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#### **ABSTRACT**

**Objective.** To propose and preliminarily assess a model for helping providers select, based on empirical evidence, the optimal in-office developmental/behavioral service to offer families: (1) when to refer patients for diagnostic evaluations; (2) use screening measures to assist with referral decisions; (3) offer patient education; (4) watch vigilantly over time; and (5) when to offer reassurance and routine monitoring. The rationale is that if providers can respond optimally to children's developmental and behavioral needs, children may be more likely to receive early intervention that can ameliorate or eliminate disabilities. This is known to reduce the risk of school failure, drop out, criminality, teen child-bearing, and unemployment.

**Subjects and Sites.** Data from four previously published studies on the relationship between parents' concerns and children's developmental/behavioral status was grouped and reanalyzed in order to test optimal decision-making regarding parents' concerns. Subjects were 771 children between 0 - 8 year of age and their parents who approximated demographic characteristics of the US. Settings included teaching hospitals, private pediatric practices, day care centers and public schools.

**Measurement and Procedures.** In all four studies, parents' concerns were elicited by *Parents' Evaluation of Developmental Status (PEDS)* and children were administered a battery of developmental and behavioral tests.

**Results.** The relationship between *PEDS* and concurrent measures revealed five distinct groups of families who either had different types of concerns or children with differing levels of risk. Children at highest risk were those whose parents had multiple of the concerns predictive of disabilities (OR = 20.1, CI = 10.5 – 36.3). Responding with screening tests reduced sensitivity below acceptable levels suggesting that referrals for diagnostic evaluations are the best response. Parents whose children had moderate levels of risk for disabilities were those with either single of the predictive concerns or with communication barriers, defined as incomplete, inconsistent or nonsensical responses on *PEDS* (OR ranges 4.4 to 7.6). These groups benefited from screening first to reduce false positives. Nevertheless, children in these groups who passed screening were likely to perform below average in areas critical to school success. This suggests the need for patient education and watchful waiting. Parents whose children had low levels of risk were those with no concerns or concerns nonpredictive of disabilities (OR ranges 1.0 – 1.3). Screening these groups resulted in an unacceptable loss of specificity which suggests that patient education should be offered to those with nonpredictive concerns and routine monitoring for those with no concerns at all.

**Conclusions.** – The results suggest that clinicians can make reasonably accurate decisions about which psychosocial services to provide families if these decisions are based on the empirically derived relationship between parents' concerns and children's developmental status. Such an approach is not only brief but also offers a three fold improvement over the usual rates of disability detection in pediatric offices.

## Toward a Model for An Evidenced- Based Approach to Developmental/Behavioral Surveillance, Promotion and Patient Education.

Health care providers typically offer families a range of office-based developmental and behavioral services. These include: (a) screening for developmental and behavioral problems; (b) referring children with suspected disabilities for needed evaluations and community programs; (c) promoting optimal development and behavior through in-office counseling and patient education; (d) reassuring parents who appear to be worrying needlessly and encouraging those whose children appear to be developing normally, and (e) carefully monitoring over time children who may have emerging but currently subclinical problems<sup>1-2</sup>. Selecting the most appropriate service(s) for each family appears challenging. For example, fewer than 30% of children with developmental or behavioral disabilities are detected by their primary health provider.<sup>3</sup> This suggests that clinicians have much difficulty deciding when to reassure or counsel, versus screen or refer.<sup>4-9</sup>

The goal of this study is to propose and preliminarily assess a model for helping providers select, based on empirical evidence, the optimal in-office developmental/behavioral service to offer families. Since medical reasoning usually begins with the chief complaint, the model was conceptualized using data from research on parents' concerns about their child's development and behavior. To summarize briefly, prior studies showed that: (1) Certain parental concerns (e.g., cognitive and expressive language skills) predict the presence of developmental problems while others do not (e.g., concerns about behavior); (2) The type of concerns found to be predictive vary according to children's ages;<sup>10-15</sup> (3) Parents regardless of socioeconomic status and educational level are equally accurate in their concerns, apparently due to their tendency to compare their children to others; and (4) Parents' concerns, if carefully

elicited and interpreted according to available evidence, were found to have 75% to 80% sensitivity to childhood disabilities and 70% to 80% specificity to normal development—figures not only in keeping with standards for developmental/behavioral screening tests but which are also three times higher than the current in-office detection rates.<sup>4,10-21</sup>

Prior research also suggests that there are five discrete groups of families who seem to require unique developmental/behavioral services from their child's health care provider:<sup>10-15</sup> (1) parents with two or more of the concerns predictive of developmental or school problems tend to have children with disabilities; (2) parents with only one predictive concern, tend to have children without disabilities but with below average performance in language, intellectual or academic skills; (3) parents who hold concerns not predictive of developmental/academic problems tend to have children with behavioral problems but without other kinds of disabilities; (4) parents who have difficulties with literacy or who do not speak English well often have difficulty expressing their concerns but have children who tend to either have disabilities or below average performance in areas critical for school success; and (5) parents without concerns and without literacy/language barriers tend to have children without disabilities.

The possibility that these five groups need different developmental/behavioral services from their health care providers is tested in the present study. To do this, data from prior studies on parents' concerns<sup>10-15</sup> were grouped and reanalyzed in order to ensure sufficient power for testing the value and appropriateness of various in-office services.

### **Methods**

#### Subjects and Sites

The data was drawn from studies involving 771 parents and their children.<sup>10-15</sup> The studies were conducted in five sites around the United States (Tennessee, Nevada, Massachusetts, Colorado, and Florida) in private pediatric practices (N = 123), teaching hospitals (N = 134), day care centers/preschool programs and public

schools (N = 289), and younger siblings of public school students (N = 225). Sites were selected to ensure that the sample reflected US demographics<sup>22</sup> and the majority of recruited families agreed to participate: 64% were white, 22% were African American, and 14% were Hispanic or other ethnic groups. Parents, 89% of whom were mothers, completed an average of 13.1 grades of school. Eighteen percent had less than a high school education and 25% were of low socioeconomic status (as determined by eligibility for Medicaid or the federal free/reduced lunch program in the public schools). The children were between 0 and 8 years of age: 54% were male, 48% were first born, and 45% were only children.

### Measurement and Procedures

At each site, parents were administered *Parents' Evaluations of Developmental Status (PEDS)*<sup>23</sup>, a brief approach to eliciting and interpreting parents' concerns about development and behavior. Table 1 shows a completed questionnaire. Items are written at the fifth grade level (in Spanish and in English) which enables more than 90% of parents to complete the measure independently in waiting or exam rooms. If not, *PEDS* takes two to five minutes to complete by interview. Parents' responses are then categorized on a score form that can be used repeatedly across the well-visit schedule. In prior studies, *PEDS* was found to have 88% test-retest and inter-rater reliability.<sup>10-11,15</sup>

Across studies, parents completed *PEDS* in writing or during an interview conducted by a psychological examiner or educational diagnostician. In most sites, a second examiner blinded either to parents' concerns or to their empirical significance, administered to children a battery of tests. Tests were administered and interpreted in a standardized manner to ensure that parents' concerns did not affect the results.

Test selection varied across and within studies on the basis of children's ages. Throughout, multiple screening tools, diagnostic tests, or assessment measures (tests that fall between screening and diagnostic tests and identify general but not specific diagnoses) were administered in order to identify disabilities or probable disabilities. Both assessment and diagnostic

measures were administered to 511 of the 771 subjects and included: the Woodcock-Johnson Psychoeducational Battery: Tests of Achievement: (N = 352), the Child Development Inventory (N = 403), the Possible Problems Checklist of the Child Development Inventory (a measure of health and well-being (N = 403), Kaufman Assessment Battery for Children (N = 39), the Bayley Scales of Infant Development (N = 21), Stanford-Binet Intelligence Scale-4th Edition) (N = 33), Slossen Intelligence Test (N = 408), Test of Language Development (N = 20), Arizona Articulation Proficiency Test (N = 16), and the Vineland Adaptive Behavior Scales (N = 91). The 511 who received diagnostic or assessment level tests were also administered one of two broad-band developmental screening tests: either the Battelle Developmental Inventory Screening Test (N = 103) or the Brigance Screens (N = 408). The remaining 260 children were administered multiple screening measures including the Articulation Screening Test (N = 181), a criterion-referenced measure of preacademic and academic skills (N = 160), the Battelle Developmental Inventory Screening Test (N = 260); and the Eyberg Child Behavior Inventory (N = 96).

To the performance of the 511 children who received diagnostic and assessment tests was applied eligibility criteria, drawn from the federal law that funds special education programs, the Individuals with Disabilities Education Act, for placement in early childhood special education and public school special education programs. The remaining 260 children who were administered multiple screening tests were considered probably disabled if they failed one or more measure and probably normal if all three were passed. Table 2 shows the criteria used to categorize test results.<sup>10-15</sup>

### Results

Of the 771 children, 130 (17%) had, or appeared to have, developmental/academic or behavioral disabilities. Only 29 of the 130 were enrolled in special education programs. The remaining 641 did not meet, or appear to meet, special education criteria. Of the 130 with special needs, 98 had parents with one or more of the concerns found to be predictive of disabilities (sensitivity =75%)

while of the 473 of the 641 without disabilities, had parents with concerns in other areas or no concerns at all (specificity = 74%).

Logistic regression analyses were run to identify differences in children's risk of disabilities and school failure among the five groups of parents, i.e., those with: (1) two or more of the concerns predictive of developmental disabilities; (2) a single predictive concern; (3) concerns not shown to be predictive of developmental disabilities, (4) no concerns but parental communication barriers (as determined by nonsensical answers, inconsistent or incomplete responses on *PEDS*; and (5) no concerns and no apparent difficulties communicating. The presence or absence of disabilities served as the dependent variable and the presence or absence of membership in each of the above groups served as the predictor. Table 3 shows the frequency and odds ratios for developmental disabilities within each of the five groups. Also shown is the percentage of children without disabilities who performed below average, (i.e., one or more standard deviations below the mean or percentile ranks of 16% or lower) in the domains most associated with school success: language, reading skills, or intelligence. Such children are likely to experience school difficulties.

Because several of the five groups had similar levels of risk (e.g., those who held concerns not associated with disabilities had risk levels similar to those with no concerns at all, and the group with communication barriers had risk levels similar to the group with a single of the concerns predictive of disabilities), the following questions were explored. Are there clinically meaningful differences among groups suggesting that providers' responses should vary according to group membership? Which possible provider responses to parental concerns maintain sensitivity and specificity to disability status within acceptable levels for screening measures (70% - 80%)?<sup>19-21</sup>

**High Risk.** Families with multiple of the concerns predictive of disabilities had children with a high risk of receiving a diagnosis of language impairment, learning disabilities, mental retardation or other handicapping conditions (OR = 20.1). This

finding raises the question, should providers offer additional screening to reduce false positives or refer this group directly for diagnostic testing? To explore the best response, the sub-sample of patients given the most extensive battery of both diagnostic/assessment measures along with screening tests (i.e., the Battelle Developmental Inventory Screening Test or the Brigance Screens, both of which approach standards for screening accuracy with sensitivity and specificity between 70% to 80%)<sup>24-25</sup> were analyzed separately. For this group of 511, there were 63 families with multiple concerns: 30 had children with disabilities and 33 had children without disabilities. If screening rather than referring all 63 families, 9 of those needing referrals would have been missed although 18 of those without disabilities would have been spared evaluations. When these decisions were substituted for referral decisions, sensitivity for the total group of 511 dropped by more than 10%, from 74% to 62% (47/76) while specificity improved slightly from 73% to 77% (315/435). In comparing the two accuracy indices, it is clear that screening in response to multiple significant concerns lowered sensitivity below acceptable levels<sup>19-21</sup> with only small increases in specificity. In further considering the value of referring the entire group with multiple predictive concerns, it is also important to note that 15 of the 33 over-referrals were children who performed in the below average range on measures of intelligence, language or academic achievement, and that under the screening condition, 9 of them would not have been referred for further testing.

Because referrals rather than screening tests seem to be best response in the presence of multiple predictive concerns, it is important to consider whether there are there specific patterns of parental concerns that suggest the type of referral needed? For the majority of children with disabilities (90% of whom have learning disabilities, speech-language impairments or mental retardation<sup>26</sup>), the testing required for special education eligibility falls into two types: speech-language evaluations (to determine the presence of speech-language impairments) versus psychological testing, i.e., intellectual, adaptive behavior or

educational testing (to determine the presence of mental retardation or learning disabilities). To identify which parental concerns helped identify children's needs for certain types of evaluations, cases were selected in which parents had two or more of the predictive concerns and children had either speech-language impairments, learning disabilities, or mental retardation (N = 45). The broad type of disability (speech-language versus learning disabilities/mental retardation) was used as the dependent variable in a logistic regression analysis. Predictor variables were the ten kinds of parental concerns. This analysis revealed that two or more concerns in the areas of receptive language, self-help, school and social skills predicted the presence of speech-language disabilities with 79% accuracy (19/24). Mental retardation/learning disabilities (the two high frequency conditions requiring psychological testing) could be identified with 71% accuracy (15/21) by one or no such concerns but concerns in other areas (e.g., fine or gross motor, expressive language, etc.) with 71% accuracy (15/21). For both decisions, sensitivity fell within acceptable levels (70% to 80%)<sup>19-21</sup> illustrating that providers' selection among these two referral options can be based on the types of concerns parents' raise.

**Moderate Risk.** Children whose parents had a single significant concern and those whose parents had communication barriers had moderate risk for disabilities (OR = 4.4 – 7.6). This finding raises the question, should providers respond by referring both groups for diagnostic testing or by first administering a screening test. To explore the best response, the subset of 511 subjects given both diagnostic/assessment measures and screening tests (Battelle or Brigance) were reanalyzed. Table 4 compares the original values for sensitivity and specificity (in which both groups were referred for diagnostic testing) to the values produced when screening results were substituted whenever parents had a single of the predictive concerns (N = 110) or when they had identifiable communication barriers (N = 24). Basing referral decisions on screening test results produced a slight loss of sensitivity (3%) but an improvement in

specificity (8%). Because many more children are normal than not, higher levels of specificity significantly reduce the numbers of over-referrals. However, as shown in Table 3, many children whose parents have either a single predictive concern or a communication barrier have below average performance in areas critical for school success. This suggests that the children in these groups who are not referred for evaluations because they pass screening tests remain at some level of risk for school failure. Thus, providers should offer this subset of patients vigilant developmental/behavioral monitoring while counseling their parents on techniques for promoting healthy development.

**Low Risk.** Children at the lowest risk for disabilities were those whose parents had either no concerns or only those concerns found to be nonsignificant predictors of developmental problems (83% of such parents expressed concerns only about behavioral difficulties). Nevertheless, both groups contain some children with developmental disabilities who would be missed if none were referred. This raises the question, should this group receive a second screen to ensure that as few as possible with disabilities are missed. To test the value of offering a second developmental screening test, the following analysis was conducted: From the group of 511 who were administered both screening and diagnostic/assessment tests, those whose parents had either no concerns or only concerns shown to be nonsignificant predictors of developmental problems were selected (N = 312). Their performance on developmental screening measures was then compared to developmental status as measured by diagnostic tools. Of the group of 312, 13 had disabilities and 9 of these children were detected by additional screening. Of the 299 without problems, 227 passed a second screen. When these results were substituted for the original nonrefer decision (for which sensitivity was 74% and specificity was 73%), sensitivity improved to 85% (65/76) but specificity dropped to 57% (246/435). This suggests that using a second developmental screening test with groups having a low incidence of developmental disabilities

should be avoided because it leads to excessive over-referrals.

Although developmental screening does not appear useful for the above two groups, it may be that the concerns non-predictive of developmental problems, may instead predict the presence of emotional or behavioral problems. This hypothesis was assessed on the subset of 527 children who were administered measures of emotional and behavioral status. Children who failed developmental measures and whose parents had a single significant concern and those whose parents had multiple significant concerns were removed from the analysis since these children would have been referred for further evaluations that could ostensibly assess any behavioral or emotional difficulties. This left a group of 328 children whose parents held nonpredictive concerns or no concerns at all. Children's performance on the Eyberg Child Behavior Inventory<sup>27</sup> (N = 69) or on the 17 items of the Possible Problems Checklist of the Child Development Inventory<sup>28</sup> that assess emotional well-being and behavioral self-control (N = 259) was then intersected with the presence or absence of behavioral or other nonpredictive parental concerns. As shown in Table 5, 82% of children with scores 1 1/2 or more standard deviations above the mean on the Possible Problems Checklist or who exceeded cutoffs on Eyberg (greater than 15 of the 36 items) had parents with one or more concerns about behavior or other concerns not predictive of developmental disabilities. However, only 69% of children who performed more averagely had parents with no concerns. This suggests that parents' concerns about behavior, self-help, and so forth are sensitive but insufficiently specific indicators of behavioral and emotional difficulties. Unlike parents holding one or more of concerns shown to be significant predictors of developmental problems, 80% of children whose parents have behavioral or other non-predictive concerns have apparently normal behavioral and emotional status.

Even so, parents who hold concerns about behavior or other non-predictive concerns and whose children pass behavioral/emotional screening tests, are known to experience substantially more parent-child conflicts than parents who

raise no concerns about behavior, self-help skills, etc.<sup>13,15</sup> This finding was corroborated using the sample shown in Table 5. Children whose parents had complaints about behavior averaged 9.2 of 36 items on the Eyberg Child Behavior Inventory and 1.5 of the 17 items on the Possible Problems Checklist whereas those children whose parents held no concerns averaged 5.6 Eyberg items and 0.7 Possible Problems Checklist items. These differences were significant [ $F(1,55) = 10.10, p < .002$ ;  $F(1,242) = 16.377, p < .0001$ ]. In light of the limited risk of significant behavioral and emotional problems, advice from health care providers appears to be the optimal first response to concerns about behavior, self-help skills, etc., followed by screening if problems persist.

### Discussion

The results support the value of categorizing children into high, moderate, or low risk status for disabilities on the basis of the five distinct clusters of parents' responses on PEDS (multiple predictive concerns, single predictive concern, nonpredictive concerns, no concerns, no concerns but communication barriers). The findings illustrate that clinicians can use the relationship between risk status and the five types of parental responses to make reasonably accurate decisions about which in-office developmental/behavioral services to provide. These decisions enable clinicians to identify and follow distinctly different paths in responding optimally to parents' developmental and behavioral issues, i.e., refer, screen, watch carefully, offer patient education, versus reassure. The paths are illustrated in Table 6, one of the *PEDS'* forms, on which is also shown the decisions made for the patient described in Table 1.

While the current results are encouraging, additional research is needed to confirm how well the method works when administered by pediatric providers and particularly when used longitudinally, i.e., at each well visit. Such research should follow a large cohort over time in order to determine whether different kinds of provider responses lead to improved patient outcomes. More rigorous emotional and behavioral measures should be administered in order to cross-validate the

recommendations made in this study. Use of a less varied concurrent battery may also be desirable although the current study illustrates that the findings are not a function of specific tests but can be generalized to a variety of measures. Future research might also explore more discrete categories of parental concerns in relation to specific diagnoses (e.g., do parent's concerns about motor tone or reading skills identify children with cerebral palsy or dyslexia). Additional studies might address the extent to which the *PEDS*' model addresses the unique needs of children with both developmental and behavioral co-morbidities.

#### **Implications for Practice**

Failure to ask parents about their concerns and to ask them carefully, means that many parents do not share their worries.<sup>29</sup> Systematically eliciting parents' concerns with standardized questions such as those used in *PEDS* (e.g., only about 50% of parents understand the word "development",<sup>30</sup> so it must be paired with "learning" and "behavior"), prompts approximately 60% to respond with complaints about behavior and development. In response health care professionals can attach to parental concerns, children's risk for disabilities and school failure. This provides a method for evidenced-based decision-making about a wide range of developmental and behavioral services, including when to refer and where, when to screen and what types of screening measures to administer, when to provide patient education, watchful waiting, or simply monitor apparently normal development and behavior. Such an approach results in a three-fold improvement in disability detection rates as compared to studies showing the percentages of children with disabilities identified in pediatric practices.<sup>3</sup> Application of the *PEDS* model should also save providers substantial amounts of time and expense<sup>31</sup> because lengthy screening measures can be reserved only for those with moderate, but not high or low levels of risk for developmental/behavioral problems.

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Table 2. Criteria for Special Education Classification

<b>CATEGORY</b>	<b>CRITERIA</b>
<b>Special Education</b>	
Speech-Language Impaired	performance 2 or more standard deviations below the mean on measures of expressive and receptive language
Mental Retardation/ Developmental Delay	IQ less than 74 (or in the case of children less than 2 years of age, a DQ < 70), and performance 2 or more standard deviations below the mean on adaptive behavior measures
Specific Learning Disabilities	performance 1 or more standard deviations below the mean and 1 or more standard deviations below IQ on measures of reading or prereading, math or premath, or written language in children 3 years and older only
Other/ Probably disabled	children with hearing impairment, physical impairment, autism, or serious emotional disturbance who were previously tested and found eligible for special education services. Children who failed one or more screening tests were categorized as probably disabled
<b>No Special Education Eligibility/Probably normal development</b>	None of the above

**Table 3. Children's Frequency and Risk of Disabilities By Clusters of Parental Concern(s)**

	Clusters of Parental Concern(s)				
	Multiple Predictive Concerns  N = 86	Single Predictive Concern  N = 180	Nonpredictive Concerns  N = 151	No Concerns but Parental Communication Difficulties N = 26	No Concerns and No Apparent Communication Barriers N = 328
<b>Odds Ratios of Developmental Disabilities and 95% Confidence Intervals</b>	20.1  10.52 – 36.31 p < .0001	7.6  4.26 – 13.69 p < .0001	1.3  0.60 - 2.72 p = NS	4.4  1.46 – 12.96 p < .008	1.0
<b>Number and Percent with Disabilities</b>	45 52%	53 29%	10 7%	5 19%	17 5%
<b>Number and Percent Not Disabled but Below Average</b>	14 16%	30 17%	20 13%	9 35%	37 11%
<b>Total disabled or below average</b>	59 69%	83 46%	30 20%	14 54%	54 16%

**Table 4. Substitution of Screening Test Results with Children whose parents had difficulty communicating or who had a single predictive concern, compared with referral decisions**

	NO	DISABILITY YES	
No concerns or NonPredictive Concerns; Single Predictive Concern and Child Passed Brigance; or No Concerns and Communication Barriers, and Child Passed the Brigance	351	22	373
Multiple Predictive Concerns; or Single Predictive Concern and Child Failed Brigance Screens; or No Concerns and Communication Barriers and Child Failed Brigance Screens	435	76	138
<b>Sensitivity</b>	84	54	
<b>Specificity</b>	(54/76)	= 71%	
	(351/435)	= 81%	
<b>Results If Screening Tests Results Were Not Substituted And Referrals Made Instead</b>			
<b>Sensitivity</b>	(56/76)	= 74%	
<b>Specificity</b>	(318/435).	= 73%	

**Table 5. The Accuracy of Nonpredictive Concerns in Detecting Children with Significant Behavioral/Emotional Problems**

		Performance on the Eyberg Child Behavior Inventory or Possible Problems Checklist of the Child Development Inventory		
		passed	failed	
Parental NonPredictive Concerns	No	206	5	211
	Yes			117
		<b>300</b>	23 28	
	Sensitivity		(23/28) = 82%	
	Specificity		(206/300) = 69%	







Title: A Method For Deciding How To Respond to Parents' Concerns about Development and Behavior

Author: Frances Page Glascoe, Ph.D.  
Division of Child Development  
Department of Pediatrics  
Vanderbilt University School of Medicine

Correspondence: Dr. Frances Page Glascoe  
Division of Child Development  
Department of Pediatrics  
Vanderbilt University School of Medicine  
2100 Pierce Avenue, room 426  
Nashville, Tennessee 37232-3573

Telephone: 615-936-0249  
Fax: 615-936-0256  
e-mail: Frances.P.Glascoe@Vanderbilt.edu

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Key words: developmental screening, developmental surveillance, parents' concerns, child development, behavior problems



