GUIDING PARENTS THROUGH BEHAVIORAL ISSUES AFFECTING THEIR CHILD’S HEALTH: THE PRIMARY CARE PROVIDER’S ROLE

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INTRODUCTION

Will was a charming 15 year-old African American young man, born in Oakland, California. He grew up in a housing project near Oakland Children’s Hospital. As Will was progressing through school, he became increasingly frustrated by his poor academic performance. He always had difficulty in school; it seemed to take him twice as long to read assignments in elementary school. By the time he was in the 8th grade, he had been “passed on” twice, even though his reading and math skills had not progressed much beyond the 4th grade level. Will was engaged in school mostly because of athletics…he was a star running back on his high school football team. He took great pride in his athletics. Unfortunately, he was suspended from the team when his GPA dipped below 2.0. Three months later he dropped out of school. He was arrested and convicted for selling marijuana; he said “to pay bills.” After two years of incarceration, he was released. Within two months, he was dead; shot in the head by a rival.

Will was one of my first clients in the teen clinic at Oakland Children’s Hospital. His very sad story highlights why I will never give up general pediatrics, although I am also the medical director of an adolescent medicine program for males. Child healthcare providers must do a better job of finding, intervening, case-managing, and following up for developmental or behavioral problems in childhood, if we are to prevent other tragedies. The field of Pediatrics continues to evolve. We continue to develop more and more vaccines and other strategies to reduce the risk of infectious diseases and we are intervening in high risk pregnancies and neonatology, preventing chronic illness in former premature infants. We are developing better strategies in prevention for some of our major other causes for mortality; as an example, recent recommendations for enhancing SIDS prevention were recently announced (Table 1). The next frontier in Pediatrics is enhancing our screening, detection, and intervention in childhood behavioral and developmental problems.

Adult Dysfunction is Linked to Childhood Behavioral Problems

Every day in the United States, on average, six to seven youths are murdered. Our prison system is overwhelmed by continued infusions of new offenders. There is a growing body of evidence describing the link of early childhood problems with adult dysfunctions (Table 2).

There is also a growing body of evidence that suggests that earlier interventions may help to prevent these problems. One representative program, funded by the National Institute of Mental Health, is the “Nurse Home Visitation Program.” In this program, currently operated at centers in Colorado, New York, and Tennessee, visiting nurses meet with new and prospective families frequently, support the pregnancy and follow the children for the first two years of life. Children are closely monitored for developmental and behavioral issues. If there are issues discovered, they may be addressed by a focused behavioral intervention (if minor) or by referral to experts. The study results demonstrated that by age 15 years, these study participants as teens had fewer behavioral problems, less substance abuse,
fewer arrests, and even fewer sexual partners.²

USING PRIMARY CARE TO IDENTIFY AND INTERVENE IN CHILDHOOD DEVELOPMENTAL AND BEHAVIORAL PROBLEMS

So how do we identify behavioral and developmental issues? Healthcare providers who work with children should be vigilant in three ways. First, we must identify risk factors that lead to poor parenting. Examples are unplanned pregnancies, adolescent parents (without proper guidance), or homeless families. Second, we must carefully examine developmental status—using developmental surveillance at all visits and standardized tools for developmental screening at health maintenance visits. Finally, there are standard issues that should be discussed and anticipated relevant to specific developmental ages in infancy and early childhood development.

BEING VIGILANT FOR FAMILIES AT RISK

Infants born from unplanned pregnancies statistically have poorer outcomes (more premature, lower birthweight infants, less well child care, and less breastfeeding) than in families where infants were planned.³ While many parents who have unplanned pregnancies do very well with their children, unfortunately, poor parental motivation and preparation may interfere with their ability to be the best parents for their children. Families that live in poverty may have conflicting interests—they wish to provide the best parenting for their children, but are struggling to make a decent living or find stable housing and these may not allow them to spend the amount of true quality time with their children. Similarly, teen parents are often not equipped yet for the level of maturity and responsibility that is required to raise their children with an optimal developmental outcome; often they are still struggling with their own developmental issues. Yet some parents do very well. One of my families comes to mind; the parents had their first child when the father was 17 and the mother was 16. Yet, they were wonderful, nurturing parents. They developed a plan for their own continued development. The father went to work and the mother finished her education; then they swapped. With excellent familial and community support, this family has successfully parented their child.

USING DEVELOPMENTAL SURVEILLANCE AND SCREENING

Pediatricians, family physicians, nurse practitioners, and physician assistants that take care of children also must be vigilant for developmental and behavioral issues at every office visit. Developmental surveillance is the classic method when a healthcare provider observes behavior and development and the parent-child interaction, and determines if this is normal or not. This is done on every patient and parent encounter. Developmental surveillance works well when the child is not in the office for a health supervision visit. A new patient in the office for an illness or healthcare concern is observed for developmental tasks and parents questioned about age-appropriate skills. However, developmental surveillance may grossly underestimate the number of children with developmental or behavioral problems.⁴

At health maintenance visits, many physicians still use developmental checklists typically embedded in pediatric encounter forms. Although they

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Table 1. New SIDS Prevention Guidelines from the AAP

- Infants should be placed wholly on back position for every sleep.
- A firm crib mattress, covered by a sheet, is the recommended sleeping surface.
- Keep soft objects and loose bedding out of the crib
- Do not smoke during pregnancy.
- A separate but proximate sleeping environment is recommended.
- A pacifier should be used when placing infant down for sleep
- Avoid overheating.
- Avoid commercial devices marketed to reduce the risk of SIDS.
- Do not use home monitors as a strategy to reduce the risk of SIDS.
- Assure that others caring for the infant are aware.


Table 2. Information from NIMH Fact Sheet

“Such forces such as weak bonding, ineffective parenting (poor monitoring, ineffective, excessively harsh, or inconsistent discipline, inadequate supervision), exposure to violence in the home…puts children at risk for being violent later in life. This is particularly so for youth with problem behavior such as early conduct and attention problems, depression, anxiety disorders, lower cognitive and verbal abilities…”

contain age-specific tasks, such checklists are neither validated nor standardized. There are no objective screening criteria to enable clinicians to determine how many failed items are too many. Should the child who misses one of the four or five tasks listed be referred? Two of five? Physicians would never use such haphazard methods for screening for diabetes or other conditions. Even when screening tests are used, they are generally used after a clinician notices a developmental problem on surveillance, rather than for screening the entire symptomatic and asymptomatic populations as recommended by the authors of the different tests5 (Table 3).

While developmental surveillance is an informal, continuous process that may or may not involve the use of formal measures, developmental screening involves the use of standardized screening tests. Developmental screening is a brief evaluation of developmental skills that is applied to a total population of children to identify children with suspected delays who require further diagnostic assessment.4

Developmental screening is therefore preferred over surveillance alone. The American Academy of Pediatrics recommends the use of standardized screening tools at each health maintenance visit.4 The ideal screening test must be highly sensitive (ie, detect nearly all children with problems) and reasonably specific (ie, not mislabel). It must also be relatively quick to administer and inexpensive. As with any screening test, a failed developmental screen implies the need for more conclusive “gold standard” evaluation. Finally, a prerequisite of any screening program is that an effective intervention be available.

Early intervention developmental evaluations for children with suspected developmental delays are available free to families through a combination of state and federal funds. Should a developmental or behavioral issue be discovered, then early intervention services are provided through third party payers (Medicaid, SCHIP, private insurance, EPSDT) or are provided by the local government (for the uninsured). These services must be provided due to the Americans with Disabilities Act. Each state will decide which agency provides which services. The benefit of early intervention services for children with a variety of disabilities has been well documented.4

Screening tests can be categorized as general screening tests that cover all behavioral domains or as targeted screens that focus on one area of development. (Targeted screens are beyond the scope of this short review and will not be discussed). Some general screening tests may be administered in the office setting by professionals and others completed at home (or waiting room) by parents. Because of the malleability of child development, standards for developmental/behavioral screening tests are lower than what is usually accepted for medical screens. Even with this limitation, good developmental/behavioral tools have sensitivity of 70%–80% to detect suspected problems and specificity of 70%–80%. Although as many as 30% may be “over referred,” these may be children whose skills are below average and specific suggestions from definitive testing of child developmental problems may help to address relative deficits, even if not truly delayed development. The 20%–30% of children who have disabilities and are not detected by the single administration of a screening tool are likely to be identified on repeat screening at subsequent health maintenance visits.4

So how are we doing? What is happening at provider offices? We are NOT doing well at all in the United States. Interestingly, Family Physicians are using validated screening tools more than Pediatricians.6 Perhaps this is due to the Pediatrician feeling that he/she is the ultimate child development expert and therefore screening is not needed. As was noted above, we now know that surveillance is not enough (Table 4).

So which test should we use? The development screen developers (especially William Frankenburg, MD, MSPH, developer of the Denver Developmental Screening Test and Frances Glascoe, PhD, developer of Parents Evaluation of Developmental Status) continue to disagree about which tool is “better.”7,8

**Which Screening Test to Choose?**

A busy healthcare provider has many issues to cover in a well child visit. While usually scheduled for twice the time of an acute care or chronic illness visit, health maintenance visits are very busy. Providers must address parental concerns, closely examine nutrition, behavior and development, screen for physical illness, perform a physical exam...
and assess growth, provide anticipatory guidance, and perform screening tests and immunizations. The features of a good developmental test for clinical practice must be one that is easy to store and use, easy to administer (sometimes by ancillary health professionals), highly sensitive and specific, easy to interpret quickly by providers, and low cost.

The three most suggested tests that are used in child health maintenance visits are the Denver Developmental Screening Test II (DDSTII), Ages and Stages Questionnaires (ASQ), and Parents Evaluation of Developmental Status (PEDS). Other tests, generally considered beyond the scope of generalist practice are the Child Development Inventories and the Bayley Infant Neuromotor Developmental Screener. These will not be discussed.

The Denver Developmental Screening Test

The Denver Developmental Screening Test was originally copyrighted in 1969 by Dr. William Frankenburg and later adapted to the DDST II. This test has been generally accepted in pediatric practice since its release, although there is confusing information in the literature about how well the test performs. The test has been performed over the last 35 years in practice, so enjoys immense popularity. The advantages of this test are that it teaches developmental milestones, is easy to interpret in a busy office, and is inexpensive. The test author describes the DDSTII as a developmental “growth chart” to track development, perhaps increasing the sensitivity. Recently, in an attempt to make it more office friendly, the DDSTII authors developed a prescreening tool with use of the Parents Developmental Questionnaire II (PDQ II). If the PDQ II is abnormal, then the authors recommend a DDST II performed. However, this strategy has not been evaluated well, as of yet.

The DDSTII, like all tests, has disadvantages as well. The test requires cooperation of the infant or toddler, since many of the tasks to evaluate are active, such as drawing objects or throwing a ball. And of course, from nine months to three years, many children are rather stubborn and fearful and may not cooperate. Other critics have remarked that not all tasks are culturally appropriate for all kids. The test requires a significant time to use, especially compared with the other two, parent questionnaire-based, tests.

The Ages and Stages Questionnaires

The Ages and Stages Questionnaires is another commonly used and cited test. This questionnaire format test is still developmental milestone driven, but does not require the child to be cooperative. The parent completes a developmental questionnaire with data specific by age, either prior to the visit at home, in the waiting room, or in the examination room. There are separate questionnaire packets for ages four months to age five years—two month intervals to age two years, then three month intervals to age three, then six month intervals to age five. The questionnaires are especially good for parents who are motivated to closely examine the development and behavior. Since it is milestone driven, it teaches parents expected developmental stages.

There are a few significant disadvantages to this test as well, unfortunately, that have limited the use of this comprehensive questionnaire format. First, developmental ages do not always match with the American Academy of Pediatrics periodicity schedule of health maintenance visits; after six months the AAP recommends visits every three months, but the questionnaires are every two months at this age. Do we use the 14 month questionnaire at the 15 month visit? This must affect the performance of the test to detect subtle abnormalities. The other disadvantages are related to storage and utilization. There are multiple forms to store and each has five pages, although having the questionnaire on a CD does improve this issue somewhat. Another concern is that less educated parents may find this issue somewhat. Another concern is that less educated parents may find a five-page questionnaire daunting. And if it is a daunting task, the test might be completed in a more haphazard fashion, decreasing the utility of the test. The next screening test addresses this issue with its overall simplicity.

Parents Evaluation of Developmental Status

The Parents Evaluation of Developmental Status (PEDS) was published in 1998 by Dr. Frances Glascow. This simple test is predicated on two assumptions—that parents know their children better than anyone else and that parents are naturally inclined to compare their children with other kids of the same age. The test is a simple 10 item questionnaire that is the same for all ages to eight years. This very intriguing test would not seem at first glance to be robust enough to detect behavioral or developmental issues, since it is not developmental milestone driven. The ten questions in the PEDS test are in Figure 1.
The PEDS test is very easy to administer, at home, in the waiting room, or in the exam room. If the test has not been administered, physicians can enter the exam room, introduce themselves and the test and have the parent complete the questionnaire while the physician is reviewing the record, plotting growth, and deciding on immunizations or screening tests. The PEDS test is superior to the others in that it also elicits behavioral concerns, not just concerns over developmental delays. Other advantages are that it has simple, easy to complete forms; it is inexpensive and it performs as well in sensitivity as the longer, more involved testing. Some physicians, however, do not use the test since it does not “feel” right to evaluate development without milestones. Many physicians calm this
concern by still asking developmental surveillance questions. This strategy would seem to improve the performance of the test, but has not been evaluated in the literature. The PEDS test also may have poorer specificity; children may be "over-referred." However, these behavioral concerns may be improved by targeted behavioral interventions that may correct weaknesses, even if there is not a significant delay. After a thorough review of the literature, the pediatricians of the Morehouse School of Medicine decided to implement use of the PEDS test for our patients.

It is, of course, up to the individual provider to decide which test to use, but validated, standardized screening tests are routinely recommended at every health maintenance visit. The tests may also be employed if the parents have a concern over the child’s behavior and development. Many of the concerns that parents raise, or that child healthcare providers anticipate are discussed in the next section.

TARGETING AGE-APPROPRIATE PROBLEMS

Now that we have identified the families at high risk and have screened children appropriately at health maintenance visits, the third aspect of improving the child’s behavioral and developmental outcome is to ask about behavioral issues relevant to the child’s age and to provide age-appropriate anticipatory guidance on these issues. Parents, especially new parents, may not be aware that their child health provider can assist with developmental or behavioral issues. Asking questions relevant to the child’s developmental stage opens the door for other questions or concerns. The important thing is that parents do understand that their concerns about the child’s behavior or development have been evaluated thoroughly and they are either reassured, suggested a strategy to improve, or referred to an expert. The most comprehensive reference on this issue is Bright Futures (www.brightfutures.org). The Bright Futures project was begun in 1990, funded by the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau. A distinguished panel of experts developed health supervision guidelines in infant, child, and adolescent health. The guidelines were reviewed by nearly 1,000 health professionals, educators, and child health advocates throughout the United States. Published originally in 1994, the guidelines were updated and revised in 2000 and 2002. High yield issues by age are listed in Table 5. There are many other issues that are discussed in anticipatory guidance, including nutrition and safety that are not mentioned in the table. The table only includes high yield behavioral or developmental issues to age 4 years.

After the four-year visit, most behavioral and developmental issues are identified by the school district or from parental concerns related to poor academic achievement or continued behavioral disturbances. “Hyperactivity” and attention deficit hyperactivity warrants some extra discussion. This disorder is often identified because of poor adaptation of the child to the classroom style of sitting in rows and being quiet, along with declining school performance related to the increasing complexity of the work. Many children are referred to their child healthcare provider because of the difficulty in transitioning from the active play and learning that occurs in kindergarten to the rows of desks in first grade. These children should be evaluated thoroughly, but many will not meet the diagnostic criteria for true ADHD and with some targeted behavioral advice will improve and be able to learn well and keep up with classmates.

NEXT STEPS IF BEHAVIORAL OR DEVELOPMENTAL CONCERNS ARE FOUND

What do we do once we have identified a developmental or behavioral concern, or issue identified on screening? Further history and physical will often then allow the clinician to determine if it is a minor, age-appropriate issue, or a more pervasive problem. It is beyond the scope of this review to discuss specific focused behavioral interventions for less significant issues, but there are many that have been described and prevention/intervention validated in the literature. Issues such as poor night time sleeping in infancy, the appetite drop in toddlers, or enuresis in school age children are examples of issues that may have solutions through specific interventions.

But what about infants that have more significant issues? If you are concerned that there is an underlying, global or pervasive cause to the developmental or behavioral issue (eg, autism spectrum disorder, dyslexia, or ADHD) then referral is appropriate. Referrals may be made to Developmental-Behavioral Pediatricians, Child Psychologists, Child Psychiatrists, and Early Intervention Therapists. Any of these professionals may be appropriate, and of course, in some communities, options may be limited.

For example, if you have performed a history and physical and do not see evidence of a disorder with a recognizable pattern (eg, isolated speech delay, but the remainder of development is normal), then many providers will refer to governmental Early Intervention Programs and use their therapists. (These are Oromotor [Speech] Therapy, Occupational Therapy, or Physical Therapy.) Other providers will have a cadre of therapists that they refer to directly, without using the case management services of governmental early intervention or school districts. Unfortunately, many school districts are
overwhelmed by the myriad of developmental and learning problems. All children that are identified with behavioral or developmental issues are entitled to an equal educational experience by the Americans with Disabilities Act and school districts must provide the necessary services, regardless of cost. However, long waiting lists for assessments sometimes prompt healthcare providers to refer to the private sector for assessments and development of recommended individualized education program plans (IEP) to help the child to overcome any challenges and optimize educational outcomes.

There is also a great deal of overlap in which professionals should be consulted for work with the child/family, eg, if one of the doctorate level specialists agrees with the developmental delay, then he/she will likely refer to the same therapists as early intervention. And, if one of the specialists in early intervention performs a developmental assessment and suspects a global issue, they may recommend a referral to a doctorate level specialist. I have had subtle cases of autism suspected by occupational therapists, confirmed on referral to a developmental-behavioral pediatrician.

**CONCLUSION AND RECOMMENDATIONS**

We MUST detect, intervene and unravel early childhood behavioral and developmental problems. Identifying families that are high risk, screening children with validated tools on health maintenance visits, performing developmental surveillance on all office visits, and discussing age-appropriate behavioral concerns are methods to identify and intervene for these children. As our children’s morbidity and mortality changes from infectious diseases and neonatal deaths to behavioral-developmental issues (and of course the emerging epidemic of obesity and consequent complications), we must also change our own approaches to prevention and intervention, especially at health maintenance visits. We must as a community intervene with these children to prevent the adult dysfunctions (mental illness, substance abuse, criminal activity, domestic violence.) The next person that accosts you for spare change (or worse) may have had their developmental issues missed by our last generation of pediatricians.

**REFERENCES**


