VOL. XVIII No. 2 SPRING 2004

Children and Families

THE MAGAZINE OF THE NATIONAL HEAD START ASSOCIATION

Safe Transportation for Head Start

Planning for Exceptional Services

Off to a Good Start

Accurate and Inexpensive Developmental Screenings

The first step in early intervention

Identifying problems in children as early as possible and then intervening effectively makes sense. More important — it works, saving lives, money, and angst. As the National Academy of Sciences stated in *From Neurons to Neighborhoods,* "Compensating for missed opportunities, such as the failure to detect early difficulties or the lack of exposure to environments rich in language, often requires extensive intervention, if not heroic efforts, later in life."

Study after study shows that intervention prior to kindergarten has huge academic, social, and economic benefits, including savings to society of $30,000 to $100,000 per child. While undoubtedly substantial, the dollars saved are not the only measure of value — especially to the one-in-25 households with a disabled preschooler. Intervention during infancy or the preschool years can improve a child's health, learning, and social and emotional development in ways that might be impossible just a few years later.

Margaret Dunkle
Senior Fellow
Center for Health Services Research and Policy
George Washington University
Los Angeles, California

Louis Vismara
Consultant
California State Legislature
Sacramento, California

Fortunately, our country's track record for finding and helping young children with physical conditions such as leukemia, juvenile diabetes, and asthma is improving. Unfortunately, the same isn't true when it comes to mental health and learning and behavioral problems, which all too often go unattended, missing the critical womb-to-5 window of opportunity when a child's brain, body, and behavior change at the most astonishing rate.

Late identification of these problems forces states, schools, and taxpayers to foot the bill for expensive special education fixes to problems that might have been resolved, or at least treated more effectively and more economically, during the preschool years. Consider these facts: At least 5 to 8 percent of children under age 5 have some sort of disability or chronic condition such as autism, cerebral palsy, diabetes, epilepsy, mental retardation, or orthopedic problems. The American Academy of Pediatrics cites much higher figures. The Academy says that 12 to 16 percent of children have developmental or behavioral disorders. Nationwide, more than 5 percent of children ages 3 to 5 are enrolled in special education programs. The number of children with autism, for which early intervention is essential, is soaring. A 2003 editorial in the *Journal of the American Medical Association* estimated that nationwide one in every 170 children is affected by an Autism Spectrum Disorder. The number of people with autism in California's Developmental Services System doubled between 1998 and 2002.

Caucasian children with serious disabilities are often identified at much younger ages than ethnic- or language-minority children. A study of Pennsylvania children covered by Medicaid found that Caucasian children were diagnosed with autism more than one year earlier than their African-American or Latino counterparts (age 6.3 for Caucasian children, 7.9 for African-American children, and 7.4 for Latino children).

Why are so many developmental and behavioral problems missed in young children?

We know early intervention and money help over the long haul, so why do so many developmental delays and problems go unaddressed? The most obvious explanation would probably be that we don't know how to spot developmental or behavioral problems in very young children — but this is not the case. Good screening instruments do exist. In a 2001 policy statement, *Developmental Surveillance and Screening of Infants and Young Children*, the American Academy of Pediatrics (AAP) noted three parental-report tools that take just a few minutes to administer and accurately identify children with problems and developmental delays: the 10-question PEDS (Parents' Evaluation of Developmental Status, available in English and Spanish), the Ages & Stages Questionnaires (available in English, Spanish, French, and Korean), and the Child Development Inventories (available in English and Spanish). These tools capture parental information about their children so that doctors, educators, administrators, and specialists can follow up with effective interventions. In fact, these simple instruments identify 70 to 80 percent of children with problems. Even better, repeated or periodic screenings increase these percentages. That's the good news.

The bad news is that only 15 percent of pediatricians always use a screening tool. Seven out of 10 rely on their clinical judgments, even though this method identifies fewer than 30 percent of children with mental retardation, learning disabilities, language impairments, or other developmental disabilities, and less than 50 percent of children with serious emotional and behavioral disturbances. Physicians who simply "eyeball" their youngest patients miss half of the problems that a two-minute screening tool would catch immediately.

> "If every child had a reliable developmental check-up and communities followed up with services, thousands of children would have better lives."

Working toward early identification and intervention

If every child had a reliable developmental check-up and communities followed up with services, thousands of children would have better lives. In our home state of California, at least 124,000 children under age 5 have or will develop a disability or mental or behavioral disorder (using a conservative 5 percent disability rate). If every child was screened using a reliable screening tool, at least 75 percent, or 93,000 children, could get needed help early, when it could do the most good. With repeat screenings, this number would go up even more. As things stand, however, fewer than half will be identified as needing help.

What we can do

Our country's inadequate record of identifying young children who need help could be quickly turned around if policymakers and communities set their minds to it. Here are five steps that Head Start programs can take to lead the way.

1. **Make sure every Head Start program uses a high-quality developmental screening tool that is accurate, reliable, and easy to use.** Head Start rules already require programs to screen each child within 45 days of entering the program, so why not use the best tools available? ➥

The long-term cost of special education is ratcheted up every time a child enters school with problems that could have been — but weren't — addressed during the preschool years. Examples include…

- A child who can barely speak because he can barely hear.
- An autistic child spinning and flapping, who would be in a regular classroom if he had received intensive behavioral therapy at age 3.
- A first-grader diagnosed as mentally retarded after his family moved to an older home with lead-based paint.
- An exceptionally smart but out-of-control boy who is in therapeutic day school rather than a gifted-and-talented program because he never received help for ADHD (attention deficit-hyperactivity disorder).

Q: Is it OK to use the "Denver" instead? A: No.

According to policy statements by the American Academy of Pediatrics (AAP), the American Academy of Neurology, and the Child Neurology Society, the "Denver" is not nearly as high in quality as the three screening tools the AAP calls "excellent": the PEDS (Parents' Evaluation of Developmental Status), the Ages & Stages Questionnaires, and the Child Development Inventories.

The AAP Policy Statement on *Developmental Surveillance and Screening of Infants and Young Children* states, "…the Denver-II screening test is used widely but has modest sensitivity and specificity depending on the interpretation of questionable results." The Denver does not do a good job of doing precisely what a screening instrument is supposed to do, which is to identify children who have problems and those who don't.

The American Academy of Neurology and the Child Neurological Society are even more direct in their statement, *Screening and Diagnosis of Autism*: "Because of the lack of sensitivity and specificity, the Denver-II (DDST-II) and the Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ) are not recommended for appropriate primary-care developmental surveillance."

Parents should be told that if their child's pediatrician plans to use the "Denver," they should let the doctor know that they would rather have their child screened with the PEDS (Parents' Evaluation of Developmental Status), the Ages & Stages Questionnaires, or the Child Development Inventories.

2. **Provide parents with copies of the completed screening instrument to take to their child's pediatrician or doctor.** This way, even if a high-quality screening is not done in the physician's office, parents will be armed with results from (to quote the American Academy of Pediatrics' policy statement) "high-quality developmental screening instruments" — information likely to be more persuasive to doctors than parental concerns voiced during a brief office exam. Parents need to know that they have the right to expect their child's doctor to use a good screening tool, not just "eyeball" their child during a well-child visit.
3. **Identify and fund services for very young children with delays and disabilities.** Considering that we know the value of early care, it is surprising that our government uses so little of our tax money where research shows it would do the most good — the earliest years of life. Currently the federal per-child contribution for the approximately 700,000 children ages 3 to 5 who are in special education (IDEA) *is less than half that for school-age children*, and the gap is widening. The federal contribution for infants and toddlers age 0 to 2 has dropped by more than $150 per child since 1992. This "penny wise, pound foolish" approach ends up costing families, schools, communities, and taxpayers dearly over the long haul. While President Bush's 2005 budget proposes more than a $1-billion increase in funding for special education (IDEA), only two percent of this increase is for children ages 0 to 5, further widening the funding gap between school-age and preschool-age children**.** Encourage your elected officials and community leaders to support increased funding for the youngest children with problems and developmental delays — IDEA for infants and toddlers (also known as "Part C") and IDEA for 3-5 year-olds (also known as "Part B, Section 619").
4. **Integrate early identification and treatment of mental health and learning and behavioral problems into core educational standards and procedures.** Some states and commu-

Schools and communities can change what happens in doctors' offices.

- Head Start programs and schools can educate others about the importance of screening by sending letters and information to local newspapers, sending home flyers with older siblings, and partnering with the health departments and other agencies.
- Community groups can sponsor speeches and training workshops on early identification.
- The school board or city or county council can hold hearings to assess the community's performance in identifying and helping young children with developmental problems.

Why have parental report tools?

Several studies show that a parental report of current skills is predictive of developmental delay. The use of parental reports has the added an advantage of showing respect for parents' expertise by actively involving them in their children's evaluation.

Systematically eliciting parental concern about development is an important method of identifying infants and young children with developmental problems. Parental concerns about language, fine-motor, cognitive, and emotional-behavioral development is highly predictive of problems.

Source: Developmental Surveillance and Screening of Infants and Young Children *(RE0062), a position statement published by the American Academy of Pediatrics in the July 2001 issue of* Pediatrics.

> "Unaddressed social and emotional issues in very young children too-often escalate into serious behavioral problems in adolescents."

nities are already taking concrete steps to emphasize that social and emotional well-being directly affects learning: Unaddressed social and emotional issues in very young children too-often escalate into serious behavioral problems in adolescents. This holistic approach — so familiar to Head Start programs — recognizes that learning and developmental problems, social and emotional risk factors, and mental health problems often occur in combination with one another, and that piecemeal solutions are ineffective. The Los Angeles County Children's Planning Council and First 5 LA have identified the degree to which preschool children who need special education actually receive it as a core indicator of school readiness. And a 2003 Illinois report on children's mental health recommended that the legislature require that the State Board of Education incorporate social and emotional standards into the Illinois Learning Standards. Check to make sure the standards in your state and school district reflect the important role that social and emotional well-being plays in learning.

5. **Train parents, Head Start teachers, and staff members to use the parent-based screening tools,** rather than depend entirely on doctors and other professionals to look for and flag problems. These common-sense tools help parents describe their concerns about their child's learning, development, and behavior in ways that enable "experts" to quickly zero in on problems and identify effective interventions.

Early identification is the essential first step to ensuring that infants and preschoolers with problems get the help they need to grow and learn. Head Start programs can be leaders by making it a priority to ensure that every child in Head Start is screened — early and often — using an effective and reliable screening tool.

A number of problems — like some disabilities — cannot be fixed, at least not yet. But our country's unfortunate record of identifying infants and preschoolers with problems can be fixed. *We just need to do it.* C&F

Margaret Dunkle is a senior fellow with the Center for Health Research Services and Policy, Department of Health Policy at George Washington University. Dunkle lives primarily in Los Angeles. The California Endowment and Annie E. Casey Foundation support her work.

Louis Vismara, M.D., is a parent of four children, one of whom has autism. A retired invasive cardiologist, he currently works as a consultant with the California State Legislature and is a Commissioner on the California First 5 Commission.

This article was adapted by the authors from two previously published articles: "A Different Kind of Test," a commentary that appeared in Education Week, September 24, 2003 (visit www.edweek.org/ew/ewstory.cfm?slug=04dunkle.h23 to read the article or www.edweek.com to learn more about the organization), and also from "Research Reflections" that appeared in Exceptional Parent Magazine, January 2004 (visit www.eparent.com/researchreflections/research reflections_01_04.htm to read the article or www.eparent.com to learn more about the publication). For a footnoted version of this article, e-mail requests to mcd729@aol.com.

For more information...

For information on PEDS (Parent' Evaluation of Developmental Status), visit www.pedstest.com or call (888) 729-1697.

For more information on the Ages & Stages Questionnaires, visit www.brookespublishing.com or call (800) 638-3775.

For more information on the Child Development Inventories, visit www.childdevrev.com or calling (612) 850-8700.