whose screening results indicate concerns are referred to the Lincoln County Health Department for further follow-up.

Children, aged 1 to 60 months, in the Washington State Child Welfare system are screened with the ASQ-3™ through Child Health and Education Tracking (CHET). In Washington State’s Yakima and Kittitas Counties, the ASQ-3™ is being pilot tested in child care settings serving high-risk populations. Parents, as well as providers, have been educated on the importance of developmental screening.

Nationally, the Help Me Grow National Center

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<td><strong>State</strong></td>
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<td>Alaska</td>
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<td>Oregon</td>
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works to replicate in other states the Connecticut Help Me Grow system that connects at-risk children to needed services, including developmental screening. The Easter Seals’ Make the First Five Count provides access to the ASQ-3™. The United States Departments of Health and Human Services and Education have collaborated on a Developmental and Behavioral Screening Initiative. (See Dr. Willis’ editorial on page three for more information.)

The Future

The above-mentioned efforts are only a few of the many developmental screening initiatives underway. The difficulty remains in breaking down the barriers between early childhood systems and health care providers, enhancing cross-system communication, and assuring access to support and services.

In a number of states, developmental screening efforts are housed in departments of early intervention or early learning. For Washington State, the Department of Health has taken the lead in pulling sectors together, including training community providers and exploring a data system for universal developmental screening. We look forward to continued advances through the Washington State Universal Developmental Screening Partnership (see the Washington State Report on page 22) and the Early Childhood Comprehensive Systems Grant.

It is important to continue to monitor opportunities and think creatively on ways to streamline and optimize these efforts to identify and support the needs of young children and their families. We also need to learn from each other’s experiences to advance policy, outreach, and implementation while considering ways to develop or expand regional collaborations in the future. How can efficiencies be improved and redundancies reduced? How can we maximize impact while minimizing cost?

As we move forward, opportunities to collaborate, streamline and increase public awareness include:

- The Centers for Disease Control and Prevention’s Learn The Signs, Act Early is informing new outreach for community-wide developmental screening from the Departments of Health and Human Services and Education.
- The Adverse Childhood Experiences (ACE) work in Washington State and nationally shares many similarities and goals of the universal developmental screening work.
- The Survey of Wellbeing of Young Children, the recently developed screening tool in the public domain, opens new possibilities for screening without the costs of proprietary tools.
- Washington State has a cooperative model for childhood vaccines that could be instructive for a developmental screening collaboration.
- Researchers at the University of Washington are developing a “baby book” for the on-line generation called Baby Steps. Included are ways to monitor a young child’s developmental milestones and activities to encourage emerging developmental skills.

I hope each reader can identify additional resources, initiatives, and creative ideas that can further these efforts and share them with the rest of us!

Katherine A. TeKolste, MD, is a developmental-behavioral pediatrician at the University of Washington School of Medicine, a faculty member of the University of Washington Leadership Education in Neurodevelopmental Disabilities (LEND) Program, and co-director of the Washington Medical Home Partnerships Project. She served for seven years on the Early Support for Infants and Toddlers (ESIT) State Interagency Coordinating Council. She is a member of the Washington State Department of Health’s Partnership for Universal Developmental Screening and is active in efforts to advance access to and follow-up of developmental screening through the Great MINDS grant and the recently-awarded Early Childhood Comprehensive Systems grant.

Email: Kat423@uw.edu

REFERENCES

The MCH Navigator has a new website!

http://www.mchnavigator.org/

The MCH Navigator, housed at Georgetown University, is a learning portal for maternal and child health professionals, students, and others working to improve the health and well-being of women, children, and families.

Key features of the new site include: 1) a searchable, web-based resource inventory of free learning opportunities, 2) a collection of training spotlights which include a repository of tailored resources on hot topics in the field of MCH, 3) a library of learning opportunities to support MCH 3.0 and the new vision of the MCH Block Grant, and 4) a learning collaborative that utilizes social media and allows MCH professionals to provide feedback on learning opportunities, as well as Navigator staff to answer questions about specific training needs. Current highlights include:

The MCH Workforce Development Center:

- Grantee Spotlight on Dorothy Cilenti, Project Director for the MCH Workforce Development Center
- New fact sheet on the MCH Workforce Development Center

Resources for the Practicing MCH Workforce:

- Title V in Your State
- MCHB Discretionary Grant Information System (DGIS)
- MCHB Region Staff

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Maternal Mental Health

An Important Part of Child Development

Wendy N. Davis

Why is it important for us to include maternal mental health in our conversations about universal developmental screening? It might seem intuitively obvious that the mental and emotional health of parents has a critical impact on childhood development, yet the worlds of child development and maternal mental health have too often operated separately. Our growing understanding of their important connection is a welcome change, increasing our ability to develop effective preventions and interventions, and support family resiliency.

Maternal Mental Health and Child Development

During pregnancy, anxiety and mood disorders increase the risk for negative maternal and fetal outcomes, such as maternal hypertension, miscarriage, and premature birth. (1) After pregnancy, they are associated with less nurturing (reading, singing, playing, cuddling), less ability to follow child safety and health guidelines, lower rates of breastfeeding, and increased family conflict. (1)

Marian Earls, MD, FAAP, a national expert in infant stress and maternal depression, writes “Because maternal depression compromises bonding, babies often avoid interaction, and attachment is at risk. The type of mother-child relationship creates an environment for the infant in which s/he withdraws from daily activities. Emotional and social development, as well as intellectual, language, and physical development, are at risk. If the mother continues to experience depression, and there is no intervention for the dyad (mother-child relationship), the child’s developmental issues are likely to persist and be less responsive to intervention over time.” (2)

Integrating Maternal Depression Screening with Developmental Screening

Two key concepts have improved our ability to integrate maternal depression screening with developmental screening in health care systems. One is the understanding that screening can be delivered by diverse providers—not only health care professionals but also educators, home visitors, clinic
office staff, and other allied providers. The Edinburgh Postnatal Depression Scale (EPDS), the most widely used screen for perinatal depression, was in fact first developed for home visitors and can be easily utilized in a non-medical setting. (3) The other is that screening is not diagnostic. Because it is not a treatment intervention but a validated method to identify the need for further assessment, health care systems can be more flexible in staffing and protocols.

**Screening for Perinatal Depression**

It is imperative that we assess the mental and emotional states of parents before attempting to engage them in parent education or intervention efforts. Using a validated screening tool and protocol for referral not only gives the provider more information about the family’s needs, it gives parents the opportunity be honest about their ability to regulate mood, focus, and remain patient under stress, and ultimately receive the help they need.

It is not uncommon for mothers with anxiety and depression to try to hide their symptoms from providers, potentially setting up a situation where mothers appear to comply but are actually feeling overwhelmed. They might appear to accept education but be unable to follow through, leading to decreased alliance with the provider and a sense of incompetence. The most common validated tools used to screen for perinatal depression are the Edinburgh Postnatal Depression Scale (EPDS) and the Patient Health Questionnaire (PHQ).

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It is not uncommon for mothers with anxiety and depression to try to hide their symptoms from providers, potentially setting up a situation where mothers appear to comply but are actually feeling overwhelmed.

**Helping Families Raise Healthy Children**

Sponsored by the RAND Corporation, a Pennsylvania initiative, *Helping Families Raise Healthy Children*, mobilized and aligned local early intervention and behavioral health systems to improve their capacity to identify and engage families at risk for both parental depression and early childhood developmental delays. The authors of the 2014 report, *Transforming Systems for Parental Depression and Early Childhood Developmental Delays: Findings and Lessons Learned from the Helping Families Raise Healthy Children Initiative*, attribute the initiative’s

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**Central Oregon Maternal Mental Health Initiative**

In 2011, the Deschutes County Children and Families Commission and Oregon State, with a grant from SAMHSA’s Project LAUNCH, initiated a tri-county initiative to improve the systems that serve young children. The initiative began with a community education conference for stakeholders and continued with the following activities:

- Formation of a steering committee
- A community needs assessment
- Development of a strategic plan for maternal mental health
- Physician grand rounds
- Community provider trainings in partnership with St. Charles Hospital
- A partnership with the Oregon Pediatric Society to provide in-office training on maternal mental health screening for nine primary care practices
- Development of patient education materials in English and Spanish
- Creation of screening and referral algorithms for providers, including screening protocol, telephone numbers for family support and referral, and emergency contacts
- Development of a public service announcement in English and Spanish aired on television for one year
- A partnership with Postpartum Support International and development of a “warm line” housed through the local domestic violence shelter, Saving Grace

Results of an evaluation of the screening and referral system will be available by December 2014. For more information, visit www.deschutes.org/ecwellness
high rates of referral and engagement to several features designed to reduce barriers to accessing care, including improvement of cross-system communication and collaboration. (The authors also mention the provision of mobile services. For more on that topic, see the article by Paula Kobos on page 14.) (4)

It is a public health tenet to screen for high-prevalence and high-risk conditions; however, the best screening initiatives must be embedded in coherent systems of resource referral.

The authors also recommend mandating universal screening for depression in the early intervention system, making parental mental health challenges a qualifying risk factor for early intervention at-risk tracking services statewide, adding depression as a tracking category for early intervention services, and facilitating cross-system collaboration and communication among the early intervention, behavioral health, and parent and child health care systems. They also recommend the development of cross-system training and referral protocols for families identified as needing behavioral health services and other supports. (4)

Conclusion

How do we create effective prevention and intervention efforts that address developmental challenges and the existence of parental stress and depression? It is not enough to guess who is at risk, and not enough to simply screen without a protocol for resource sharing and referral. It is a public health tenet to screen for high-prevalence and high-risk conditions; however, the best screening initiatives must be embedded in coherent systems of resource referral.

A report by Oregon’s Maternal Mental Health Initiative Workgroup (see page 12) recommends provider training and support, public awareness, and screening and assessment, all embedded within an integrated system. (5) Collaborations to integrate screening and referral for maternal mental health and child development increase the chances for success in prevention and intervention for families, creating a stronger combined system of care.

Wendy Davis, PhD, Executive Director, Postpartum Support International, has a counseling practice in Portland, Ore. She chaired Oregon’s Maternal Mental Health Workgroup and helped write the Oregon Maternal Mental Health Patient and Provider Education Act.

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RESOURCES

Postpartum Support International (PSI) www.postpartum.net Provides training to professionals and support and resources for families in every state. Telephone Warmline in English and Spanish 1-800-944-4773 (1-800-944-4PPD)

Postpartum Depression. MedEdPPD.org www.mededppd.org

Maternal Mental Health. Oregon Health Authority. www.healthoregon.org/perinatalmentalhealth


REFERENCES


Mobile phone text messaging is an innovative tool that offers potential for child developmental and maternal mental health screening. The popularity of texting among women of childbearing age, the enforced brevity of text messages, and the availability of low-cost cell phones combine to create a health care platform with promise. In addition, this platform may appeal to some hard-to-reach women, including those with mental health or substance abuse issues, and those who, because of their culture, may have fears about conventional western medicine. (1-3)

Text4baby is probably the best known texting program in the United States (see page 15). But before Text4baby, researchers around the globe tried other pregnancy-related, text-messaging health interventions. I wondered if any of these projects had useful ideas for Region X practitioners and researchers. This is what I learned.

Pregnancy-Related Text Messaging Interventions

In November 2012, I systematically searched peer-reviewed research and found 29 studies related to the acceptability, feasibility, or outcomes of pregnancy-related, text-messaging health interventions. I wondered if any of these projects had useful ideas for Region X practitioners and researchers. This is what I learned.

<table>
<thead>
<tr>
<th>Primary purpose of text message</th>
<th>n (%)</th>
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<tr>
<td>Client support (e.g., encouragement, problem-solving) and education</td>
<td>10 (48%)</td>
</tr>
<tr>
<td>Health assessment data transmission (laboratory and other test results)</td>
<td>5 (24%)</td>
</tr>
<tr>
<td>Contraceptive reminder</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>Health worker communications and education</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Appointment reminder</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Fund transfer</td>
<td>1 (5%)</td>
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*text messaging may serve more than one purpose in a study

1For a complete list of studies reviewed for this article, please contact the author.
to take birth control pills, and convey clinical tips to midwives. Text messages also reminded women about antenatal care appointments and transferred funds for women to travel to the hospital.

Some text messages conveyed support and education from providers to their clients, including two-way, “as-needed” texting. A small, clinician-facilitated, texting-based support group assisted newly diagnosed, HIV-positive pregnant women. (4)

A Sample of Findings

Most interventions had some success. For example, text messaging was linked to improved knowledge about oral contraceptives and continued oral contraceptive use at six months. Text messaging also showed promise for providing continuing professional education and for improving timely antenatal care. One study suggested text messaging may make caring for women with gestational diabetes more efficient without sacrificing quality. (5)

Some studies highlighted positive impacts on antenatal mental health. For example, pregnant women with concerns about fetal Down syndrome reported reduced anxiety when they got rapid negative laboratory test results by text message. (6) Women who received text messages for support and education reported increased confidence and reduced antenatal anxiety compared to women who did not receive these text messages. (7)

Studies also described some limitations. Text message reminders did not seem to reduce the odds of missing oral contraceptives during a cycle. Nor did they increase the odds of following strict birth control recommendations when taking a teratogenic acne medication. No studies found a link between educational and supportive text messages and improved birth outcomes. And some pregnant women didn’t think text messages would change their opinions about getting flu shots—but did think text messages might prompt vaccine discussions with their providers.

Participants shared both positive and negative opinions about text messaging. Some viewed text message reminders as desirable proactive communication from providers. Women also described text messages as motivating and decreasing isolation. However, some participants noted the potential for messages to be perceived as offensive, pressuring, or guilt-producing. Privacy and cost were mentioned both as reasons to enroll and not to enroll in text messaging services.

Conclusions

The evidence for pregnancy-related, text-messaging interventions is emerging and global. Text4baby evaluations document the program’s wide reach, acceptability,
and early successes with childbearing women in the United States. Future Text4baby studies, including one with Region X military families (8), will add valuable knowledge for families and practitioners interested in texting interventions.

This research inspires thoughts about incorporating texting into screening programs for families. Text messaging offers an accessible, non-judgmental, potentially private virtual health care space that may lend itself to simple child development screening. A carefully designed, texting-based tool might be useful to screen for sensitive mental health, substance use, and family violence problems. Texting also has potential to rapidly convey a variety of laboratory screening results, minimizing anxiety and frustration from waiting when results are positive—and prompting faster follow-up when results are concerning. And a text-messaging reminder system may prompt women to keep appointments where they could be screened for problems—or where they can opt to spontaneously disclose serious problems.

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REFERENCES
I t has been four years since both our children—Morgen and Jack—received a diagnosis of autism spectrum disorder, and I am still devastated. Like many parents, I bury myself in medical terms, bleeding the emotion out of the facts. Instead of saying, “Jack has autism and at age seven is considered to have the developmental ability of an 18-month old,” I use medical terms like “autism spectrum disorder,” “low-functioning,” “sensory processing disorder,” and “non-verbal” to soften the truth. The truth hurts and overwhelms me.

It has been four years since our autism diagnosis, and both our children have now lived with an autism diagnosis longer than they have lived without it. Both our children were born healthy. They did not suffer any terrible illnesses and were wonderful babies. Of course, they weren’t perfect. Morgen was a stubborn baby and toddler but brilliant, inquisitive, and sweet-spirited. Jack was our laid-back baby. Compared to the always-busy Morgen, Jack wanted to chill and watch. He loved to snuggle and was content to be held. Jack was slower to reach his developmental markers, yet not slow enough to cause great concern.

From Suspicions to Answers

At first it was easy to dismiss the red flags. I’d tell myself “Jack’s not that behind, he’s only 11 months old. Some children develop at a slower pace.” But as months passed, I began to suspect something was wrong. I finally worked up the courage to ask our pediatrician. “Give him time,” he said. “Let’s wait another six months and evaluate where he is developmentally.” Having faith in our pediatrician, I pushed away my doubts and waited.

Two months later, my sister’s mother-in-law, Julie, a first grade teacher and volunteer at our church nursery, contacted me. She delicately explained her concerns about Morgen. “The school can help him,” she said, handing me the name and number of our local developmental preschool, Keewaydin Discovery Center. She encouraged me to request an autism spectrum disorder evaluation.

When I called, they arranged for me to get a
New NCBDDD Report on Autism Spectrum Disorder

New data from the National Center on Birth Defects and Developmental Disabilities Network show the number of children identified with autism spectrum disorder continues to rise. The new estimate is approximately 30% higher than the estimate for 2008. Of those identified with autism spectrum disorder, less than half were evaluated for developmental concerns by the time they were three years old.


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brochure explaining autism. I was genuinely surprised by what I read in the section labeled “symptoms of autism.” The list of symptoms was long and diverse but clearly applied to BOTH of our children. The fears I had pushed down came back with a vengeance. I remember feeling heartbroken and yet at peace with the direction we were heading. Finally we had some answers and help from the Birth to Three program.

Our experience in the Birth to Three program was life changing. We found the teachers to be knowledgeable, compassionate, hardworking, and genuinely fond of our children. For the first time as parents, we found other people going through a similar situation.

What We Learned

Early intervention plays a crucial role in a child’s education. It is important to act quickly if you suspect your child has a delay and disability. Unfortunately, many pediatricians and families tend to wait and see, costing a child valuable time. If there is one message I could shout to the world, it is this: You don’t need a medical evaluation to begin receiving Birth to Three services. If a pediatrician is hesitant to diagnose a disability at an early age, that child can still be referred to the Birth to Three program. Therapy can target developmental delays present in a child, even without a diagnosis. Please, if you suspect a child has a delay, don’t “wait and see.” Act now. This is my regret with my son Jack. We allowed ourselves to be talked into waiting and, as a result, he aged out of the program after a mere seven months.

Additionally, I would love to see the medical community collaborating more with the Washington State Department of Early Learning. My dream is to see local hospitals create a position that would act as a liaison between pediatricians and local schools. The position would help pediatricians stay current on the ever-changing services and therapies available in their communities and educate them on the importance of early intervention. In addition, the position would work directly with families to help them craft the perfect team for their child’s individualized needs.

As an experienced parent of two boys with autism spectrum disorder, my goal is early identification of needs and service options for families. Through better coordination with doctors and service providers, children with special needs can look forward to an enriched and higher quality of life.

Amanda Beers Crawford currently resides in Kennewick, Washington, with her husband and children. She is a piano instructor specializing in teaching children with developmental disabilities to play the piano. At age four, Amanda was diagnosed with a profound bi-lateral hearing loss. Amanda is a classically trained pianist who has been performing and competing for 25 years. Her hard work and dedication resulted in winning the title of Miss Washington 2002 and a placement in the “top 15” at the Miss America Pageant. During her year of service, Amanda traveled nationally speaking to legislators, organizations, and celebrities about the issues facing the deaf and hard of hearing community, of which she is a member. Amanda now advocates for children with special needs and their families.

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State Reports . . .

Early Identification of Developmental Delays and Maternal Depression

Kristine Green and Marcy Custer

Through commitment and collaboration, the Alaska State Department of Health and Social Services has made significant steps in the last five years in the early identification of developmental delays and maternal depression. Examples of activities include:

**Medicaid.** In May of 2012, Alaska Medicaid adopted the Bright Futures Periodicity Schedule© for the Early Periodic Screening Diagnosis and Treatment program. The Bright Futures Periodicity Schedule recommends developmental screening using a standardized screening tool at 9, 18, and 30 months of age, or whenever there is a concern, and developmental surveillance at other visits. It recommends autism screening at 18 and 24 months of age.

**Office of Children’s Services.** In 2012, as part of a coordinated statewide system to achieve universal developmental screening for children to five years of age, the Early Intervention / Infant Learning Program made available free online versions of the Ages and Stages Questionnaire (ASQ-3™) and Ages and Stages Questionnaire: Social Emotional (ASQ:SE™) to health care providers in Alaska. As part of this effort, a developmental nurse practitioner assists each provider in setting up an electronic medical record system to assure records are accurate and accessible. The availability of these online screening tools significantly improves accessibility to developmental screening.

**Public Health Nursing.** In 2010, public health nursing adopted standardized developmental screening tools that included the ASQ-3™, Parents Evaluation of Developmental Status (PEDS™), Parents Evaluation of Developmental Status: Developmental Milestones (PEDS:DM™), and Modified Checklist for Autism in Toddlers (M-CHAT™). Public health nurses use a standardized screening tool with every well-child visit. In December 2013, a revised M-CHAT™ and Follow-Up Interview (M-CHAT-R™ and M-CHAT-R/F™) became available, with improved questions and easier scoring. Public health nursing is adopting these revised tools as they should do a better job of detecting early the symptoms of autism.

**Section of Women’s Children and Family Health.** Because of itinerant staffing and the complexity of the health care system in rural Alaska, children living in rural areas are generally identified later than their urban counterparts for developmental delays. To address this disparity, the state expanded the Pediatric Neurodevelopmental Outreach and Autism Clinic to 10 additional locations in rural areas across the state. Over the last three years, there has been a steady increase in the number of younger children in rural areas being identified with developmental delays, and families seeking evaluations for intervention services.

**Home Visiting Programs.** Both the Nurse-Family Partnership and Healthy Start programs screen infants and toddlers for appropriate growth and development. They also screen women during pregnancy and the postpartum period for symptoms of maternal depression. For more information about these programs, see the spring and fall 2013 issues of the Northwest Bulletin.

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Idaho State’s Infant Toddler Program’s Comprehensive Child Find System

Lauren Ertz

In the State of Idaho, the Infant Toddler Program (ITP) is the lead agency responsible for implementing the Individuals with Disabilities Education Act (IDEA) Part C. As the lead agency, ITP must ensure a statewide comprehensive, coordinated, multidisciplinary system to provide early intervention services for infants and toddlers with delays or disabilities and their families.

Important components of the statewide system required by Part C include a public awareness program and a comprehensive child find system. (1) The purpose of these systems is to ensure the state is making every effort to reach out to communities about early intervention and detection, and identify as many children as possible who may have or are at risk of having a developmental delay or disability.

As many as one in four children through the age of five years are at risk for a developmental delay or disability. (2) Significant resources have gone into outreach and screening activities across Idaho to identify children who may need early intervention services, as well as to increase awareness about ITP.

Developmental Milestones

Developmental Milestones is ITP’s monitoring program responsible for child find, child monitoring, and public awareness activities. This program is available at no charge for any child under the age of three years living within the state. Parents enroll in Developmental Milestones by filling out an Ages and Stages Questionnaires (ASQ-3™) online or by mail. Children found to be behind their peers in any developmental area are referred to ITP for an evaluation to determine the need for early intervention services. When a child turns three, the family is sent information about Easter Seals’ Make the First Five Count Campaign where they can continue with the ASQ-3™ until their child turns five.

Currently, around 6% of Idaho’s children under the age of three years are enrolled in Developmental Milestones. Additionally, ITP serves 2.87% of the state’s infants and toddlers, ranking Idaho 5th in the nation among Part C programs. (3) The increase in the number of children served is a direct reflection of recent Developmental Milestones initiatives: centralizing the monitoring process, implementing on-line screening, and collaborating with the Idaho Newborn Hearing Screening Program, to name a few. The ITP has increased public awareness of Developmental Milestones at both the state and local level through a variety of ways, including targeted outreach activities, home visiting programs, and referrals from ITP when children are evaluated but not eligible for early intervention or when families no longer have a need for early intervention.

Conclusion

The comprehensive child find system is a critical component of a state’s early intervention program. In Idaho, child find activities are a top priority. Centralizing the system has improved our ability for statewide collaborations and monitoring, as well as created accountability at the local level to ensure child find activities are implemented consistently.

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REFERENCES:
Developmental Screening: Aligning Health Care and Early Learning Policy in Oregon

Oregon Health Authority

Dana Hargunani

Under Governor Kitzhaber’s leadership, Oregon State is simultaneously transforming both its health and early learning systems. New regional organizations integrate physical, mental, and dental Medicaid services (Coordinated Care Organizations or CCOs) and early learning services (Early Learning Hubs). These new organizations are held accountable for specific metrics and outcomes, but they have substantial flexibility to meet the needs of their diverse communities. These transformations will dramatically increase Oregon’s ability to achieve desired short- and long-term outcomes for population health and prosperity.

Developmental Screening

Developmental screening is central to these transformations. The state’s Metrics and Scoring Committee adopted developmental screening in the first three years of life as one of Oregon’s 17 CCO incentive measures. Quality pool dollars1 are distributed, in part, based on a CCO’s ability to improve or meet a benchmark for this measure. Compared to 2011 baseline data, Oregon’s rate of developmental screening increased from 20.9% to 31.7% in the first three quarters of the initial measurement year (January–September 2013). Many of Oregon’s CCOs have partnered with local public health providers, including home visitors, to successfully increase their rates of developmental screening.

Developmental screening is also integral to Oregon’s Early Learning System. The state has incorporated developmental screening requirements into the newly established Quality Rating and Improvement System for child care. Early Learning Hubs are also required to set community targets for developmental screening in coordination with their local CCOs as part of their application and contract with the state’s Early Learning Division. Funding from Oregon’s Race to the Top–Early Learning Challenge grant and the Early Childhood Comprehensive Systems grant is being used to build resources and professional training on developmental screening.

Aligning Policy

Oregon’s Health Policy Board and Early Learning Council formed a joint policy committee with the goal of aligning health and early learning policies. The committee has adopted recommendations for a statewide, coordinated system of developmental screening that includes:

- Shared incentives and accountability for screening
- Training requirements for participating providers
- Secure information exchange across provider systems
- Shared messaging regarding the importance of developmental screening
- Best practices for care coordination and case management

In close partnership with the Early Learning Division, a new child health team within the Oregon Health Authority will oversee implementation of these recommendations. Partnership with state and local public health entities will be integral for the success of these efforts.

Dana Hargunani, MD, MPH, Child Health Director, Oregon Health Authority, advises on health policy for children and families across the agency. She is a general pediatrician and serves as a member of the Oregon’s Early Learning Council and oversees state-level developmental screening activities.

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1 As part of an agreement with the Centers for Medicare and Medicaid Services, the Oregon Health Authority established a financial pool or "quality pool" to hold CCOs responsible for spending on health care, as well as quality of care provided. This model will increasingly reward CCOs for value and outcomes, rather than utilization of services.
The Universal Developmental Screening Partnership (UDS Partnership) was created to make universal developmental screening available to all young children in Washington State. Led by the Department of Health, this voluntary, multi-sector partnership consists of state and local agencies, programs, and providers. (See box for a listing of grant and project support.) Early in the partnership, a framework and an outcome map were created. The process of creating the outcome map was intentionally inclusive, incorporating other statewide early childhood plans, and resulted in a guide each of the partners could use in their respective work. It solidified a common vision, set goals, established desired outcomes, and outlined strategies.

In 2010, developmental screening became a state performance measure in Washington State’s Title V Maternal and Child Health Services block grant. In 2012, local health jurisdictions were required to focus on state performance measures related to developmental screening and the Adverse Childhood Experiences (ACE). While local health jurisdictions could choose either or both, twenty-one of the thirty-two local health jurisdictions chose to work on developmental screening in their communities.

Current Activities

Examples of current activities include: the Department of Health is coordinating with the Department of Early Learning’s Quality Rating and Improvement System (QRIS) to establish trainings for child care providers. The Department of Early Learning is involved in incorporating Part C Early Intervention Services and home visiting into the universal development screening framework. The Department of Health and the UDS Partnership are exploring data needs and options for a cross-sector data system. The Washington Chapter of the American Academy of Pediatrics is providing physician training. WithinReach is operating Help Me Grow Washington.

Conclusion

Universal developmental screening bridges health, early learning, and communities. The current Early Childhood Comprehensive Systems (ECCS) grant allows the Department of Health to coordinate the efforts of the UDS Partnership to build a system that serves all young children in Washington State.

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Grant and Project Support for Universal Developmental Screening Partnership:

- CDC Autism Grant
- Learn the Signs. Act Early
- Great MINDS (Medical Homes Include Developmental Screening)
- Project LAUNCH (Linking Actions for Unmet Needs in Children’s Health)
- Early Childhood Comprehensive Systems
- Washington Chapter of American Academy of Pediatrics
- WithinReach, Help Me Grow Washington
- Washington State Department of Early Learning
- Early Support for Infants and Toddlers (IDEA Part C)
Resources . . .


Postpartum Support International. [www.postpartum.net](http://www.postpartum.net)

Screening and Assessment. Section on Developmental and Behavioral Pediatrics, American Academy of Pediatrics. [www2.aap.org/sections/dbpeds/screening.asp](http://www2.aap.org/sections/dbpeds/screening.asp)


Technical Assistance Center on Social Emotional Intervention for Young Children. [http://challengingbehavior.fmhi.usf.edu/communities/program_leaders.htm](http://challengingbehavior.fmhi.usf.edu/communities/program_leaders.htm)


WithinReach. [www.withinreachwa.org/](http://www.withinreachwa.org/)

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**State Early Intervention Contacts**


Oregon Early Intervention and Early Childhood Special Education. Oregon Department of Education. [www.ode.state.or.us/search/results/?id=252](http://www.ode.state.or.us/search/results/?id=252) and [www.ode.state.or.us/gradelevel/pre_k/eiecse/dyhc_finalenglish.pdf](http://www.ode.state.or.us/gradelevel/pre_k/eiecse/dyhc_finalenglish.pdf)