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## Making Early Developmental Screenings Routine

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Dane Fliedner has a simple message for parents: "You know your child better than anyone."

Fliedner, a pediatrician who works at a clinic just south of Los Angeles, is part of a growing number of pediatricians who see parental observation as a powerful tool for predicting a child's possible disabilities, developmental delays and other challenges.

It is the same message that the Los Angeles County Early Identification & Intervention Group has been trying to spread for the last two years. The group, which now collaborates with roughly 100 agencies in the sprawling county of Los Angeles in Southern California, is a strong advocate for a three-pronged approach: early screening using high-quality tools based on parent observation; quick follow-up from health care providers; and help for families in finding and accessing the resources they need.

"I think that families need to understand that appropriate and timely screening is important," said the Long Beach-based Fliedner. The earlier a problem is identified, he added, the earlier a child gets help. And if a child is not being routinely screened, parents need to feel empowered to speak up.



### Lunch-table Discussion Launches County-Wide Campaign

The idea for the L.A. group began simply enough over lunch in October of 2003. A group of ten friends and colleagues—experts in the fields of mental health, education, philanthropy and advocacy—talking about what they knew about early identification of children with disabilities, developmental delays or other problems. The group was called together by Margaret Dunkle, senior fellow at the Center for Health Services Research & Policy of George Washington University, and included educational therapist Cynthia Landes, developmental pediatrician Mike Regalado of Cedars-Sinai Medical Center,

Madeline Hall of the Los Angeles County Office of Education, Karen Kirsche of the LA Unified School District, Zelna Banks of the Early Intervention program, Dorothy Fleisher and Annalei Klump of the W.M. Keck Foundation, and Sam Chan and Ilda Rueda De Leon of the County Mental Health Department.

The conversation addressed the critical importance of catching problems early, especially in under-served populations – and ended with everyone looking at Dunkle.

"When do we start?" they asked her.

Dunkle's answer was simple: right away. So she became the convener of the Los Angeles County Early Identification & Intervention Group. Dunkle is well aware that the scope of her group's mission is enormous.

"Very few places are as big as Los Angeles," said Dunkle. Los Angeles County has a population greater than 42 states and is home to at least 37,000 children, age five and under, who have or will develop a disability or mental or behavioral disorder. In all, there are more than 2.7 million children under age 18 in the county.

"When Los Angeles does something, it has a tremendous impact on the state, and when California does something it has a national effect," said Dunkle.

The group began meeting monthly, each meeting hosted by a different organization: one month at the 100-year-old nonprofit Children's Institute Inc., another at the County Health Department and another at the Westside Children's Center. Between meetings, Dunkle's e-mail newsletters keep everyone in the know. The group has been sustained by, and has grown through, old-fashioned word of mouth, she said.

"It's really quite amazing," Dunkle said. "At every meeting there are new people. For all of its diversity and complexity people in Los Angeles County are on the same page about early identification and intervention. The issue touches almost everyone personally." The sales pitch or "elevator statement" as Dunkle calls it, is clear and concise: "We want every child in Los Angeles County to be screened for developmental delays and (we want) follow-up for each child who needs it," she said.

## **Using Parents as Experts**

To that end, the group wants pediatricians and parents to have access to and to use age-appropriate, culturally sensitive, accurate, reliable and valid screening tools—specifically the Parents' Evaluation of Developmental Status (PEDS) and Ages and Stages Questionnaires (ASQ).

"Some tests like the Denver (Denver Developmental Screening Test), while

they were an innovation in their day, have not kept up with today's standards. They don't do a good job of picking out the kids with or without problems," Dunkle said.

The Denver misses up to 50 percent of mental retardation and 70 percent of language impairments according to Dunkle and to Frances Glascoe, an adjunct professor of pediatrics at Vanderbilt University and the developer of PEDS. Glascoe said some pediatricians still believe that they can judge children by looking at them, but informal observations "miss actually about 70 percent of kids."

The ASQ was developed by Diane Bricker and Jane Squires, to flag possible social-emotional, behavioral and mental health problems as well as problems with learning.

### **Ages and Stages Questionnaires (ASQ)**

- Designed for children up to 60 months (five years) of age
- Addresses developmental areas of communication, gross and fine motor skills, problem solving, personal and social development
- Questions are age-specific
- Comes in English, Spanish, French, Korean and other languages.
- Parents indicate child's developmental skills on 25 to 35 items at each well-child visit
- Depending on age being screened, reading level ranges from third- to 12th-grade comprehension
- Gives a single pass/fail score
- Takes 10 to 15 minutes to complete)

Glascoe and other experts say that pediatricians must learn to value parents' observations, know how to evaluate a parent's answers on a screening and know how to identify red flags. Parent-based screening tools like the PEDS and ASQ also get parents involved in a meaningful way, they are less subject to bias based on ethnicity and gender and are low-cost and effective.

"Parents are around their children all the time so they notice things that other people don't," notes Glascoe.

### **Bringing Pediatricians On Board**

Getting pediatricians to buy into that, though, is difficult. Physicians are not

taught that parental observations are a good indicator of a potential problem, and in some institutions they are still taught to rely on the outdated Denver.

But Long Beach's Fliedner says using these tools helps him in his practice, by enabling him to make the best of the very short time he gets with patients. The screens can be done at home, in a waiting room or with the help of a nurse practitioner, aide, receptionist or office manager during a well-child visit. Pediatricians are pressured to see as many patients as they can and Fliedner admits that when time is short, patients only get the basics.

### **Parents' Evaluation of Developmental Status (PEDS)**

- Consists of 10 questions for parents
- Designed for children aged nine and under
- Identifies children as at low, moderate or high risk for various disabilities and developmental delays
- Determines whether physician should refer; do further screening; provide parent/patient education; or monitoring
- Comes in English, Spanish, Vietnamese and several other languages
- Written at a fifth-grade comprehension level
- One page long, takes about two minutes to complete.

But when a parent brings a completed screening to Fliedner, he can quickly see if the child has been flagged for a delay. If there is a red flag on the PEDS, he administers the ASQ and guides the family toward useful interventions. If there are no flags, Fliedner knows he can focus on the next issue.

"It allows you to spend more time on other things," said Fliedner.

In the past, physicians were not reimbursed for using these tools, but just over a year ago a CMS Relative Value Unit (a special code on medical forms) was assigned to the developmental screens. That means that physicians can now be reimbursed, eliminating at least one excuse to skip the screening.

### **A Parent Champions Early Screening**

What's even better about tests like the PEDS is that they are so parent-friendly.

"It's not intimidating and actually you can do it right on-line," said Nancy Wiseman, a Massachusetts mother. Wiseman's daughter was diagnosed with

autism at age two, and she remembers how hard it was to find help with screenings, referrals and treatment.

Seeing the difference early, intensive intervention has made for her daughter motivated Wiseman to start First Signs, Inc., an agency focused on improving early identification of, and interventions for, autistic children and children with other developmental disorders. Wiseman's group teaches parents how to advocate for their children and points them to the resources that can help them once a diagnosis has been made. When problems are not identified early, Wiseman said, the long-term effects can be devastating.

Dunkle points to Wiseman as an example of how widespread the need for early identification is. There are other advocates working in North Carolina, Tennessee and Louisiana to help make people more aware of the need for early intervention.

In a question and answer session for her new book, *"Could It Be Autism? A Parent's Guide to the First Signs and Next Steps"*, Wiseman said that her daughter has made "profound progress over the years, thanks to early identification and intensive intervention."

"It's absolutely critical to get the word out about the importance of early childhood screenings," said Wiseman. "We are encouraging parents to take the screening and bring it to their well visit... We need to create a kind of push-pull kind of effect so that parents are asking for a screening at every well-child visit."

## **By the Numbers**

High-quality screening tools immediately identify 70 to 80 percent of children with problems, but fewer than 15 percent of pediatricians routinely use any kind of screening tool, according to Dunkle.

Nationwide, one in six children have a developmental delay, disability or a learning, behavioral or social-emotional problem and five to eight percent of children under five years of age have a disability or chronic condition like autism, cerebral palsy, epilepsy, mental retardation or orthopedic problems.

"Early screening and intervention are not magic bullets that can fix everything. But they do make the future of that child and his or her family a hell of a lot better," said Dunkle. "Intervention in early childhood really does work best and cost less over the long haul."

Dunkle is proud to say that the Los Angeles-based group has already made its presence known on Capital Hill. It is playing a significant role in drafting the newest Head Start legislation and now due to its recommendations, high-quality screens are part of the bill that has passed the House of Representatives. "If you have early intervention you can make a big

difference."

## Resources

- For more information about early developmental screenings and becoming an advocate for your child visit First Signs [1].
- Publisher Random House has an excerpt from Nancy Wiseman's book, "Could it Be Autism [2]" on-line.
- For information on upcoming events, links and articles about early identification and screening contact Developmental Behavioral Pediatrics Online or The American Academy of Pediatrics [3].
- For more information or to get involved in the Los Angeles County Early Identification & Intervention Group Margaret Dunkle, Convener, Los Angeles County Early Identification & Intervention Group, and Senior Fellow, Center for Health Services Research & Policy, George Washington University. Mcd729@aol.com [4] or MargaretDunkle@gmail.com [5].

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### Source URL:

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### Links:

[1] <http://www.firstsigns.org>

[2] <http://www.randomhouse.com/broadway>

[3] <http://www.aap.org/>

[4] <http://www.connectforkids.org/mailto:Mcd729@aol.com>

[5] <http://www.connectforkids.org/mailto:MargaretDunkle@gmail.com>