Collaborating With Parents

Using *Parents' Evaluation of Developmental Status* to Detect and Address Developmental and Behavioral Problems (*2nd Edition*)

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There are many of us who work on Parents' Evaluation of Developmental Status (PEDS), PEDS: Developmental Milestones, and PEDS ONLINE. It takes a village: to ensure that print orders are received promptly, i.e., yesterday(!) and address customer questions about what to order (thanks to Amy Thomas); develop and edit print materials, vet translations via coordination with international and North American researchers (thanks to Shirley Kathryn Woods and Donna Strawser); maintain an informative and helpful website (thanks to John Lafon for www.pedstest.com); create and maintain an online scoring service and assist clinicians (thanks to Michael Camp and Angel Kennedy); advise researchers including graduate students, and maintain current psychometric studies; and ultimately to manage and direct all these many efforts (thanks especially to Helen Shouse)!

Foreward

Parents' Evaluation of Developmental Status (*PEDS*) is pronounced (with a regrettable lack of phonetic correctness) as "pēēds" in America, and "pĕds" elsewhere in the world. *PEDS* was originally validated in 1998 and its technical manual, *Collaborating with Parents,* was revised in 2002 to cover new research on the tool. This 2nd edition of *Collaborating With Parents* provides new psychometric studies conducted in 2012 on a nationally representative sample of families.

Within are chapters addressing *PEDS'* research with updates to its standardization, reliability, validity and accuracy. Also included is information about utility including measurement issues in primary care versus early childhood services, (e.g., differences in policy recommendations, time constraints, implementation issues, costs/benefits, etc.)

Impressive updates these are. *PEDS* is used or required in almost every US State, in many languages, and in many other nations. The data used for this second edition of *"Collaborating with Parents"* involves more than 47,000 families—an unprecedented size for psychometric research. The many studies enable careful scrutiny of how *PEDS* works with unique populations (e.g., American Indians, Spanish-speakers, and in other nations). Studies by other researchers are also covered in detail. Utility research, cited throughout this manual shows that *PEDS* clearly facilitates parent-provider collaboration, shortens well-visit length by reducing "oh by the way" concerns, encourages impoverished parents to return for well-child care, and greatly improves detection rates in primary care).

Collaborating with Parents (2nd Edition) is now strictly a technical manual. Prior editions included abundant information on developmental-behavioral promotion, how to explain results to parents, etc. But providers rarely accessed the manual and thus could not make use of the clinically-relevant information within. Instead, the manual was used almost exclusively by researchers and panelists selecting measures for various State and federal initiatives. So, the clinical guidance, training and implementation suggestions, etc. from prior editions are now housed in a new book entitled, *Identifying and Addressing Developmental-Behavioral Problems: A Practical Guide for Medical and Non-medical Professionals, Trainees, Researchers and Advocates* available from Ellsworth and Vandermeer Press, LLC (*www.pedstest.com*). This book has its own pages on the website that house downloadable materials (e.g., milestones charts, age-specific encounter forms, two-way consent forms, links to resources, pre-/post-measures for training, etc.).

I welcome research on *PEDS* and all of us are happy to consult with researchers on projects and initiatives, and if nothing else, to help make sure scoring and interpretation are in accordance with the *PEDS Brief Guide to Scoring and Administration*, and to facilitate translations and international adaptations. If you need advice, guidance or ideas, please view the enormous range of information on *www.pedstest.com,* and if more information is needed, please contact us through the website.

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Chapter I

Introduction to *Parents' Evaluation of Developmental Status (PEDS)*

How and Why *PEDS* was created

Having trained in early childhood special education and taught in the public schools for years, I was eventually hired as an educational specialist at Vanderbilt University where I worked in the Division of Developmental and Behavioral Pediatrics testing children's academic skills. In 1987, our division chief decided to take a position elsewhere and turned to me and said, "you are the only educator here, you need to take over training residents on our rotation." I thought, "mmmm (if not nnnnnn)—I don't have a clue about what residents need to learn." So I decided to go hang out in the residents' continuity clinics to find out what they did, and what the attending faculty were teaching them; all with hope that such observations would help me know what I needed to teach on my rotation.

I noticed residents and preceptors trying to make a large range of decisions about families—like when to give them advice, when to screen, when to wait and see, when to reassure, and when to refer—but unsure of the best approach. I noticed their use of selected items from the Denver or Harriet Lane Manual, but that such items not only failed to give clinical guidance on how best to respond, but in my clinical opinion, lacked sensitivity to apparent problems. Sure enough, after reviewing published literature on early detection in primary care, studies consistently confirmed limited early detection rates: The majority of children with disabilities and delays were not identified by their physicians.

I discovered that clinicians often started encounters with questions to parents, and that eliciting and addressing parents' concerns were a significant component of well-visits. But I noticed that parents struggled to share their worries when asked broad questions such as "What brings you here today?" At the same time, clinicians struggled with how to ask parents about their concerns, but often used wording parents didn't seem to understand. Sometimes providers managed to come up with a good question or two that got parents to communicate but it was also obvious that clinicians didn't always know what to do with the concerns parents raised.

Meanwhile, back in the Division of Developmental-Behavioral Pediatrics, we worked with parents whose children were suspected of disabilities. Parents often said things such as, "When my child was 2 years old, I told my pediatrician I was concerned, but she just said, 'let's wait and see'. Now my child is 5, has serious problems, and has missed all opportunities for early intervention that might have prevented this or at least made it better."

So, several avenues of inquiry seemed useful:

1. Are there screens available that are accurate, brief, and provided decision guidance?

2. How can we question parents about their children's behavior and development and do their concerns identify problems in their children?

3. If so, can parents' concerns aid providers in wise

decision-making about such things as when to refer, advise and monitor vigilantly, etc.?

To address the first question, I invoked the help of a third-year resident (who eventually completed a fellowship in developmental-behavioral pediatrics) and an academic pediatrician. We ordered and tried out every broad-band screening tool on the market. We developed a rating scale focused on time demands, accuracy and other variables and then ranked measures accordingly.[1,2] In so doing, we managed to alienate just about every famous developmental-behavioral screening test author on the planet! Most tools were poorly constructed, inaccurate (or lacked proof of accuracy), and were overly lengthy, if not also difficult to administer and teach. There seemed to be no oversight from publishers or professional societies. Although the American Psychological Association and American Educational Measurement Research Council, have guidelines for how tests should be constructed, most screening test authors failed to take these messages to heart!

Several graduate students and psychologists agreed to work with me on detailed studies of several promising or prominent measures.[3-10] We found a few measures that were quite accurate, but too long for primary care or failed to address the wide range of issues confronting families. Ultimately no screens provided guidance on what to do with results; residents didn't know where to refer or what their options were. The most well-known and widely used measure, the Denver, was particularly problematic. Its length meant that residents were generally just doing a few items and making up their own scoring criteria. The Denver items were far too easy –meaning that almost all children passed. Even if residents found time for the whole Denver, materials were often missing from the tool kit and children weren't always cooperative. The Denver PDQ fared no better, unfortunately.

. . . . .

To address the second two questions, I embarked on studies of parents' concerns. The first thing I learned was what not to ask! I went to our inner city pediatric clinics and tried talking with families, figuring that if I could communicate effectively with parents whose educations were limited that I'd develop effective questions. At first I just ended up torturing quite a few families who often looked like deer in the headlights! In so doing, I found that some of the questions we typically ask don't work well (e.g., "Do you think she has any problems?" or "Are you worried about his development?"). Only about 2% of families responded to questions like these, even though the disability prevalence rate is about 16%.

So why don't these questions work? The words "problems" or "worries" are too strong and many parents, when they first start noticing troubling things about their children, aren't sure they are worried. Further, the word "development" is only understood by about 50% of families[11] so I realized I couldn't use that word on its own.

After struggling with about 100 families, I finally came up with a single item that seemed to work well, i.e., " Please list any concerns about your child's learning, development, and behavior." For some reason the word "concerns" is less ominous than "worries" (at least in English). Pairing "learning" and "behavior" with development helped parents know what I wanted them to talk about—and talk they did!

But I wasn't convinced that this question encouraged parents to think systematically about their child's development. For example, the parent who says, "My child won't mind me" may not have considered whether her child hears well enough, understands the commands given, has the motor or attentional skills to execute task, etcs. So it seemed wise to prompt parents to think about development, like professionals do, as a range of domains.

Prompting parents to think through development domains presented a new challenge because most parents are unfamiliar with professional terms like, "expressive language" or "gross motor". So I worked with another 100 or so families and came up with additional questions that probed the various developmental-behavioral/social-emotional domains (as well as health issues) but without confusing professional jargon. A detailed and family-friendly line of questioning helped—parents started discussing issues across a wide-range of domains.

So now it was time to see if parents' concerns identified actual problems and if so which types of problems. So, I applied for a small grant and had a psychologist

test 100 children while I interviewed their parents (either over the phone or in person). Sure enough some concerns predicted measurable difficulties and identified more than 75% of children with problems. Other concerns were more reflective of "the worried well"—those in need of parenting advice.

Then I co-wrote a paper and submitted it to a pediatric journal. Reviewers' responses were a deafening cry of outrage—not because the science or methods were problematic—but because the whole notion that parents' concerns improved detection rates over and above pediatricians' rates was quite offensive to pediatric researchers. As one reviewer wrote, "It is counterintuitive that an ignorant parent would know more than a skilled physician"! Ahem! These weren't exactly the sorts of comments one expects from a scientific review.

Undaunted, I rewrote the paper to make sure it was clear that this wasn't a contest between pediatricians and parents, and that skilled questioning, professional scoring, and interpretation were required. Upon resubmission, reviewers were more attentive to evidence than to pre-existing prejudices and accepted the paper for publication.[12]

But, that was just a start because there were many other issues in need of exploration. To name a few: Could parents across socioeconomic and levels of education respond equally well? (Yes). Could we rely on parents to spontaneously raise concerns (No, especially for those with limited education). Did speech-language concerns predict speech-language problems or instead other types of problems? (Both.) How do parents derive their concerns? (Mostly by comparing their child to others.) Do parents' concerns identify all disabilities or just some? (All.) And, given the scathing reception from the first journal submission, lots of confirmation seemed essential before recommending that providers elicit parents' concerns and make use of these as a method of early detection and developmental-behavioral triage.

Many papers later[13-23] *all consistently confirming the value of parents' concerns in early identification across socioeconomic status and language background, I finally figured out (at 3:00 one morning!) that I'd created a screening test emulating what providers try to do at each visit—elicit parents' concerns—but with PEDS studies in hand providers could also decide based on evidence how best to address concerns, i.e., when to refer, screen further, monitor vigilantly, advise parents on child-rearing issues, versus reassure that all is well.*[24-26] *Eureka!*

Premises Underlying *PEDS*

To fully understand the value of *PEDS*, it is important to recognize its underpinnings and rationale:

1. *PEDS* is both a screening and surveillance tool measuring children's development, behavior and social-emotional/mental health status from birth to 8 years of age (0 through 7 years, 11 months). Surveillance is a longitudinal process of monitoring concerns, milestones, risk factors, etc. while screening means a brief test that provides immediate cutoff scores to indicate when referrals are needed. *PEDS,* especially in conjunction with *PEDS: Developmental Milestones* accomplishes both screening and surveillance with the same tool and complies with recommendations from the American Academy of Pediatrics.[27]

2. *PEDS* prompts parents to think about their child's development including social-emotional/behavioral/mental health, along with health status in 10 domains: cognitive, expressive language, receptive language, fine motor, gross motor, self-help, behavior, social-emotional, academic, and health/other. Parents respond, in their own words. *PEDS* thus promotes true collaboration between parents and professionals.

3. *PEDS* directs professionals to an appropriate decision based on risk levels (for developmental and/or mental health problems) associated with various types of concerns and children's ages.

4. Screening and surveillance lead to much more than a simple binary result—pass or fail. Instead, professionals make a wide range of decisions about how to best help families, i.e., when to refer, screen further, advise and educate, monitor vigilantly, versus reassure. These decisions must

depend on evidence-based support so that we don't "wait and see" when, in fact, referrals are needed. So voluminous research studies are basis for the *PEDS* decision-support algorithm.

5. Another premise behind *PEDS* is that developmental problems should be ruled out before proceeding to mental health evaluations. The reason is that we don't want to plunge in with behavior modification or counseling before we know, for example, how well a child hears and understands what we say. For this reason, when behavioral/social-emotional risk is present but is also combined with any developmental risk (e.g., expressive or receptive language problems, fine or gross motor problems, difficulties with cognition or school skills), the *PEDS* algorithm prioritizes developmentally-focused evaluations (e.g., psychoeducational, speech-language, physical therapy evaluations, etc). Nevertheless, providers are prompted: a) to use clinical judgment to decide if mental health, social work or other types of evaluations are also needed and; b) to follow up/collaborate with referral sources to decide if additional evaluations are needed (e.g., if developmental problems are ruled out, to proceed when indicated, with mental health services or parenting assistance).

6. A final and particularly critical underpinning is that, unlike most other screening tools, *PEDS* is designed to detect, not just children with disabilities and thus eligible for special education services/early intervention, but also children with delays, who are ineligible for special services, but still in need of help if they are to succeed in schools [e.g., those with language, academic, or intelligence quotients < 85 (16th percentile or less)]. Help for such children comes in other forms (e.g., parent training, Head Start/ Early Head Start, quality day care, after school tutoring, summer school, etc.). So, *PEDS* sorts the probably disabled from the probably delayed enabling providers to make focused referrals.

PEDS Components

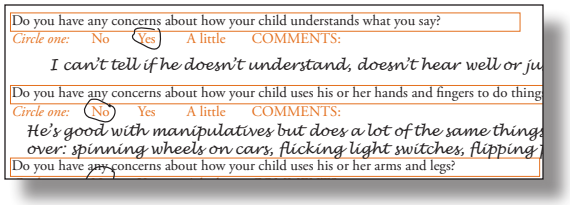
PEDS is available in print and online. A description of both applications is described in this section along with costs and copyright issues.

***PEDS* In Print** includes the following:

1. ***PEDS Brief Guide to Scoring and Administration*** provides directions for using *PEDS* correctly. *PEDS* users must deploy the Brief Guide to ensure accurate administration, scoring, and interpretation of results.

2. ***PEDS Response Form*** elicits parents' concerns in 10 domains: expressive language, receptive language, fine motor, gross motor, behavior, social-emotional/mental health, self-help, school skills, global/cognitive, and health/parental issues. Parents answer 10 questions in their own words (either by writing their verbatim comments or in the case of literacy problems, professionals can write down parents' concerns during an interview—either face to face or over the telephone). Two of the questions are entirely open ended. The remaining 8 questions are open-ended and include a space for comments followed by an intensity question (e.g., "Do you have concerns about how she/he uses her hands and fingers?" *Circle One: Yes No A little Comments:*). Figure 1 is a clip of the *PEDS Response Form* and at the end of this chapter is an entire case example (showing *PEDS + PEDS:Developmental Milestones*).

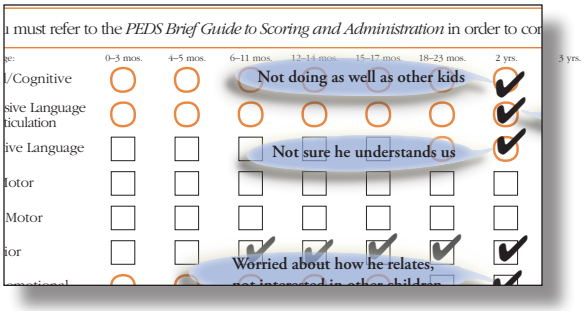
Figure 1. *PEDS Response Form* Detail



Professionals are encouraged to add their own concerns to the *PEDS Response Form* before scoring but are not allowed to remove any parental concerns. The *PEDS Response Form* is available in more than 20 languages. A fresh Response Form is needed at each visit; Response Forms used at prior visits may be discarded when a new Response Form is completed.

3. ***PEDS Score Form*** on which professionals, after reading through parents' comments, categorize concerns into the various domains of development. (Note, parents don't always answer the intent of question asked, hence why comments are categorized by content and not in relation to the question.) The Score Form shows which domain-related concerns are predictive of developmental or social-emotional/behavioral problems and which are not.

Figure 2. *PEDS Score Form* Detail



The Score Form directs *PEDS* users to a specific evidence-based decision shown on the *Longitudinal Interpretation Form*:

4. ***PEDS Longitudinal Interpretation Form*** (which is printed on the back of the Score Form) leads to one of five different evidence-based decisions.

•**Path A** is a high risk path for which referrals are indicated. Path A divides into those who need speech-language evaluations versus those who need psycho-educational testing (e.g., measures of intelligence, adaptive behavior, academics). Professionals are encouraged to use their knowledge of the family to decide if other referrals are needed such as social work services, physical and/or occupational therapy, mental health, parent training, subspecialty medical care, etc.

•**Path B** is a moderate risk path for which additional screening is recommended (e.g., via *PEDS: Developmental Milestones*). Additional screening determines whether a referral is needed or whether developmental-behavioral promotion, healthcare and vigilant monitoring is the best response.

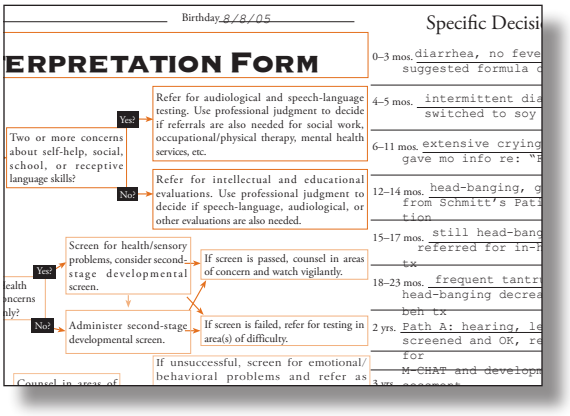
•**Path C** is a "low risk but concerned" path for which developmental-behavioral promotion is the best response. Most parents on this Path raise concerns only about behavioral or social-emotional issues. Nevertheless, when such concerns persist beyond 4 ½ years of age, Path C suggests additional mental health services with intensive parent training.

•**Path D** is a moderate risk path (and rarely used if *PEDS* is administered correctly) but it captures professional judgment that the reporting caretaker is uninformed (e.g., a teen parent or older sibling who doesn't do much of the child's caretaking; a parent with florid mental health problems, a parent who was not administered *PEDS* in a language they understood, etc.).

•**Path E** is a low risk path and assigned when parents (and professionals) lack concerns and thus perceive a child as typically developing (or advanced).

The *PEDS Score and Interpretation Forms* are reused over time with the same child thus creating a longitudinal record of performance. This single-page form often serves as a "problem checklist." The Interpretation Form provides space to write comments (e.g., about referrals made, content of parenting information provided, follow-up plans, etc.).

Figure 3. *PEDS Interpretation Form* Detail



Costs of *PEDS* In Print

PEDS in print costs about $0.39 cents per encounter for print materials. A fresh Response Form is needed at each visit. The reusable over-time Score Interpretation Form is amortized across the well-visit schedule between birth and age 8.

Administration and scoring time costs clinics ~$1.20 (given staff/clinician salaries averaging $60.00 per hour). Although providers still need to dictate reports, explain results to parents and, at times, make referrals, given a Medicaid/private payer reimbursement rate of $8.00 - $20.00 per screen, *PEDS* remains economical, if not also profitable, for clinics. *PEDS* is also known to shorten visits by 3 minutes by reducing "door knob concerns" which is not accounted for in the above total cost estimate of $1.59 for materials and administration time.

If *PEDS* needs to be administered by interview, clinic costs (for staff/provider time) will increase by ~ $1.00 for a total of $2.59.

Copyright Issues with *PEDS* in print (and other developmental-behavioral screens)

Developmental-behavioral screens are enormously expensive to develop and maintain: Translations require careful vetting; norming, reliability and validation/accuracy studies must be conducted every 10 years or so (especially because of rapidly changing demographics), and thus retesting the many cutoff scores per age range is essential; researchers need advice; test users need training information, administration guidance, etc. For this reason, no screens with a developmental component are freely available nor should they be. Instead publishers must depend on the revenues generated by test sales to constantly improve measures.

So, in the case of *PEDS*, all Forms are designed to be scannable (ugh!) but only completed *PEDS* Forms may be scanned. ***PEDS cannot be photocopied, laminated or reproduced in any manner.*** Its sole electronic application is described below. Software developers for electronic records are prohibited from programming *PEDS Tools* on their own (but are allowed to create fields for capturing results—with advice from the *PEDS* publishing company, PEDS*test*.com, LLC). Any deviation from the above constitutes copyright infringement; punishable with hefty fines if not incarceration. Eek!

PEDS Online

PEDS is available via a web-based screening service. *PEDS Online* also offers *PEDS: Developmental Milestones* (6 – 8 questions, 1 per developmental domain) and the Modified Checklist of Autism in Toddlers (M-CHAT). Together, these three measures provide basic but entirely evidence-based compliance with American Academy of Pediatrics recommendations for screening and surveillance: eliciting/addressing parents' concerns, monitoring milestones, detecting mental health problems, and screening for autism spectrum disorders at 18 months and again at 24 months.

PEDS Online depends on an extremely sophisticated (and extremely expensive) text-based scoring analyzer. The analyzer searches through parents' comments for words and phrases associated with typical versus problematic development, no matter the question actually asked, and assigns domains based on the types of concerns. From there, the various *PEDS* Paths are assigned. A ten year, million dollar project, the inter-rater agreement on assignment of categories and paths is 95% to 97% respectively—an unparalleled level of reliability for screening tests. For this reason (and from our own abortive attempts to program *PEDS* in other ways such as from the "yes/no/a little" answers) we do not allow researchers, providers, or software developers to create their own scoring. Although integration with electronic records is feasible, *PEDS Online* can be easily used with paper charts by printing out results.

Features of *PEDS Online*

- *PEDS Online* provides automated scoring, a summary report for parents to take home, and a referral letter when needed to share with other professionals. *PEDS Online* also generates ICD-9 and procedure codes to optimize accurate billing and reimbursement.
- The *PEDS Online* website offers a parent portal so that parents can complete measures before an appointment (e.g., via a link on clinics' websites) or in the waiting room. Parents do not see results. Alternatively, office staff and providers can administer the various measures by interview (or ask parents to complete questions in writing for staff to enter into the web-based scoring service). *PEDS Online* generates a database for each clinic so that a standing, exportable record is available. This feature is useful for quality improvement initiatives and for retrieving any lost records. Multi-site clinics can establish a master account wherein clinical supervisors/administrators can view records across sites.
- Each child's record in the database is held open for 30 days. So if a visit was too swamped to complete the M-CHAT, the measure can be administered at a follow-up visit.
- *PEDS Online* can be trialed at *www.pedstest.com/online*. The site is capable of integration with electronic records but most users simply copy/paste results into their existing software (during the inevitable wait for electronic records software consultants to establish the necessary fields and encrypted data exchange required to populate electronic records).
- *PEDS Online* comes with all available translations of *PEDS* and the *PEDS:DM*. Users are directed to *www.mchatscreen.com* for all translations of the M-CHAT. Users are also provided a Brief Guide to *PEDS Online* that explains results, and includes links to referral and parenting information sites.
- Spanish language version of all measures and a Spanish version of the parent summary report are also available.

Costs of *PEDS Online*

Cost depends on volume and ranges from ~$2.22 to $2.75 per child (for one or all screens). The time-savings for professionals is enormous given that referral letters, parent summaries, scoring and ICD-9/procedure codes are generated by the *PEDS Online*. If parents are able to complete measures on their own (e.g., from home or from an office computer), there is no time-related staff/provider costs for administration. If an interview is needed instead, time frames are estimated at 2 – 5 minutes per screen administered. Given that Medicaid reimbursement is about $8.00 per screen and most private payers offer $10.00 - $20.00 or more, *PEDS Online* enables providers to provide quality screening, efficiently, in an electronic environment, and…. get paid well for a job well done.

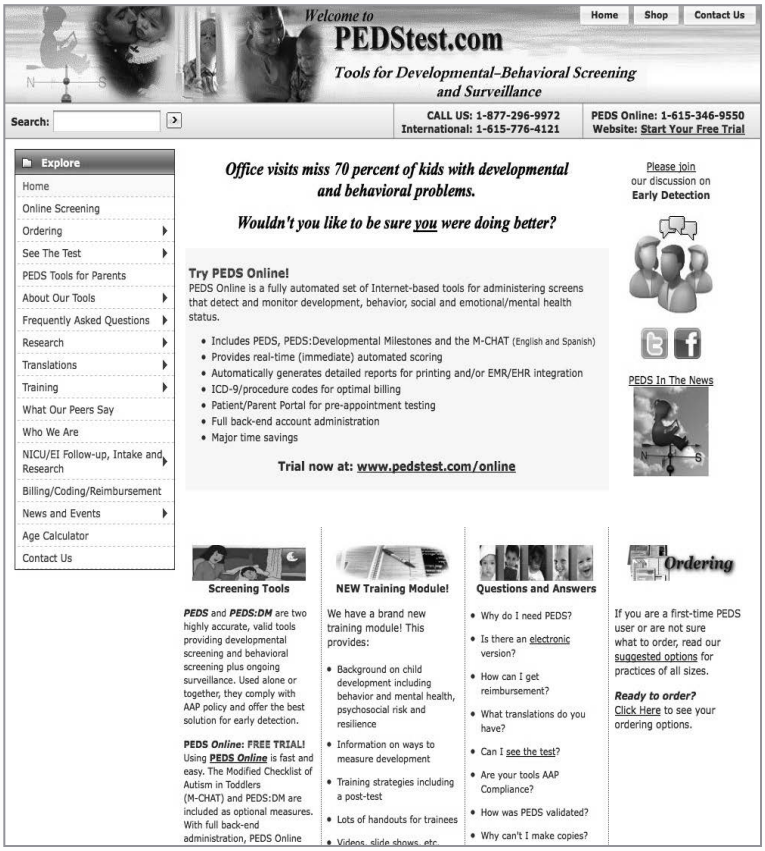
Self Selected Parents

For parents unattached to clinics or services, there is a separate website where parents can use *PEDS Online* on their own. Although it is better when children receive quality screening through healthcare programs, not all providers use good tools—"wait and see" is an all too common response to parents' worries. So, parents can go to *www.forepath.org* to complete the three measures housed within *PEDS Online*. Parents are charged $9.95 (via Pay Pal) for this service and receive detailed reports on results.

The *PEDS* website: *www.PEDStest.com*

The overall website for *PEDS* and *PEDS:Developmental Milestones* (*PEDS:DM*), collectively known as *PEDS Tools* is located at *www.pedstest.com*. Figure 4 is a screen shot showing the menu for the site. A repository for information about *PEDS Tools*, *www.pedstest.com*, houses:

Figure 4. Screenshot of *www.pedstest.com* Home Page



- Videos on how the tools work, case examples, frequently asked questions, and details on billing and coding. There are a number of downloadable slide shows such as "Why Screen", designed for use by those who need to encourage use of quality tools (even if accurate measures other than *PEDS Tools*).
- A training module is housed on the site and explains the how's and why's of child development, developmental domains, disabilities, use of *PEDS Tools* including scoring practice, and a pre-post-test if needed. Implementation guidance is also included. The module can be used for self-training (by emerging and practicing professionals) and for group training (including advice on active learning experiences, collaboration across disciplines, etc.).
- Because *PEDS Tools* are designed only for children 0 through 7 years – 11 months, the website also includes several freely downloadable, accurate measures for use with children 8 years and older. These include the Safety Word Inventory and Literacy Screener (SWILS), the Brigance Parent Child Interaction Scale (BPCIS), the Pictorial Pediatric Symptom Checklist (PPSC) and the Family Psychosocial Screen (FPS). The latter three measures are also provided in Spanish.
- Information for parents is included on the site. This includes links to websites where guidance can be found on dealing with the usual issues of childhood as well as services for children with special needs. There are 6 – 8 parenting handouts in English and Spanish posted as Word documents so that users can edit and personalize them.
- There is a separate module for Neonatal Intensive

Care Unit follow-up/Early Intervention intake. This section describes the use of *PEDS* along with the Assessment Level version of the *PEDS:DM* that provides more items than the Screening Level version of *PEDS:DM*, produces age-equivalent scores and is more suitable for research and measurement of children likely to have strengths and weaknesses in development.

- Research abstracts focused on *PEDS Tools* are also housed on *www.pedstest.com*. We encourage researchers to send abstracts or to contact *PEDS Tools* staff and faculty with any application and scoring questions.
- Included is a chronological age-calculator for clinicians and researchers. The calculator includes an adjustment for prematurity when needed.
- The site enables ordering of *PEDS Tools* in print (with a link to the trial of *PEDS Online*). The ordering menu on the site also has links to *PEDS Tools* co-publishers (e.g. England, Australia, Philippines, Iceland).
- Also available is an opportunity to comment on the *PEDS Tools* Facebook page (*www.facebook.com/PEDStest*.)
- News and Events are shown on the site (and trainers are encouraged to send information about upcoming training events).
- Professionals can send questions to relevant *PEDS Tools'* staff through the *Contact Us* menu. Many of the messages we answer involve translations (for which our translation team helps link researchers with existing translation efforts or searchers for bilingual collaborators—translations need lots of vetting). Other common questions focus on research applications (e.g., telephone interviews and population surveys), co-publications, or ordering issues, etc. Questions and answers of general interest are added routinely to the "Frequently Asked Questions" menu on *www.pedstest.com*.

Where and How Is *PEDS* used?

PEDS' brevity and collaborative approach have resulted in its use within every US State and most US Territories. *PEDS* is also used in many other nations and researchers both here and abroad facilitated its translation into ~20 languages (with more translations under development). Some of the many settings and administration approaches to using *PEDS* include:

- Pediatric and family practice clinics (for routine healthcare)
- Public health departments (for routine healthcare)
- Public school screening (e.g., as triage via a mail-out to parents of entering kindergarten students)
- 211 (the national "warm line" service for non-emergent crisis calls) as a telephone interview
- Head Start and Early Head Start (for screening, facilitation of parent-teacher conferences, and for individualizing parent training)
- Research studies (e.g., on parents' concerns about possible autism spectrum disorder, cerebral palsy, traumatic brain injury)
- Population surveys via *Survey PEDS* (e.g., National Early Childhood Survey of Health) and needs assessment (e.g., California First Five; Australia's Child and Adolescent Monitoring System) either by telephone or mail-out.
- Neonatal Intensive Care Unit Follow-up programs (for triage by mail, for facilitating parent-provider communication during face-to-face encounters, or by generalist providers for making referral decisions)
- As part of early intervention intake for deciding on the types of testing/parent education needed
- International studies of psychosocial and developmental risk (e.g., Haiti, Zimbabwe, Uganda)
- In standardization/validation research to ensure *PEDS Tools* work effectively in other nations (e.g., Jordan, Iceland, Australia, Great Britain, etc.)

Considerations when Encouraging Primary Care Providers to Adopt *PEDS* (and/or other Quality Screening Tools)

Primary Care Issues: Time, Patient Mix, and the Hazards of Business as Usual

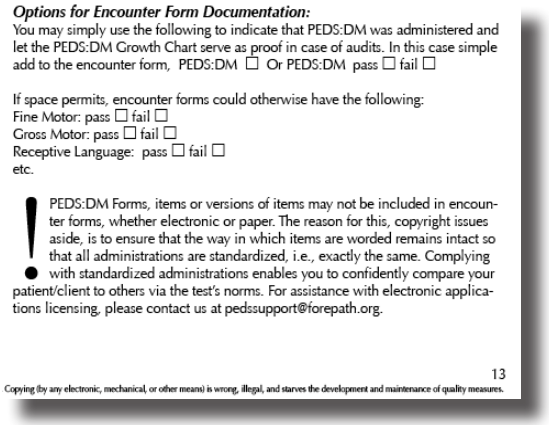
- If you are on a panel vetting screening test options for healthcare providers (e.g., for a state or national initiative) and if your background and focus is on early intervention, it is crucial to know that clinics differ substantially. Variables include length of well-visit schedule, patient mix (e.g., parental literacy levels), languages spoken/translations available, office equipment, and staffing patterns (e.g., whether a clinic has a nurse practitioner who can follow up with the results of briefer tools, etc.). These variables have an impact on what tools are workable for each setting.
- Some tools are simply too long for primary care (e.g., the Brigance Screens, the Battelle Inventory of Development Screening Test, and for many, even the Ages and Stages Questionnaire). It is fine to place these on a table of accurate options among screens: Giving clinicians options (and trials) of tools is wise so they can select measures that are workable and sustainable for their clinics. At the same time, panelists often include early childhood specialists who often prefer skills-focused measures (because these are particularly helpful for educational interventions), but are unaware of the enormous time restrictions in primary care and requirements from the American Academy of Pediatrics to elicit and address parents' concerns at each visit.
- Providers need to be disabused of the notion that informal questions to parents and ad hoc milestones are effective. Such approaches are not only notoriously ineffective at early detection,[28-30] but also massive time-wasters leading to disruptive "oh by the way" concerns, and useless elicitation of skills non- predictive of actual developmental-behavioral status. If parents complete measures and staff provide results before the exam, providers' time is far better spent, i.e., actually treating families via advice, referrals, creating follow-up plans, etc. Please see the slide show, "Why Screen" on *www.pedstest.com* for a thorough rationale!
- Clinicians are likely to perceive that adding a developmental-behavioral screening tool will take more time than current informal methods. This is false because tools using information from parents actually save time (as described in the Benefits section below). Disputing this erroneous notion is needed and may need to involve showing providers how much wasted time is spent on informal measurement of milestones.
- Clinicians often believe online screening services are not workable without an Electronic Health Record (EHR) or with their particular patient mix. Trialing *PEDS Online* (or other web-based applications) is useful for dispelling this erroneous notion.

Complying with AAP Policy

- All clinicians should, in order to comply with American Academy of Pediatrics recommendations,[27,31,32] elicit and address parents' concerns at every well visit.
- Although the AAP statement[27] included informal questions to parents, these have been shown not to work: They not only fail to identify children with problems but also fail to elicit the full range of parents' issues about their children's development and behavior.[33]
- *PEDS'* proven questions and evidence-based support is crucial for working effectively with parents. As helpful as the ASQ is at measuring milestones, the ASQ's questions about parents' concerns detect very few children perhaps because of wording issues or failure to probe all domains, and/or placement of items, i.e., at the end of the screen rather than the beginning, meaning that parents may be inhibited by a sense that their knowledge of development is being tested).[34]
- The AAP also urges providers to monitor milestones at every visit. Again evidence-based screens are also needed. *PEDS: Developmental Milestones* is the briefest option. The ASQ is another good choice but since many providers find it long for primary care, it may be best viewed as a

second-stage tool, deployed only when concerns are raised on *PEDS* or, in the rare cases when providers notice and wish to confirm a possible problem that parents have missed.

- Most clinicians have a set of age-specific milestones imbedded in their well-child visit forms. These ad-hoc measures are one of the leading causes of under-identification. So, providers should replace these items with results of quality measures (e.g., with indicators for each domain and whether milestones are met or unmet at each well-visit age, for example: expressive language: ___met ___unmet.



Options for Encounter Form Documentation:
You may simply use the following to indicate that PEDS:DM was administered and let the PEDS:DM Growth Chart serve as proof in case of audits. In this case simple add to the encounter form, PEDS:DM ☐ Or PEDS:DM pass ☐ fail ☐

If space permits, encounter forms could otherwise have the following:
Fine Motor: pass ☐ fail ☐
Gross Motor: pass ☐ fail ☐
Receptive Language: pass ☐ fail ☐
etc.

PEDS:DM Forms, items or versions of items may not be included in encounter forms, whether electronic or paper. The reason for this, copyright issues aside, is to ensure that the way in which items are worded remains intact so that all administrations are standardized, i.e., exactly the same. Complying with standardized administrations enables you to confidently compare your patient/client to others via the test's norms. For assistance with electronic applications licensing, please contact us at pedssupport@forepath.org.

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Copying (by any electronic, mechanical, or other means) is wrong, illegal, and starves the development and maintenance of quality measures.

- The AAP[27,31] also recommends an ASD focused screen is also needed at 18 and 24 months such as the Modified Checklist of Autism in Toddlers (M-CHAT)
- Some providers use the M-CHAT as their sole screening tool. This is decidedly unwise because narrow-band screens (also including the Vanderbilt ADHD Diagnostic Rating Scale) will miss most children , i.e., those with more common problems such as language-impairment, learning or intellectual disabilities. A broad-band screen must be used first and always.
- The AAP policy[32] on early detection of mental health problems in young children recommends that providers screen social-emotional and behavioral skills. *PEDS* and the *PEDS:DM* include items measuring mental health status via parents' concerns and via skills-focused questions.
- The AAP statement[27] emphasizes screening at 9, 18, 24 or 30 months but also states that its policy for ongoing screening and surveillance should establish *"…a pattern and practice of attention to development that can and should continue well beyond 3 years of age."* [27(p.406)]
- Developmental-behavioral problems emerge well beyond 24- 30 months of age and ongoing screening/surveillance is essential if we are to detect children before school entry whose problems with language, pre-academics, etc. can be ameliorated or prevented.
- Some private payers attempt to discontinue reimbursement after 24 – 30 months. Wrong and wrong!
- The AAP is actively advocating at the federal level for payment for surveillance/screening beyond 30 months of age.
- Providers with denied claims should appeal them and also alert the AAP Coding Hotline (*www.aap.org*).

Provider Measurement Preferences and Implications for adoption of *PEDS*

- Providers are likely to have preferences among measurement methods. Some are comfortable relying on *PEDS* to elicit and address parents' concerns but others prefer to measure children's milestones. Obviously, they need to do both and with evidence.
- Meanwhile, some clinicians chose to use *PEDS* because of its brevity but then over-ride its evidence with ad hoc milestones that, in fact, deter early detection.
- Ascertaining providers preferences and ensuring they use both *PEDS* and a quality milestones measure such as *PEDS:DM* and the ASQ is needed.
- Meanwhile a few much prefer hands-on screening because they fundamentally lack faith in parents' concerns or in their report about children's skills—despite all evidence. (And frankly, if the parent feels there's a problem, there is a problem—whether in parenting skills and knowledge, or actual deficits within the child). So, it may be helpful for those making decisions about tool options to share research on the extremely close association among all three measurement methods: parent report about skills, parents' concerns, and hands-on measurement (see Glascoe & Dworkin, 1995 for a review). But chances

are high that such evidence will not overcome a fundamental preference for one type of measurement approach or another. Again, this confirms the need for choices among accurate tools that include a range of administration methods.

- Within accurate milestones measures, the *PEDS:DM* offers a hands-on administration, as well as parent self-report, and observation/interview.
- Clinicians (and many parents) tend to prefer *PEDS* supported by the *PEDS:DM* (and should replace their inaccurate milestones checklists within age-specific encounter forms) with fields for *PEDS* and *PEDS:DM* results and decisions.
- All the above means that the combination of *PEDS* and *PEDS:DM* (or *PEDS* plus the ASQ) address most measurement preferences.
- Such options (and efforts to ensure compliance with AAP guidelines) confirms that clinicians need three approaches to early detection, i.e., parents' concerns and accurate milestones, whether via report or hands-on, followed by sporadic use of an ASD focused screen.
- As a consequence panelists should identify a range of measures tapping various measurement methods while training a "beaded eye" at the time-constraints of primary care and, within that, at the literacy levels of patients who may struggle with lengthy questions.

Documentation and Other Cost Issues

Providers must have documentation in their charts of completed screens including responses to items, scoring, interpretation, and decisions made—for possible audits by Medicaid or private payers. The *PEDS* longitudinal *Score/Interpretation Form* should be kept in paper charts along with the most recent *PEDS Response Form* (prior Response Forms can be removed). With *PEDS Online*, pasting results into encounter forms OR using the online database as a record of service delivery is essential. For other measures, longitudinal documentation and the latest completed screen should be kept in the electronic or paper record.

Screening in an Electronic Environment

It is worth noting that a screening test like the ASQ that is purchased for each clinic and then photocopiable, is not "free". Photocopying 6 – 7 pages per age range and on colored paper, collating, and organizing photocopies involves substantial costs, both material and time/labor. It is in fact much cheaper to purchase materials from publishers.

- Providers increasingly want online applications of measures. This is wise because there are enormous time-savers when scoring is automated, reports and billing/procedure codes generated and when parents can either complete measures via portals (e.g., from computers at home, libraries, schools, clinic computers, etc.), in writing in waiting/exam rooms, or by interview during encounters with staff entering comments.
- Many clinicians are not convinced that impoverished families have access to online applications of tools. This notion is mostly false (e.g., 80% of families in inner-city Chicago were willing and able to self-administer screens prior to an appointment, often via school or library computers, if not from home or on clinic office equipment). But disabusing providers of this notion will surely be needed.[35]
- Nevertheless, even when online applications are available (as is the case with *PEDS Tools* and ASQ Tools) all families will not complete them in advance and so a back-up plan (including access to many different translations as is provided with *PEDS Online*) is essential (e.g., paper-pencil self-administration in clinics, in-office interviews, etc.).
- Providers inevitably want full integration with online applications—meaning that results will "automagically" populate fields in an electronic record. That's reasonable but it requires support from software consultants for the various electronic records. Such support is hard to come by because most dollars for electronic record modi-

fications are devoted to adult medicine. Providers should hold out for modifications before purchasing or band together to request support. In the meantime, learning to copy/paste is a viable and easy enough approach (while pressuring EHR vendors for needed changes and software integration).

- *PEDS Online*, as with other web-based applications require providers to learn how to keep both a browser and the electronic record open, learn how to switch back and forth between them, and copy/paste results in the patient record. This is not a huge challenge but (self-) instruction is needed. See *www.pedstest.com* for guidance especially the short movie or slide show about using *PEDS Online*.
- Clinicians using paper charts can still use *PEDS Online*. In these cases, results and reports generated by *PEDS Online* can simply be printed out but also attached to an email when communicating with referral services.

Administration, Translations, and (Self-) Training Issues

As with all developmental-behavioral screening tests, there are a set of directions for how to use them. Adherence to these and referencing them frequently is essential.

- *PEDS* requires use of its *Brief Guide* for correct administration (e.g., Response Forms without comments cannot be scored; providers should add their own concerns but not remove those of parents—no matter how frivolous they may seem—parents' concerns are real to them and need to be addressed.
- To score *PEDS*, providers need to be familiar with the various developmental-behavioral domains so they can categorize parents' concerns. This is provided in the *Brief Guide* with additional information in the training module on *www.pedstest.com*.
- Providers, as described above, if more trusting of milestones than parents' concerns, may use "junk science" to over-ride the evidence behind *PEDS*, and as a consequence defer rather than refer. A quality second stage screen such as the *PEDS:DM* or ASQ should be used instead of ad hoc milestones checklists.

Preparing Parents and Providers for Early Detection

- Parents benefit from information about developmental-behavioral skills expected at each age range (e.g., milestones checklists). Providers, of course, should not use these as screens, in part because such lists are focused on the 50th percentile—meaning half of all children will not do well. Instead, 50th percentile milestones serve only as a helpful guide to expected skill sets at each age per well visit (and as a helpful teaching tool for pediatric residents who are expected to memorize milestones across age ranges).[36]
- Posting milestones in waiting or exam rooms is helpful. The Centers for Disease Control offers a free milestones card focused on the 0 – 3 year age range that could be given to parents at an initial visit (with encouragement to affix to the fridge). Many other initiatives have more detailed lists (less focused on autism spectrum disorders) that can be requested and distributed.
- The *PEDS Tools* website, *www.pedstest.com*, houses a list of milestones from birth to 8 years constructed by numerous developmentalists.
- Providers sometimes over-ride *PEDS* results when parents' comments are ambiguous (e.g., "*I don't know what a 6 month old should be saying*"). Such comments are an indicator of risk because we hope parents are learning about child development as they rear their children. So these concerns should be met with further screening and if problems are ruled out, then with advice to parents and vigilant monitoring.

Resource Identification and Referrals

Knowledge of referral options is crucial but often problematic:

- Providers are often unfamiliar with referral sources. Some will embrace the value of early detection and quality screening but wonder why bother *"when there is nothing out there in terms of services?"* This assumption is false and simply reflects lack of knowledge about options.
- Non-medical services need to do better by healthcare providers—visit, share resource lists, call back when a referral is made, etc.
- Providers need to recognize that *PEDS* identifies more children in need of attention than other measures because it identifies those at risk for future problems, i.e., due to mild or emerging delays and psychosocial risk factors.[38] These children need attention too even though some will not qualify for special needs services through the Individuals with Disabilities Education Act (IDEA).
- Use of a second stage screen helps reduce over-referrals to IDEA (together with provider awareness of psychosocial risk factors) and helps providers identify children in need of other types of services.
- Having a broad and handy list of referral resources in each exam room is invaluable (e.g., Head Start, Early Head Start, parent-training programs, quality day care/preschool, and IDEA programs). See *www.pedstest.com* for a list of national resources through which local services can be found.
- Clinicians are encouraged to refer rather than "defer" and to collaborate with IDEA programs (undoubtedly the first best start for defining problems and services needs) when children do not qualify but need other services.
- Parents are more likely to follow through with referrals when appointments are made for them.[37] Non-medical services are encouraged to allow clinics to make appointments for families—most especially those with limited education or limited ability to speak English.
- Clinicians need to understand that some families will not follow-up with referrals despite appointment making and collaboration with intervention programs. Often such parents believe they can intervene on their own—which is a good thing—but it also means that follow up with families is needed along with vigilant monitoring of children's progress.
- One of the *PEDS*' Paths focuses on "the worried well" which means that providers need to give parents advice on managing common parental concerns (e.g., toileting, reducing temper tantrums, sleeping and eating problems, etc.) Having information handouts available, especially the ability to find and print out information from reputable websites such as www.kidshealth.org is wise. Sharing links to such sites with parents (including live links on clinic websites) is helpful. A list of parent information sites, including those with information in multiple languages is provided at *www.pedstest.com.*

Implementation Planning

- Implementing screening measures within clinics is a major challenge and often the greatest obstacle to adoption of new tools.
- Finding a physician champion as well as a staff champion is essential (screening is largely a staff function because there are no Relative Value Units (RVUs) for provider time).
- Informing staff (and other clinicians) of the value of early detection and early intervention is needed.
- Figuring out a work flow for paper or electronic screens is essential. It is helpful to view existing processes (e.g., how any other measures/questionnaires "float" from the waiting room to the med tech station to the nursing station and then to exam room).
- Non-medical/referral services can help (e.g., via encouragement, training, information about time-reduction, and frequent contact about the status of referrals/evaluations).

Benefits of *PEDS*

PEDS emulates the kinds of decisions providers tend to make but does so with evidence—eliminating "wait and see" recommendations when, in fact, a child probably has problems—or over-referring when confronted with a parent who is among the "worried well."[17]

PEDS also helps focus encounters because it enables parents to tell us their specific worries (e.g., "bites others", "won't use the toilet", etc.). This information defines the content of developmental-behavioral promotion activities. And, by using *PEDS* prior to encounters, professionals can walk into exam rooms, armed with the information parents need.[39]

PEDS reduces "oh by the way" concerns—those arising at the end of the visit when there is no time left to address them. Studies show that *PEDS* shaves about 3 minutes from the length of well- child visits, leaving more time to intervene.[37]

PEDS also identifies health-related concerns—many of these issues are topics clinicians have discussed in the past—but the information given didn't sink in. So, *PEDS* identifies when providers need to repeat advice (about health as well as other issues). As we all know, mastering new information almost always requires repetition.[39]

PEDS, unlike milestones-focused measures, identifies probable disorders in development and behavior. For example, a parent answering a skills-focused screen may report that a child uses 3 word utterances at an age-appropriate level. But on *PEDS*, that same parent has the latitude to report that their child only uses the same 3 words over and over and over. Not good! Thus *PEDS* adds an important qualitative dimension to early detection.[39,40]

PEDS makes it much easier to explain troublesome findings because when parents have raised concerns, professionals can simply affirm them when difficulties are found. (e.g., "Your concerns are important and I agree that we should look further at how your child is doing."). Since most parents whose children have difficulties also have concerns, there is little in the way of an unpleasant surprise for parents when *PEDS* results are problematic.[40]

Parents whose concerns have been elicited by *PEDS* are more likely to go forward with referrals, act on parenting advice, etc. [37]

PEDS helps parents think about development like professionals do—as a range of domains. An initial complaint is often about behavior but when probed, parents are encouraged to consider such things as whether their child understands what is said, has the motor skills or attention span to complete tasks, etc.

PEDS encourages parents to notice the development of other children (e.g., when in doctor's offices, playgrounds, etc.) and to discern for themselves what is average and what is not.

PEDS helps parents view professionals as collaborators in their child's care. Parents' sense of support from providers results in a reduction in corporeal punishment and greater use of positive practices such as time out and praise.[41]

Parents are more likely to return for follow-up appointments (e.g., well-visits).[42]

Professionals find it easier to communicate with parents, share their own concerns, and acknowledge those of parents. This benefit makes parent-teacher/parent-provider conferences and disclosing interviews more productive because parents and professionals can truly co-operate in setting goals for children.[43,44]

Comments

There are numerous advantages to using PEDS due to its family-centered and collaborative approach to early detection by eliciting and addressing parents' and providers' unique concerns. PEDS is enormously helpful in: selecting specific parenting information; gathering the concerns of providers and parents; identifying probable and potential disorders in development and behavior; deciding upon types of referrals needed; and in conveying difficult news. PEDS also saves valuable time during encounters by reducing "door knob concerns" thus facilitating efforts to intervene with parents' issues.

Although PEDS is as accurate as lengthier quality screening tools, the AAP's policy[27] indicates the need to not only elicit and address parents' concerns at each visit, but also measure milestones, screen for autism spectrum disorders at 18 and 24 months, plus identify and address psychosocial risk factors periodically. Thus, PEDS should be used at all visits, along with other measures at least from time to time or as indicated (and also because PEDS calls for a second stage milestones-focused screen in about 20% of patients in order to rule in/out concerns placing children at moderate risk). So, it makes sense for providers to replace informal milestones with a measure such as the PEDS:DM. Such an approach complies with AAP policy, ensures that PEDS results are attended to with caution, helps parents learn milestones, and is helpful for non-medical interventionists who need to know what children can actually do.

Using Parents' Evaluation of Developmental Status (PEDS) and PEDS: Developmental Milestones (PEDS:DM): A Case Example

Russell Richards*, age 29 months, received health care from Paragon Pediatrics, a practice implementing the American Academy of Pediatrics' 2006 policy on developmental screening and surveillance. The practice added a 30 month visit devoted to detecting and addressing developmental and behavioral issues. Clinicians used both PEDS and the PEDS:DM. Mrs Richards filled out a PEDS Response Form while she was in the waiting room. She expressed some concerns about Russell's behavior and understanding of language.

**For this case example,no personally identifying information is included. Pseudonyms are used along with stock photography.*

PEDS Response Form

Paragon
Provider

Child's Name Russell Richards Parent's Name Mr. and Mrs. Richards

Child's Birthday 3/21/08 Child's Age 29 months Today's Date 8/23/2010

Please list any concerns about your child's learning, development, and behavior.

Mostly his behavior. He doesn't smind me or seem to listen to me at all. Tantrums all the time.

Do you have any concerns about how your child talks and makes speech sounds?
Circle one: (No) Yes A little COMMENTS:

Do you have any concerns about how your child understands what you say?
Circle one: No Yes (A little) COMMENTS:

Do you have any concerns about how your child uses his or her hands and fingers to do things?
Circle one: (No) Yes A little COMMENTS:

Do you have any concerns about how your child uses his or her arms and legs?
Circle one: (No) Yes A little COMMENTS:

Do you have any concerns about how your child behaves?
Circle one: No (Yes) A little COMMENTS:
This may just be the terrible twos, but it is really terrible.

Do you have any concerns about how your child gets along with others?
Circle one: (No) Yes A little COMMENTS:

Do you have any concerns about how your child is learning to do things for himself/herself?
Circle one: (No) Yes A little COMMENTS:
He tries to be too independent.

Do you have any concerns about how your child is learning preschool or school skills?
Circle one: (No) Yes A little COMMENTS:
I think he's too young for that sort of stuff.

Please list any other concerns.
Nothing other than behavior and listening.

Actual Size is 8.5 x 11

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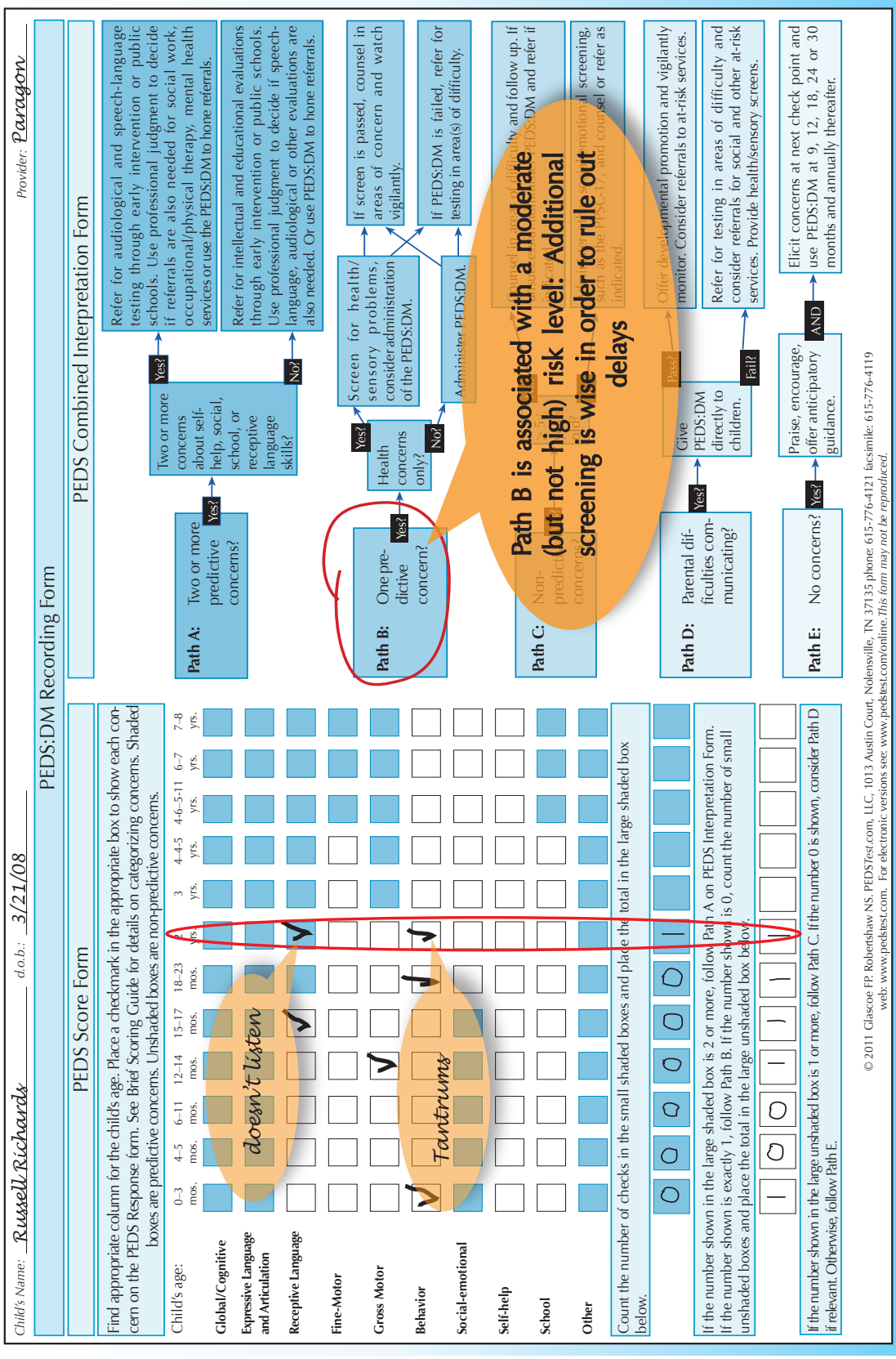
The PEDS Score Form shows how Mrs. Richards' concerns were categorized (receptive language and behavior). These concerns indicated the need to follow Path B on PEDS and to screen further due to a potentially elevated risk for developmental problems. In response the PEDS:DM was administered to determine the best course of action.



PEDS: DM forms are laminated and parents mark them with a dry erase marker. Opposite the questions are stories and illustrations to encourage reading aloud. A scoring template is placed over the answers to reveal correct and incorrect responses. Results are marked on the PEDS:DM Growth Chart—see next page—where there is also space for noting specific decisions. On the other side of the PEDS:DM Growth Chart is the PEDS Score and Combined Interpretation Form. Thus a 1 page form remains in the child's chart to track surveillance and screening activities from 0 to 7– 11 years.

Here are the PEDS:DM items at the 29 month level and Ms. Richard's responses. These were all correct answers and showed that Russell had age appropriate fine motor, receptive language, expressive language, gross motor, self-help and social-emotional skills.

Can your child scribble with a crayon or marker without going off the page much?	No A little Yes ✓	*Fine Motor*
How many of these body parts can your child point to if you say, "Where is your head?... "Where are your legs?"... "arms?"... "fingers?"... "teeth?"... "thumbs?"... "toes?"	None 1 - 2 3 or more ✓	*Receptive language*
When your child talks, how many words does he or she usually use at a time?	None 1 2 or more ✓	*Expressive language*
Can your child walk backwards two steps?	No Yes, shuffles or stops Yes ✓	*Gross Motor*
Can your child take off loose clothes such as pull-down pants or a coat?	No Sometimes Most of the time ✓	*Self-help*
Does your child pretend to do grown-up things like washing dishes, taking care of a baby, sweeping, scrubbing, or cooking?	No Sometimes Yes ✓	*Social/Emotional*

All Milestones Met

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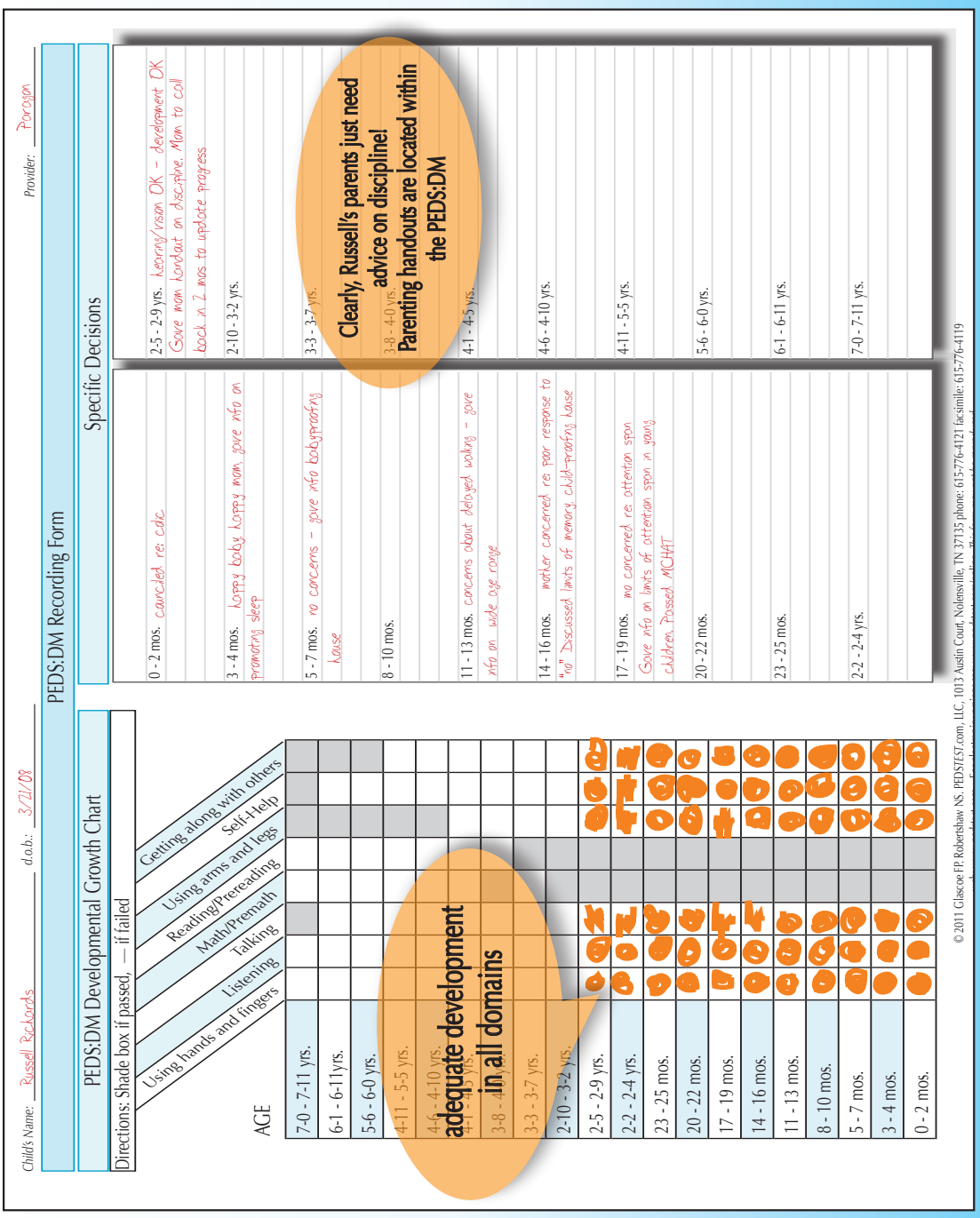
Permission is granted to photocopy these scored forms for training purposes.

Here is the PEDS:DM Growth Chart showing the trajectory of Russell's development in each domain over time. The Specific Decisions show issues raised during prior encounters and clinicians' responses to each. At the current visit, Russell received hearing screening (vision as well) which is a helpful response when receptive language concerns are raised. Having ruled out developmental problems, the issue was clearly behavioral and indicated a need to educate this parent on effective disciplinary techniques. In response, she was given an information handout on behavior management (included in the PEDS:DM Professionals' Manual) and asked to call back in two months to report on progress. If problems persisted, clinicians at Paragon were prepared to refer her for parent training classes and/or individual behavioral intervention. Referral resources are also included in the PEDS:DM Professionals' Manual.



Actual Size is 8.5 x 14

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Chapter II

PEDS Standardization

Critical Concepts in Screening and Test Construction: Standardization

Standardization ensures that a test can be used effectively with children from diverse backgrounds. Results from standardization research enable us to see how the children with whom we work compare to the national average—and thus when they are behind or ahead of most children. Standardization on *PEDS*, as with any well-constructed measure, involves:

- Ensuring that test directions are well-defined so that administration is standardized, i.e. exactly the same across children, parents, and examiners.
- Identifying the demographics of a nation. In the US, Census Bureau data determines population parameters in terms of ethnicity, parents' level of education, geographic location, income, etc.
- Constructing a sample that reflects the characteristics of the national population.
- Administering a test to the nationally representative sample
- Viewing the collective performance of the sample in order to determine what is "the norm". In the case of *PEDS*, normative performance is the frequency with which children are found to be at high risk, moderate risk, low risk but concerned (aka "the worried well"), or low risk without concerns.
- Ensuring that standardization is current. National demographics change and population differences can have an effect on test performance.
- Offering parameters for those providers working with families whose demographic characteristics differ substantially from the nation as a whole. This ensures that standardization studies offer information on likely performance rates in discrete populations [e.g., if working with a preponderance of families receiving Medicaid; families in crisis who are unable to pay utility bills, facing eviction, lacking the income needed to feed their children; children of parents who are highly educated and have few, if any, psychosocial risk factors; families with diverse ethnic backgrounds; those residing in (or recently immigrated from) other nations; those who speak languages other than English], etc.

Original *PEDS* Standardization Studies

PEDS was piloted on 200 parents and children from Middle Tennessee who were seeking outpediatric care in an inner city teaching hospital serving low-income families. Piloting consisted of trying out, with the assistance of a pediatric social worker, various wordings for the *PEDS* items and comparing the incidence of parental concerns to the prevalence of developmental problems. When the question "Do you have any worries about your child's development?" generated responses on only 2% of families (in contrast with the 16% to 18% prevalence of developmental disabilities)(*www.cdc.*

Table 2-1. Geographic Locations of Subjects

Geographic Locations	Total	
	N	%
South (Tampa, Florida)	114	14.8
South Central (Middle Tennessee)	363	47.1
North (Plymouth, Massachusetts)	114	14.8
Central (Denver, Colorado)	68	8.8
West (Carson City, Nevada)	112	14.5
Total	771	100%

gov) and the even higher prevalence of children (and parents) with mental health problems (*www.surgeongeneral.gov*). it was obvious that rewording was needed. After numerous additional trials, a final version of family-friendly questions was established, translated into Spanish, and then administered to an additional 771 families across the United States.

SITES

Standardization research was conducted in five sites selected to represent the broad geographic regions of the United States: North (Plymouth, Massachusetts); Central (Denver, Colorado which is within 250 miles of the geographic epicenter of the U.S.); South (Tampa, Florida); South Central (Middle Tennessee) and West (Carson City, Nevada). Two sites, (Plymouth and Carson City) are relatively small towns and Carson City, although bordered by the larger city of Reno to the north, is otherwise surrounded by rural areas. The Mid-South site included subjects residing in urban or suburban areas within Davidson County (Nashville, Tennessee) as well as bordering rural counties. The remaining two sites were exclusively urban.

SOURCES FOR SUBJECTS

Sources for subjects are listed in Table 2-2 and represent a mix of pediatric sites, day care centers, Head Start programs, schools, and children unenrolled in any educational program. The pediatric sites included two teaching hospitals serving largely lower income families and four private practices (three urban/suburban and one suburban/rural. At these sites, patients were recruited either as they waited for services or after services were completed. Recruitment times were determined by the pediatricians and nurses at each site. The day care sites (eight in all) included a mix of nonsubsidized and subsidized centers. The latter were designed to provide support for lower socioeconomic status parents who were either in job training or enrolled in school.

In each public school site, school personnel were asked to identify specific schools that had a balance of children from high, middle and lower socioeconomic status (i.e., approximately one-third of students participated in the federal free/reduced lunch program). At each school, a single kindergarten and first grade classroom was identified and students were recruited via consent letters sent to parents by each child's teacher. In order to ensure an adequate mix of upper, middle and lower socioeconomic groups for younger children, two- through four-year-olds were recruited if they were siblings of any kindergarten or first grade student in the target schools. In two of the four public school sites there were insufficient numbers of younger siblings and recruitment was extended to children attending preschool programs in the zone of the targeted elementary schools. These preschool programs: (a) had federal or local funding subsidies; (b) served children from varying socioeconomic backgrounds; and (c) were neither oriented for special education students nor exclusive of children with known disabilities. Overall the recruitment procedures helped ensure that the validation sample included children and families representative of the US as a whole.

Table 2-2. Sources for the 771 Subjects

Broad Sources	Specific Sources	Total N	Total %
Education Programs	Public Schools/Day Care Centers	289	37.5
	Unenrolled Younger Siblings	225	29.2
	Subtotal	514	67.7
Pediatric Practices	Private Pediatric Offices	123	16.0
	Teaching Hospital General Pediatrics Outpatient Clinics	134	17.4
	Subtotal	257	33.3
Any Source	Total	771	100

CHARACTERISTICS OF SUBJECTS

The demographic and socioeconomic characteristics of children and their parents are described below. Explanatory footnotes accompany some tables in order to illustrate similarities and differences between the study population and the US population.

Table 2-3. Gender of 771 Child Subjects

Gender*	Total N	Total %
Males	414	53.7
Females	357	46.3

Table 2-4. Racial and Ethnic Background of Child Subjects**

Race/Ethnicity	Total N	Total %	U.S.* %
White	497	64.5	73.3%
African American	166	21.5	12.7%
Hispanic/Other	108	14.0	14.0%

Note: African Americans were heavily represented in the teaching hospital sites

*from the US. Bureau of the Census, July, 1996 (*http://www.census.gov*)

Table 2-5. Ages of 771 Child Subjects

Ages of Subjects (in Years)*	N	%
0–1	45	5.8
1–2	66	8.6
2–3	158	20.5
3–4	138	17.9
4–5	121	15.7
5–6	123	16.0
6–8	120	15.5

*Children ranged from 3 months to 93 months (7 years, 11 months) of age, with a mean of 46.5 months (3 years, 10 1/2 months) and a standard deviation of 21.77 months)

Table 2-6. Birth Order of 771 Child Subjects

Birth Order	N	%
First Born	366	47.5
Second Born	254	32.9
Third Born or Later	151	19.6

Table 2-7. Informants

Informants	N	%
Mothers and Step-Mothers	688	89.2
Fathers and Step-Fathers	63	8.2
Other Primary Caretakers	20	2.6

Table 2-8. Parents' (Informants Only) Level of Education**

Parent's Education	Total N	Total %	U.S.* %
< High School	139	18.0	19.1
High School	243	31.5	34.6
High School +	174	22.6	24.1
College +	215	27.9	22.2
Mean Number of Grades Completed	13.1		12.9

*from the U.S. Census Bureau, 1996

Table 2-9. Parents' Marital Status

Marital Status	Total N	Total %	U.S.* %
Married	497	64.5	69.8
Unmarried	274	35.5	30.1

*from the US Census Bureau, 1996

Table 2-10. Parents' Employment Status

Employment Status	Totals N	Totals %	U.S.
Full-Time	374	48.5	56%*
Part-Time	142	18.5	**
Unemployed	255	33.1	**

* from the U.S. Census Bureau, 1996

** Information was not available on the frequency of part-time employment.

Table 2-11. Numbers of Children in the Home

Numbers of Children	Totals N	Totals %
1	206	26.7
2	316	41.0
3	182	23.6
4 or more	67	8.7

* The mean number of children was 2.2 (range 1–7, standard deviation = 2.0. This is quite similar to the average of 2.0 children per family found by the U.S. Bureau of the Census, 1996.

FAMILY INCOME

Families were categorized as low income on the basis of any one of the following: (a) if any child in the family participated in the federal free and reduced school lunch program; (b) if children were enrolled in a federally subsidized day care programs (for which parents' income must be below the federal poverty level; or (c) families who had profiles consistent with the characteristics of families who were enrolled in the school lunch program or in subsidized day care, i.e., headed by unemployed single parents with limited education. Profiles were used when information was not available on children's participation in the free lunch program or type of day care participation, i.e., those who participated in pediatric settings.

Table 2-12. Family Income

Income	Total N	Total %	US %
Low Income	196	25.4	20.3
Non Low-income	575	74.6	79.7
Total	**771**		

Note: The standardization data included a slightly higher percentage of low-income families when compared to the U.S. Census. However, this study involved families with young children, and they are far more likely to live in poverty (e.g., 35% of single-parent families headed by mothers are impoverished). Thus population differences seem to reflect expected trends.

Table 2-13. Ages of Subjects' Parents

Ages of Parents (in Years)*	N	%
< 20	47	6.1
21–25	126	16.3
26–30	223	28.9
31–35	193	25.0
36–40	131	17.0
41+	51	6.6
Total	**771**	

* Parents had a mean age of 30.7 years, range 12–62 years, (standard deviation = 6.47).

STUDY PROCEDURES WITH PARENTS

At each site, diagnosticians were recruited from among those employed by the public schools or local universities. In the South Central, Northern and Western sites, the diagnosticians were licensed psychological examiners or certified school psychologists, and in the remaining sites they were master's level educational diagnosticians.

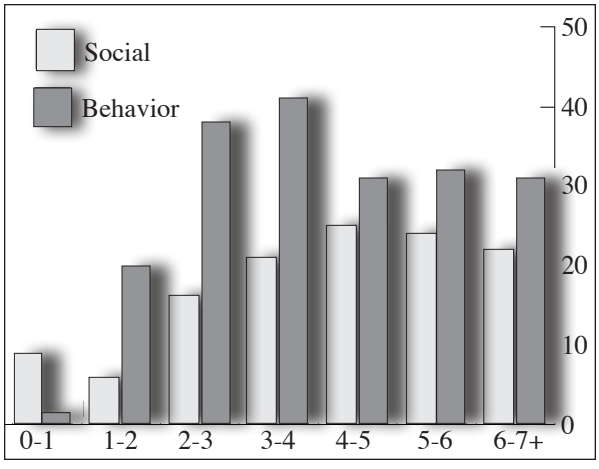
Diagnosticians administered *PEDS* and a demographics questionnaire that probed parents' perceptions of children's health status and whether or not children were born prematurely. The rationale for such questions rests in the close relationship between parents' perception of health problems and concerns about behavior and development. In the non-medical sites, parents were asked to indicate whether they had discussed concerns with medical professionals and how their provider responded to their concerns. When diagnosticians or teachers determined that parents were primarily Spanish speakers, Spanish versions were administered.

The findings here are organized by the abiding standardization questions. Analyses of variance and logistic regression were used to view differences in parents' concerns on the basis of various demographic and other characteristics. When variables interacted, e.g., when age or income was associated with differences in the frequency or types of parental concerns, these interactions were used as covariates in order to view the unique effects of each family characteristic on concerns. Tukey's post hoc test was used to identify differences among groups.

WHAT KINDS OF CONCERNS ARE RAISED MOST FREQUENTLY?

Parents held an average of 1.3 concerns (range 0–10, standard deviation = 1.73). Figure 2-1 shows the frequency of each type of concern.

Figure 2-1. Frequency of Concerns by Children's Ages



Behavioral concerns for the 2–6-year-olds differ significantly from the 0–1-year-olds. Social concerns for 4-year-olds differ significantly from 1-year-olds [F(6, 764) = 5.39,p < .00001 and 2.89, p < .008].

Table 2-14. Concerns raised by parents on *PEDS* in decreasing order of frequency

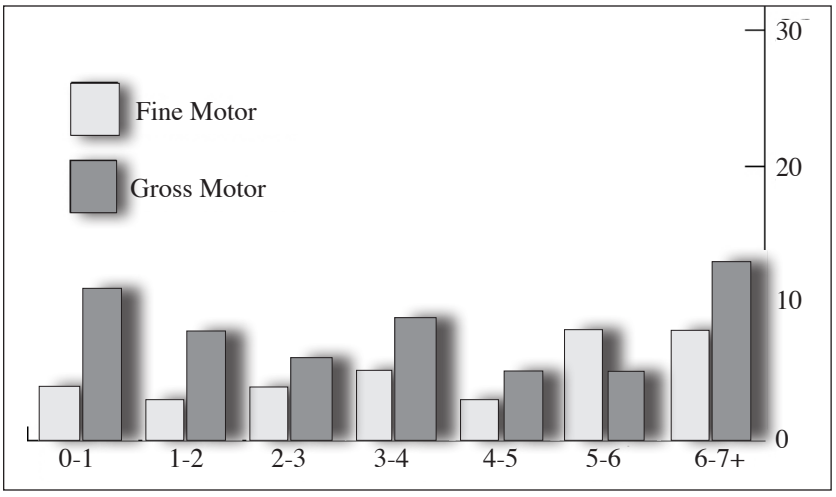
Concern	Total	
	N	%
Behavior	245	31.8
Expressive Language	185	24.0
Social-Affective	148	19.2
School	92	12.0
Self-help	71	9.2
Receptive Language	65	8.4
Gross Motor	63	8.2
Fine Motor	42	5.4
Other/Health	36	4.7
Global	30	3.9
No Concerns	**334**	**43.3**
Any Concern	**437**	**56.7**

DO CONCERNS VARY BY CHILDREN'S AGES?

Figure 2–1 shows the frequency of concerns according to children's ages. There are significant differences between groups [F(6, 764) = 3.77, p < .001]. Parents of 3, 4, and 6-year-old children had more concerns than did parents of children less than 2 years of age.

Figures 2-2 through 2-6 show which developmental concerns are raised most often by parents by children's ages. Parents of the children less than 2 years of age had significantly fewer concerns about behavior, language, social skills, school and self-help skills than parents of older children. Parents of 2 - 4-year-olds were significantly more likely to have concerns about behavior and expressive language, while parents of 6-year-olds were more likely to have concerns about behavior, language, school, and social skills.

Figure 2-2. Fine and Gross Motor Concerns by Children's Ages



There were no significant differences in fine and gross motor concerns across age groups [F(6,764) = 1.28 and 1.29].

Figure 2-3. School and Self-Help Concerns by Children's Ages

Concerns about school for 6-year-olds differed significantly from 1-year-olds. Concerns about self-help skills for 6-year-olds differed significantly from the 0,1,and 2-year-old groups. [F(6,764) = 2.39,p < .03 and 3.18, p < .004].

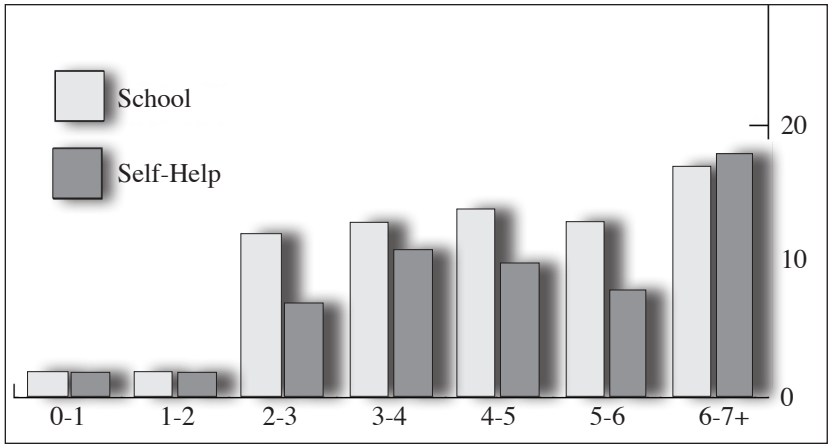
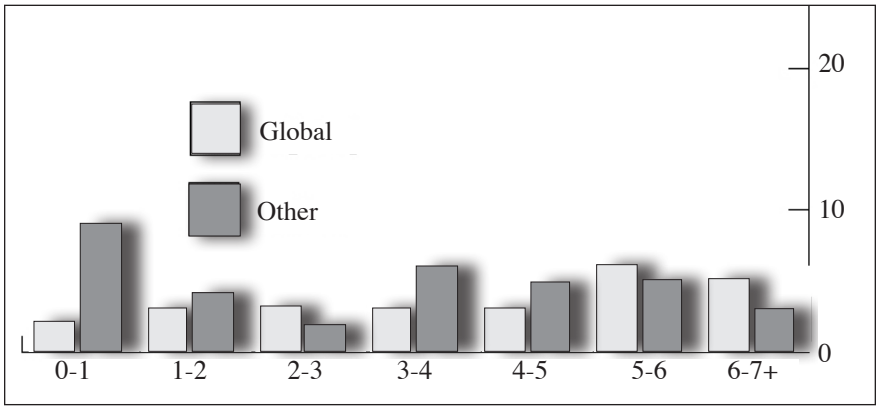


Figure 2-4. Global and Medical/Sensory Concerns by Children's Ages



There were no significant differences among age groups in the frequency of global or other (medical/sensory) concerns [F(6,764) = .83 and .63].

Figure 2-5. Receptive and Expressive Language Concerns by Children's Ages

Expressive language concerns for the 2–4-year-old groups differ significantly from the 0–1-year-old group and receptive language concerns for the 6-year-old group differ significantly from the 1 and 4-year-old groups [F(6,764) = 4.31, p < .0003 and 3.06, p < .0006].

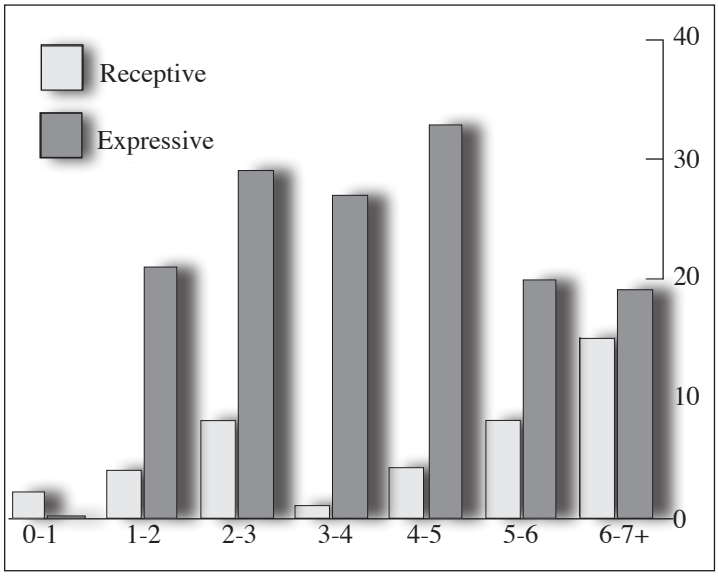
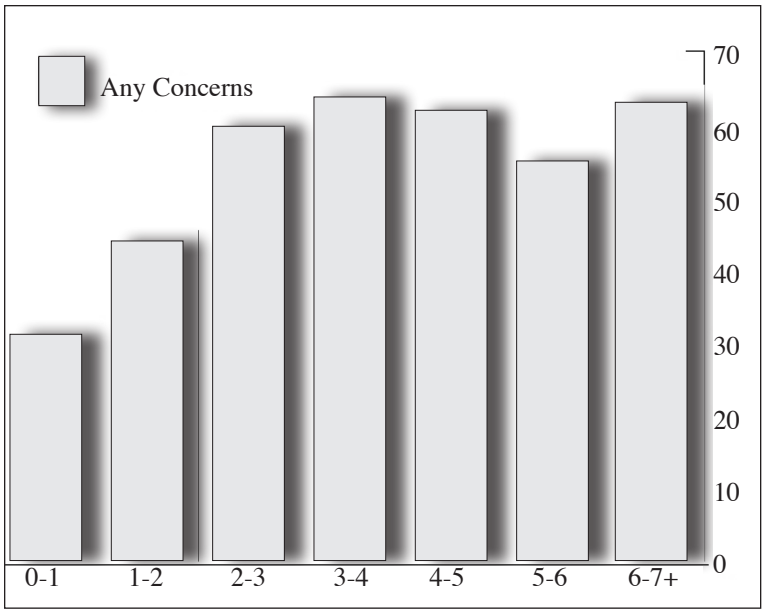


Figure 2-6. Concerns by Children's Ages



There were significant differences in the frequency of concerns for the 3,4, and 6-year-old groups versus the 0–1-year-old group [F(6,764) = 3.77, p < .001].

DO CONCERNS DIFFER ACCORDING TO FAMILY INCOME? There were significant differences in the overall frequency of parents' concerns on the basis of parents' income even after controlling for differences in children's ages. Low-income parents had an average of 1.5 concerns while higher income parents had an average of 1.2 concerns [$F(2,768) = 8.29$, $p < .001$]. Further, low-income parents had significantly more concerns about several specific areas of children's development all of which were significant even after controlling for differences in children's ages (as shown in Table 2-15).

Table 2-15. Significant Concerns in Low-income versus Non-low-income Families

Concern	Frequency in Low-Income Parents		Frequency in Non-Low-Income Parents		Odds Ratio and 95% Confidence Intervals
Fine motor	17/196	9%	25/575	4%	OR=2.1 CI=1.1–4.0
Self-help	27/196	14%	44/575	8%	OR=1.9 CI=1.2–3.2
School	35/196	18%	57/575	10%	OR=2.0 CI=1.2–3.1

DO CONCERNS VARY ACCORDING TO PARENT'S GENDER? There were no differences in the frequency or type of concerns raised according to whether mothers, fathers or other primary caretaker (usually grandparents or foster parents) responded.

DO CONCERNS DIFFER ON THE BASIS OF CHILDREN'S GENDER? Whether the child in question was a boy versus a girl, rendered no significant differences in the frequency of parents' concerns even after controlling for children's ages. When viewing each type of concern, parents were marginally more likely to raise concerns about behavior in their sons (35%) versus daughters (29%) although this was not statistically significant after controlling for children's ages.

DO CONCERNS DIFFER ACCORDING TO CHILDREN'S BIRTH ORDER? There were no differences in the overall frequency of parents' concerns on the basis of children's birth order. However, parents who discussed first born children were somewhat more likely to report concerns about their behavior (35%) than parents who discussed later born children (28%). These differences were statistically significant even after controlling for differences in children's ages and parents' income [$F(2,768) = 4.01$, $p < .05$].

DO CONCERNS DIFFER ACCORDING TO THE NUMBER OF CHILDREN IN THE HOME? There were no differences, after controlling for age and income in the overall frequency of parents' concerns on the basis of whether parents had one versus two or more children. Further, the numbers of children in the home did not lead to significant differences in the types of concerns parents raised after controlling for differences in age and income.

DO CONCERNS DIFFER ACCORDING TO PARENTS' MARITAL STATUS? There were no significant differences in the overall frequency or types of concerns parents raised on the basis of marital status after controlling for differences in income and children's ages.

DO CONCERNS DIFFER ACCORDING TO PARENTS' EMPLOYMENT STATUS? There were no differences in the overall frequency of parents' concerns on the basis of parents' employment status. However, parents who worked full-time were more likely to have concerns about children's behavior (36%) than were unemployed parents (25%). These differences continued to be significant after controlling for differences in parents' income and children's ages [$F(2,767) = 3.80$, $p < .02$].

DO CONCERNS DIFFER ACCORDING TO PARENTS' AGES? There were significant differences in the frequency and types of parental concerns on the basis of parents' ages even after controlling for differences in children's ages and parents' income [$F(2,766) = 5.36$, $p < .005$]. Younger parents had an average of one concern, while older parents had an average of

1.5 concerns. When viewing each type of concern, older parents were more likely to be concerned about children's self-help skills (11%) as compared to younger parents (2%).

DO CONCERNS DIFFER ACCORDING TO ETHNICITY? There were no significant differences in the frequency of concerns by ethnic groups [F(6,764) = 1.07] after controlling for differences in parents' income and children's ages. However, parents of Hispanic/Asian or Other backgrounds (e.g., Pacific Islander, American Indian) were less likely to have concerns about receptive language (4%) than were African American and White parents (10%). Parents of Hispanic/Asian or Other backgrounds were less likely to be concerned about their children's social development (13%) and self-help skills (4%) than were African American and White parents (20%) and (12%). Hispanic/Asian/Other parents tended to be somewhat more concerned about their children's medical and sensory status (6%) than other parents (4%).

DO PARENTS WITH DIFFERING EDUCATIONAL LEVELS HAVE DIFFERENT CONCERNS? There were no differences in the frequency of parents' concerns on the basis of parents' levels of education [F(3,765) = 1.51) after controlling for differences in children's ages and parents' income. However, parents with four or more years of college were more likely to have concerns about children's behavior (38%) than parents without high school diplomas (21%).

DO CONCERNS DIFFER ACCORDING TO PARENT'S PERCEPTIONS OF CHILDREN'S HEALTH STATUS? Parents were asked whether they considered their children's health problems to be very serious, somewhat serious, or not very serious. When parents viewed their children's health problems as somewhat or very serious, there were significant differences in frequency and types of concerns raised. These parents were more likely to have concerns about medical and sensory problems (11%) than were other parents (3%) and they raised more concerns (an average of 1.9) than did parents who felt their children's health problems were not serious (1.1). These differences were significant even after controlling for differences in children's ages and income [F(3,767) = 5.54, p < .0001].

Interestingly, parents who viewed their children's health problems as somewhat serious had more concerns (an average of 2.1) than did parents who viewed their children's health problems as very serious (an average of 1.7 concerns) or not very serious (an average of 1.1). There were also significant differences in the types of concerns raised by parents who felt their child's health problems were somewhat serious. One hypothesis is that "somewhat serious medical problems" are ambiguous, not well understood, less than fully diagnosed, or sufficiently treated—leading, in turn, to elevated levels of concerns in parents. Table 2-16 shows the likelihood with which parents raised concerns based on their health perceptions, expressed as odds ratios.

Table 2-16. Frequency of Concerns According to Parents' Perceptions of Children's Health Problems

Concern	Somewhat Serious		Not Serious or Very Serious		Odds Ratio and 95% Confidence Intervals
Fine motor	11/78	14%	31/693	4%	OR=3.5 CI=1.6–7.3
Other/Health	9/78	11%	27/693	4%	OR=3.2 CI=1.4–7.1
Receptive Language	12/78	15%	53/693	8%	OR=2.2 CI=1.1–4.3
School	17/78	22%	75/693	11%	OR=2.3 CI=1.3–4.1
Behavior	35/78	45%	210/693	30%	OR=1.9 CI = 1.2–3.0
Social	27/78	35%	121/693	17%	OR=2.5 CI = 1.5–4.2

Do concerns vary by Administration method? In three sites, parents were interviewed about their concerns and in two sites, parents were sent home questionnaires to complete independently. There were no significant differences in the frequency or types of concerns raised with either approach, after controlling for differences between groups in level of education, income, parents' ages, etc.

Do concerns vary by participation in educational programs? After controlling for variables previously associated with significant differences in parents' concerns, i.e., children's ages, parents' ages, parents' levels of education, income, employment and birth order, there were no differences in either the frequency or types of concerns according to whether or not children participated in day care, preschool or school programs.

Do concerns vary by geographic location? There were no significant differences in the frequency of concerns on the basis where families resided. Families in the Western US were more likely to have concerns about receptive language and self-help skills. However, these concerns were not significant after controlling for geographic differences in ethnicity, language spoken in the home, income, levels of education, etc.

Do concerns vary by medical versus nonmedical settings? The characteristics of families participating in the *PEDS* standardization studies varied substantially by setting for all variables except parents' marital status and children's gender. Accordingly, sociodemographic characteristics (including children's ages, developmental status, parents' levels of education and ages, income, employment, interview method, and parents' perceptions of children's health status) were controlled via analyses of covariance in order to view whether site/setting differences affected parents' concerns. Even so, there continued to be some differences in the types parents' raised in medical versus nonmedical settings. Parents in medical settings were more likely to have medical/sensory concerns [(8%) and less likely to have concerns about behavior (28%) or self-help skills (2%) as compared with parents in nonmedical settings (3%, 37%, and 13%).

Re-Standardization Studies: 2013

Tests need to be restandardized and validated every 10 years, per recommendations of the American Educational Research Association and the American Psychological Association.[1] The rationale is that population demographics change with time as do curricular demands, and children's skills. For example, authors/publishers of tools measuring children's expressive or receptive vocabulary, had to update test stimuli and then restandardize when a picture of a rotary dial telephone became so unfamiliar that it failed to elicit the target response, "telephone" (rendering instead answers like "toy" or "computer")! Even though *PEDS* lacks visual stimuli, our changing populations (e.g., ethnicities, socioeconomic factors, languages spoken at home) and new applications of tools (increasingly online versus paper-pencil) demand an update of *PEDS* Paths' frequencies, types of concerns parents raise, and how these vary by settings and administration methods. Below are descriptions and data from the 2013 standardization study.

Methods: USA 2013 Standardization

PEDS was administered at consecutive well-child visits or via public school pre-kindergarten intake, i.e., all children eligible for kindergarten in the following school year. *PEDS* was administered in writing or by interview and all responses were entered and scored via *PEDS Online*. This data collection method was used because *PEDS Online* eliminates administration and scoring errors [e.g., failure to ensure that families have commented, incorrect categorization of parents' concerns (parents don't always answer the questions asked and so often comment about a different domain than the one probed), incorrect assignment of *PEDS* Paths, inaccurate computation of a child's age]. And, as shown in Chapter 3, inter-rater reliability of *PEDS Online's* assignment of *PEDS* Paths is superior to reliability in print (also described in Chapter 3) with *PEDS Online* enjoying 98% agreement with an expert on *PEDS* regarding Path assignments with *PEDS Online*.

Sites/Settings/Samplings

Settings included general pediatric, family practice, and public health clinics and public schools. Subspecialty pediatric clinics (e.g., developmental-behavioral pediatric clinics, crisis call centers) were excluded from the standardization sample but are discussed separately later in this chapter. International samples (e.g., Israel, Australia, and elsewere) were excluded from the US norming study but are described in this chapter's section on International Studies.

There were 61,952 parent-child dyads who completed *PEDS Online*. To ensure that proportions of ethnicities were representative of the US population, one site in which ethnicity was predominately white, was eliminated. This reduced the sample size to 47,531 families. Of these families, 91% participated from health care settings and 9% participated from educational settings.

Test Dates for Study Participation

Families were administered *PEDS* between 2007 and 2011. Frequencies of participation by year are shown in Table 2-17. This information is presented because the study sample is compared in subsequent analyses to data from the 2010 US Census (wherever available).

Table 2-17. Frequency of Participation by Year

Year	Number	Percent
2007	1047	2.2
2008	3422	7.2
2009	8365	17.6
2010	23955	50.4
2011 (January through July)	10742	22.6
TOTAL	**47531**	**100**

Geographic Locations

Fifty-three (53) sites participated across 16 different US States as shown in Table 2-18. Sites reflected the four main regions of the US as designated by the US Census Bureau: West (13.2%, i.e., Arizona, California, Utah, Hawaii), MidWest (9.45%, i.e., Ohio, Minnesota), South (67.1% i.e., Florida, Georgia, Maryland, Virginia, South Carolina, Texas) and Northeast (10.3%, i.e., Pennsylvania, New York, Massachusetts).[2] Although the South is over-sampled, it is the fastest growing region within the US.

The sites included both rural and urban/suburban families. Community population size across the 53 sites ranged from 4,680 to 2,813,833 with a median of 31,947 and a mean of 198,229.

Table 2-18. Participation by State

State	Frequency	Percent
Arizona	1774	3.7
California	3469	7.3
Florida	8786	18.5
Georgia	459	1.0
Hawaii	1006	2.1
Massachusetts	3133	6.6
Maryland	2619	5.5
Minnesota	829	1.7
New York	203	.4
Ohio	3652	7.7
Pennsylvania	1549	3.3
South Carolina	419	.9
Tennessee	10503	22.1
Texas	8719	18.3
Utah	58	.1
Virginia	353	.7
TOTAL	**47531**	**100.0**

Demographics

In order to ensure that *PEDS Online* is swiftly applicable for busy providers, they are not required to enter ethnicity of child or family, parents' level of education, or poverty data. Therefore, US Census Bureau demographics for each community were used to compute most population parameters for families served by each provider. The wisdom of this approach is that communities are just that—communities—where people work and live together and expose each other to similar ways of thinking. Many communities had predominate characteristics (e.g., were almost uniformly white, African American, Hispanic, American Indian, poor, highly educated, etc.) thus enabling distinct comparisons among groups.

Ethnicity

Table 2 - 19 compares the ethnicity of the study sample to the US Census, using 2010 Census data and ethnicity projections for 2020 and beyond.[2] Whites are somewhat undersampled as compared to the 2010 Census but their proportions reflect Census projections for years slightly prior to 2020. The numbers of Hispanics are proportionate to the 2010 Census but undersampled compared to the 2020 projections. Nevertheless, 94% of those categorized as having "two or more races" were Latino (as compared with 97% in the 2010 Census). American Indians were oversampled but otherwise, the study sample is comparable to US population parameters.

Table 2-19. Ethnicity

Demographics	Study Sample N	%	Census 2010** %	Census Projections 2020
Ethnicities				
White, not Hispanic	29136	61.3%	63.7%	60%
Black/African American	5704	12%	12.6%	12%
American Indian/Alaskan Native	1426	3%	0.9%	1%
Asian	1996	4.2%	4.8%	6%
Native Hawaiian or Other Pacific Islander	143	0.3%	0.2%	0.3%
Hispanic/Latino	7605	16%	16.3%	19%
Two or more races (includes combinations of the above)	1521	3.2%	2.9%	2%
TOTAL	**47531**	**100%**		

*The Census Bureau uses "Hispanic or Latino" and "Black or African American" interchangeably
**Census Bureau percentages are > 100% due to the overlap of ethnicities.

Level of Education

Table 2-20 shows the level of parents' education in the standardization study as compared to Census Bureau figures for adults aged 18 – 39.[3] The study sample's percentages were comparable to Census Bureau data on levels of education.

Table 2-20. Level of Education

Parents' Education			
Level of Education	**Study Sample N**	**%**	**Census 2010**
< High School	7605	16%	15%
High School	39926	84%	85%
Bachelors Degree or more (reflects the percentage of those with a HS diploma who completed college including those who completed graduate school)	11179	28%	30%
TOTAL	**47531**	**100%**	

Languages Used

According to Census Bureau data,[4] 79% of families speak English at home. Of the 21% who speak other languages at home, more than half reported they speak English well. Of the 6% who do not speak English at all, 83% speak Spanish and the remainder speak a range of other languages. Table 2-21 compares Census Bureau figures from 2007 (which is the most recent available data) to the numbers of families administered *PEDS* in English, Spanish, or other languages. Providers using *PEDS Online* are supplied printable files of *PEDS* in the 25 available translations, in case these are needed for paper-pencil administration (e.g., in waiting or exam rooms, mail-out, etc.). Overall, sites administered *PEDS* in languages other than English at a slightly higher rate than Census Bureau figures predict, but the study sample is more recent (most children were assessed in 2010 or 2011). So, there's a high chance that the study sample reflects current language use (and population trends).

Table 2-21. Languages in which *PEDS* was administered

	N in study	Percent in Study	Census 2007
English	43728	92%	94%
Spanish	2852	6%	5%
Other languages*	952	2%	1%
TOTAL	**47531**	**100%**	

*Other Languages includes Somali, Tagalog, Portuguese, Chinese, Vietnamese, Cape Verdean (Brazilian Portuguese), Arabic, Hebrew, Haitian-Creole, Russian, Swahili, Galician, etc.

Children's Gender

Gender distributions in the study sample were compared to Census Bureau figures for 2011. The 0 -5 year versus 0 – 9 year age range rendered virtually identical results and so 0 – 9 Census Bureau figures are reported in Table 2-22.[2]

Table 2-22. Children's Gender

Gender	Study N	Study %	US Census 2011 (0 - 9) age range) %
Female	23480	49.4%	49%
Male	24051	50.6%	51%
TOTAL	**47531**	**100%**	

Poverty

Poverty data for the standardization sample is shown in Table 2-23, along side Census Bureau figures. The sample shows children in the study (all of whom were between 0 and 8 years of age) who received Medicaid and/or free/reduced school lunch (or whose siblings did) as compared to those who did not receive such services. The Census Bureau does not offer poverty data specific to the 0 – 8 age range but has data on poverty in children 0 – 5 years of age.[5] Census Bureau poverty data for 0 – 5-year-olds was used as a comparison because the current standardization study includes a preponderance of children under age 5.

Table 2-23. Poverty

Poverty Level	Study		Census 2011
	N	%	%
Below federal poverty level	11407	24%	22%
Above federal poverty level	36124	76%	78%
TOTAL	**47531**	**100%**	

Children's Ages

Eliminated from the following analysis were 298 cases (0.6% of the total sample of 47531) due to incomplete screens (N = 77) or a [swiftly corrected programming error in which users were not prompted to adjust mistakes when entering testdates, testdates were entered as earlier than birthdates thus rendering ages in negative numbers (N = 221)]. Because errors were well distributed across sites (48 out of 53), eliminating the 298 cases did not effect percentages of demographic information shown in the above tables. This adjustment left 47,233 cases for the following analysis.

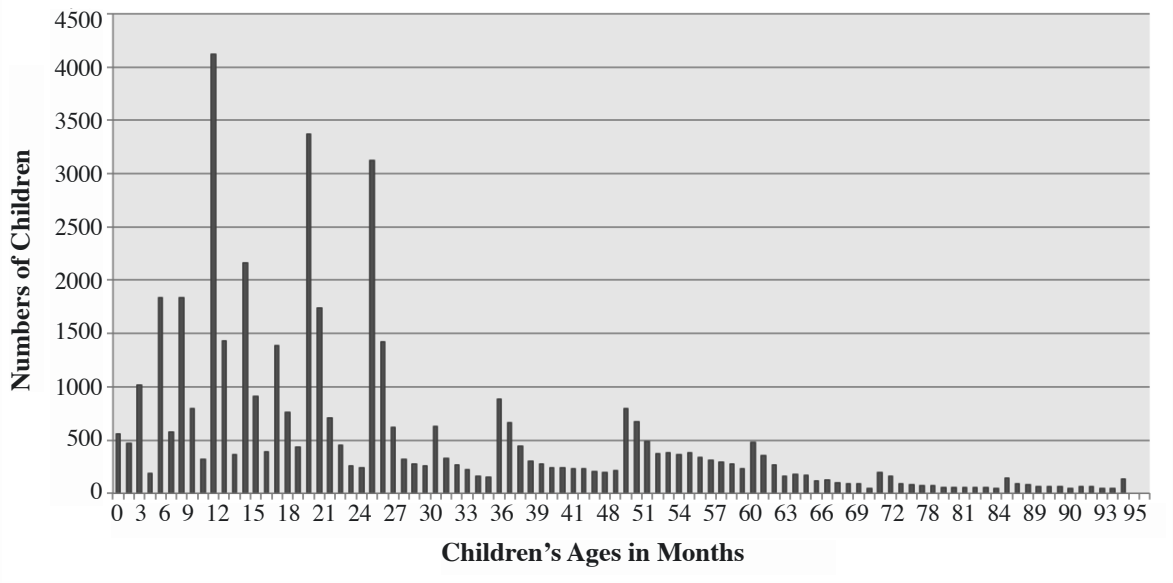
Children ranged in age from 0 months, 10 days through 95 months with a mean of 26 months and a median of 18 months (sd = 20.6 months). Table 2-24 shows the frequencies of ages in years. Figure 2-7 provides a graphic representation.

The graph shown below provides a visual representation of frequency of children's ages in the study sample.

Table 2-24. Children's Ages in Years

Age in Years	Frequency	Percent
0 (0 – 11 months)	13523	28.6
1 (12 – 23 months)	12829	27.2
2 (24 – 35 months)	7769	16.4
3 (36 – 47 months)	4125	8.7
4 (48 – 59 months)	4902	10.4
5 (60 – 71 months)	2178	4.6
6 (72 – 83 months)	994	2.1
7 (84 – 95 months)	913	1.9
Total	**47233**	**100.0**

Figure 2-7. Children's Ages in Months



Frequency of Parents' Concerns

Background

PEDS elicits parents' concerns which are then categorized into the various domains of development as shown in the examples below (in English and Spanish).

TYPICAL RESPONSES (English)	TYPE OF CONCERN If present, mark the box in the age-appropriate column on the PEDS Score Form for:
Not talking like he should; uses short sentences; can't always say what she means; doesn't always make sense; can't talk plain. Nobody understands what he is saying but me	Expressive Language and Articulation
Doesn't understand what you say; doesn't listen well	Receptive Language
Wants to be left alone; mood swings, clingy; whiny; bothered by changes; angry, disinterested in usual things; easily led; acts mean; easily frustrated; bossy; shy; class clown; is angry; mean; hates me	Social-emotional
Stubborn; over-active; short attention span; spoiled; aggravating; throws fits; only does what she wants	Behavior
Can't stay in the lines when colors; can't write name; can't draw shapes, can't hold a pencil right; can't get food to mouth with a spoon yet and so is a messy eater	Fine-Motor
Clumsy; walks funny; can't ride a bike yet; falls a lot; limps, poor balance; hates soccer	Gross Motor
Won't do things for herself; won't tell me when he's wet; not toilet trained yet; still wants a bottle; can't get dressed by herself	Self-help
Can't write his name [scored also with fine motor]; doesn't know colors or numbers; just not learning to read; can't remember letter sounds; knows spelling words one day but not the next	School
Seems behind; can't do what other kids can; slow and behind other kids; immature; learns slowly; late to learn to do things; learns but takes a long time; problems with learning everything	Global/Cognitive*
Ear infections; asthma; small for age; sick a lot; I don't think he hears well; She gets up too close to the TV and I worry about her sight	Other/Health
Typical child; development is normal; he's coming along just fine; she's advanced	No concerns If no concerns are raised, leave boxes empty and proceed to step 4

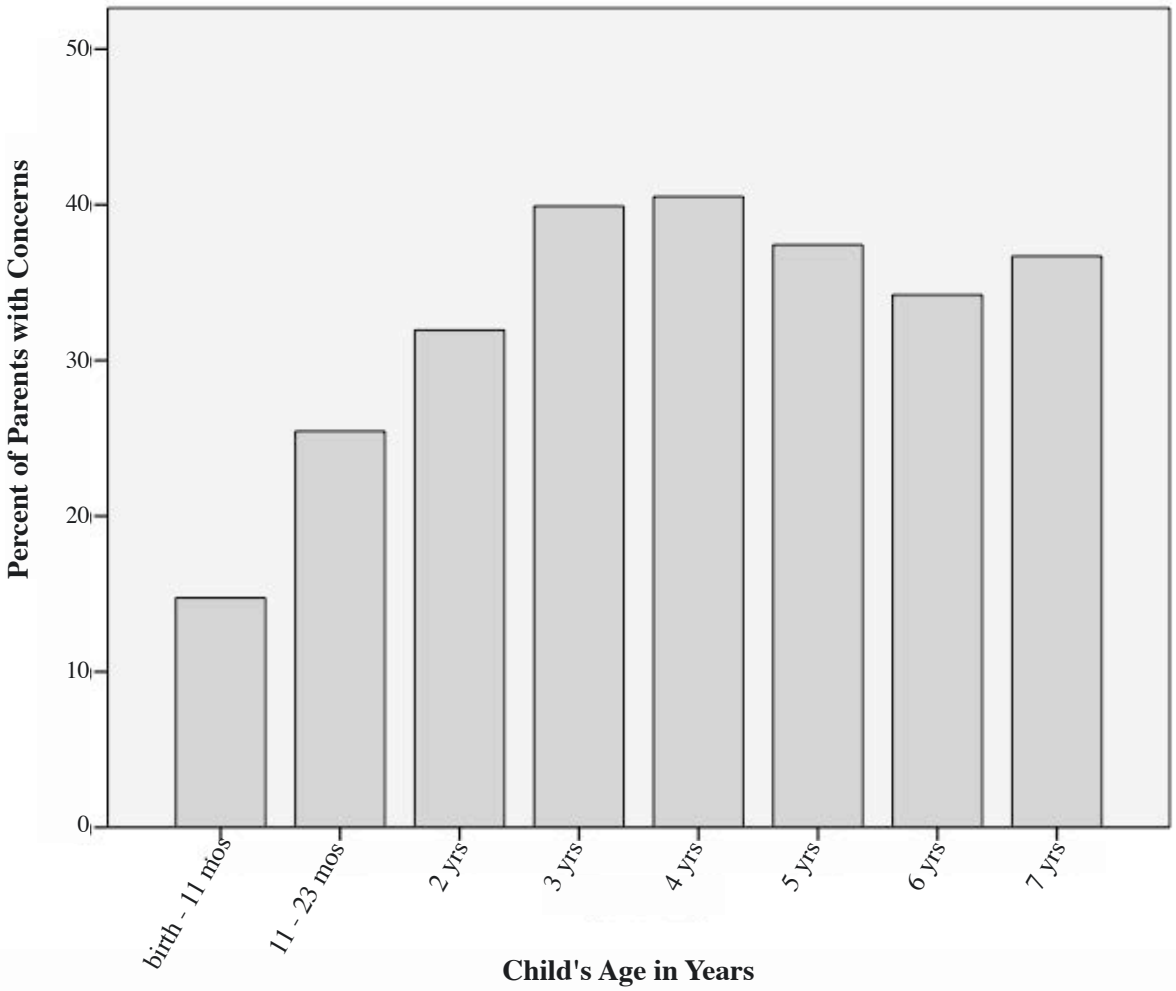
TYPICAL RESPONSES (Spanish)	TYPE OF CONCERN If present, mark the box in the age-appropriate column on the PEDS Score Form for:
No habla como debería, usa oraciones cortas, no siempre puede decir lo que quiere, no siempre tiene sentido, no puede hablar sencillo. Nadie entiende lo que está diciendo, excepto yo	Expressive Language and Articulation
No entiende lo que usted dice, no escucha bien	Receptive Language
Le gusta estar a solas, humor variable, apegado, quejumbroso, le molestan los cambios, enojado, desinteresado en cosas comunes, influenciable, actúa con mala intención, se frustra fácilmente, mandón, tímido, es el gracioso de la clase, está enojado, malintencionado, me odia	Social-emotional
Terco, muy activo, lapsos cortos de atención, malcriado, desesperante, impulsivo, solamente hace lo que él/ella quiere	Behavior
No se mantiene dentro de la línea al colorear, no puede escribir su nombre, no puede dibujar figuras, no puede sostener bien el lápiz, todavía no puede llevarse la comida a la boca con una cuchara y por lo tanto se ensucia mucho al comer	Fine-Motor
Torpe, camina extraño, todavía no puede montar bicicleta, se cae mucho, cojea, balance deficiente, no le gusta el football	Gross Motor
No hace las cosas por sí mismo, no me dice cuándo está mojado, todavía no va al baño, todavía quiere biberón, no se puede vestir solo	Self-help
No puede escribir su nombre [scored also with fine motor]; no sabe los colores o lo números, simplemente no aprende a leer, no puede recordar los sonidos de las letras, sabe las palabras del vocabulario un día y se le olvidan al siguiente	School
Parece estar atrasado, no puede hacer lo que hacen otros niños, es lento y está atrasado con respecto a otros niños, es inmaduro, aprende despacio, aprende tarde a hacer las cosas, aprende pero le toma mucho tiempo, problemas aprendiendo todo	Global/Cognitive*
Infecciones de oído, asma, pequeño para su edad, se enferma mucho, creo que no escucha bien, se pone muy cerca de la televisión y me preocupa su vista	Other
Niño típico, desarrollo normal, está creciendo bien, está avanzado	No concerns If no concerns are raised, leave boxes empty and proceed to step 4

**The Global/Cognitive category requires additional explanation because it can be challenging to categorize: Global/Cognitive is scored when parents make broad statements about overall delays without mention of specific areas of deficit. Comments usually include adverse comparisons to other children or describe delays in all areas of skill acquisition and deficiencies in rate of learning. Global/Cognitive is not scored if such observations focus on a specific domain (e.g., speech-language).*

Frequency of Any Concern by Age of Child

Prior standardization studies (reported at the beginning of this chapter) suggests that the older the child, the more likely parents are to have concerns. Concerns seem to peak around age 4 and wane, but only slightly, for children older than 4 years. This trend is confirmed again with the current sample as shown in Figure 2-8 (below). Of the 47,233 families, 27% (N=12,862) had concerns. But, there were significant differences in the overall frequency of concerns across the 0 through 7 year age range [$F(7) = 317.532$, $p < .0001$]. Parents of younger children (birth to two years) raised fewer concerns than did those whose children were 2 and older. Parents of two-year-olds had fewer concerns than did parents of children 3 through 7 years.

Figure 2-8. Frequency of Any Concern by Age (in Years)



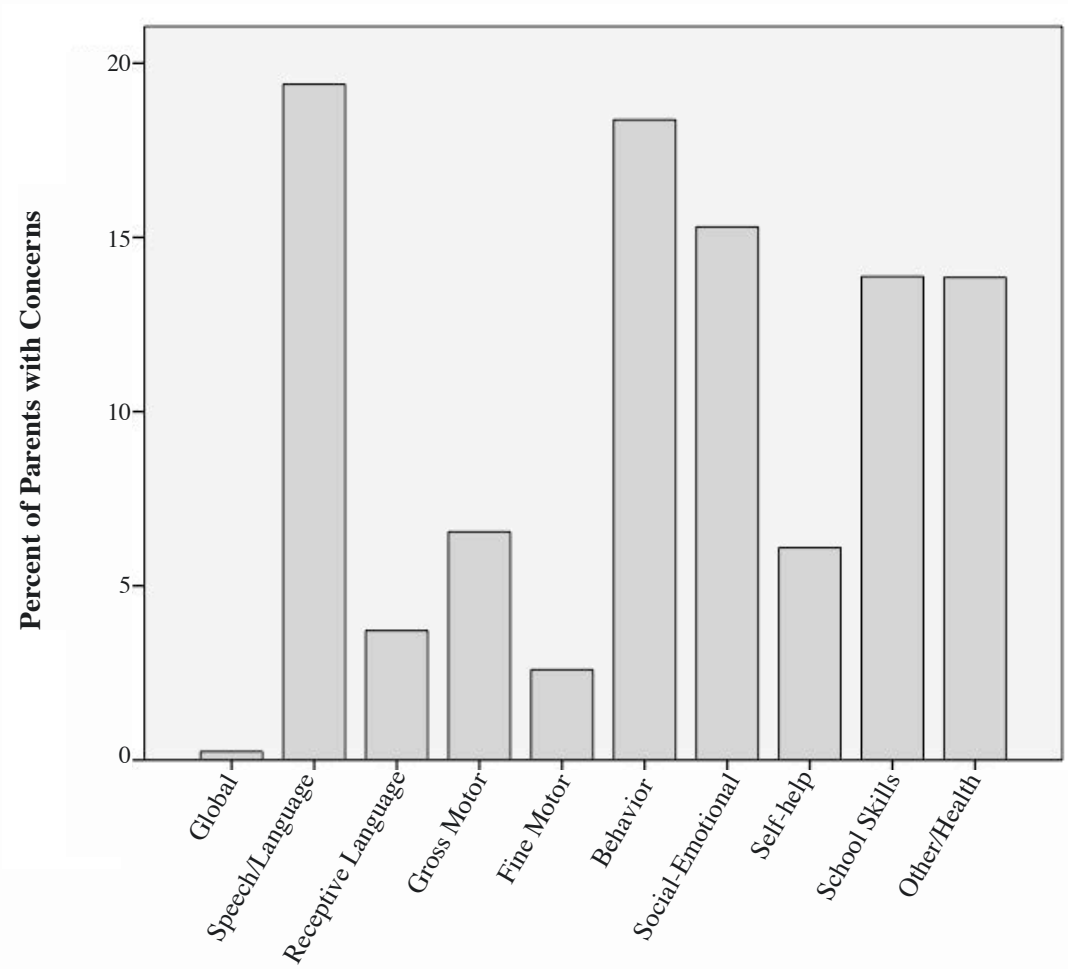
Frequency Across Concern Categories

In this section, information is presented about types of concerns raised focused on the 27% of children whose parents' raised concerns (N – 12,862). An overall summary is presented first followed by a comparison of concern categories broken out by children's ages (in years).

Overall Frequencies of Concern Categories

The types of concerns raised by the 27% percent of parents with any type of concern is shown in Figure 2-9. Expressive language concerns were common (19%) as were concerns about behavior (18%), social-emotional skills (15%), school skills (14%), other/health (14%), followed by gross motor (7%), self-help (6%), receptive language (4%), fine motor (3%), and global/cognitive (0.2%).

Figure 2-9. Categories and Frequencies of Concerns Raised across all Ages



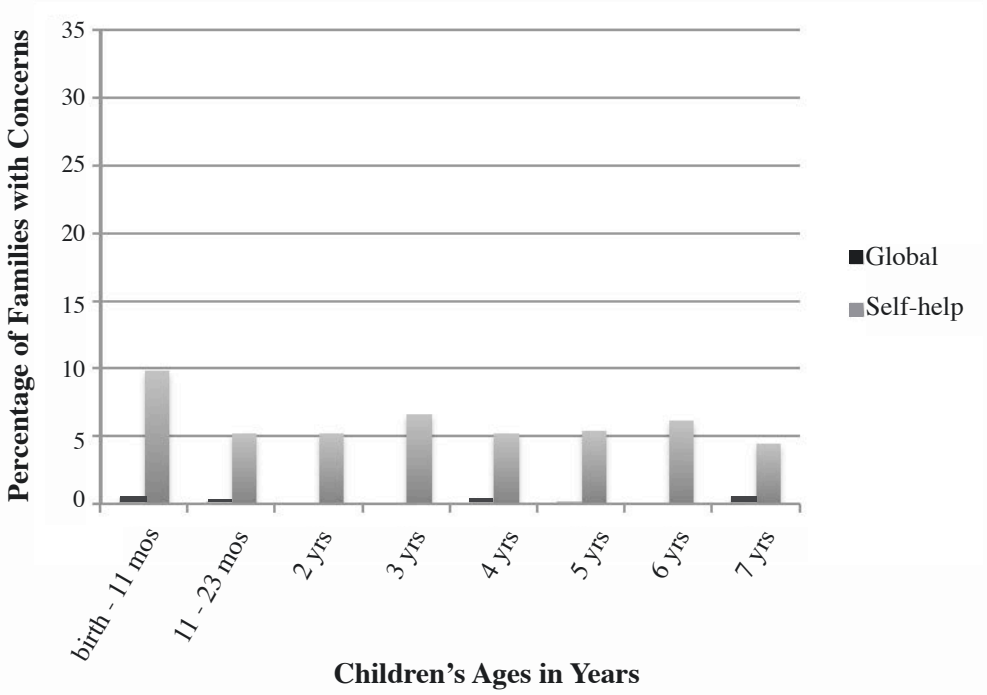
Frequencies of Categories of Concern by Age

Surely more valuable to providers than the overall summary above, is information on what types of concerns to expect according to the age of the child. The subsequent analyses compare types of concern by children's age (in years).

Global/Cognitive versus Self-help Concerns by Age

The following figure compares the frequency of Global/Cognitive and Self-help Concerns by age of child. Global/Cognitive concerns, which are overall adverse appraisals, were rare across all age ranges. Though infrequent, prior validation research shows these concerns to be a powerful predictor of undiagnosed developmental problems. Self-help concerns were more common than global/cognitive concerns, especially for children in their first year of life. Self-help concerns stabilized at somewhat lower levels in years 1 through 7. One study[6] of children measured at age 5 and again at age 7 alongside a diagnostic battery, showed that self-help concerns while not a predictor of current developmental problems, are a predictor of later problems (see Validation Chapter for additional discussion).

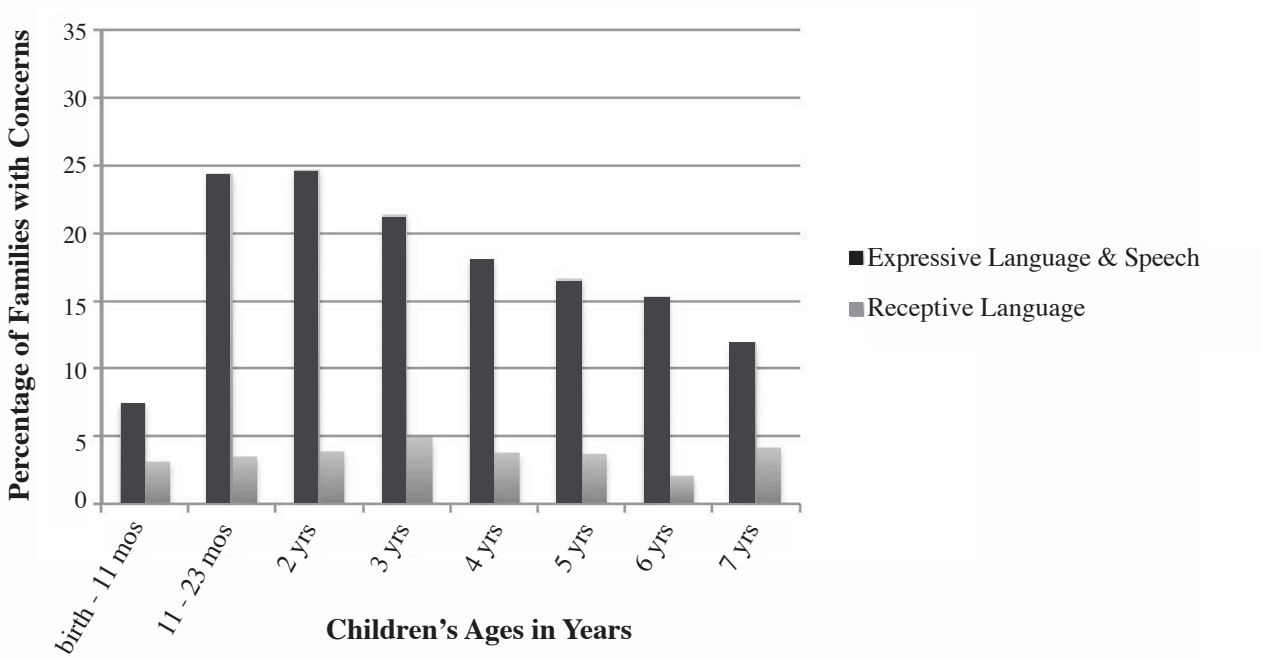
Figure 2-10. Frequencies of Global and Self-help Concerns by Age



Expressive Language versus Receptive Language concerns by Age

The figure below shows the frequency of parents' concerns about expressive language as compared to receptive language concerns. Expressive language concerns spiked between 12 and 23 months and remained high throughout the two year age range. Although waning at older ages, expressive language concerns remain one of the most common issues raised by parents and are a concern that is consistently associated with likely problems. Receptive language concerns, in contrast, were fairly consistent in frequency across age levels. They are predictive of likely problems starting at 18 months of age and throughout subsequent years.

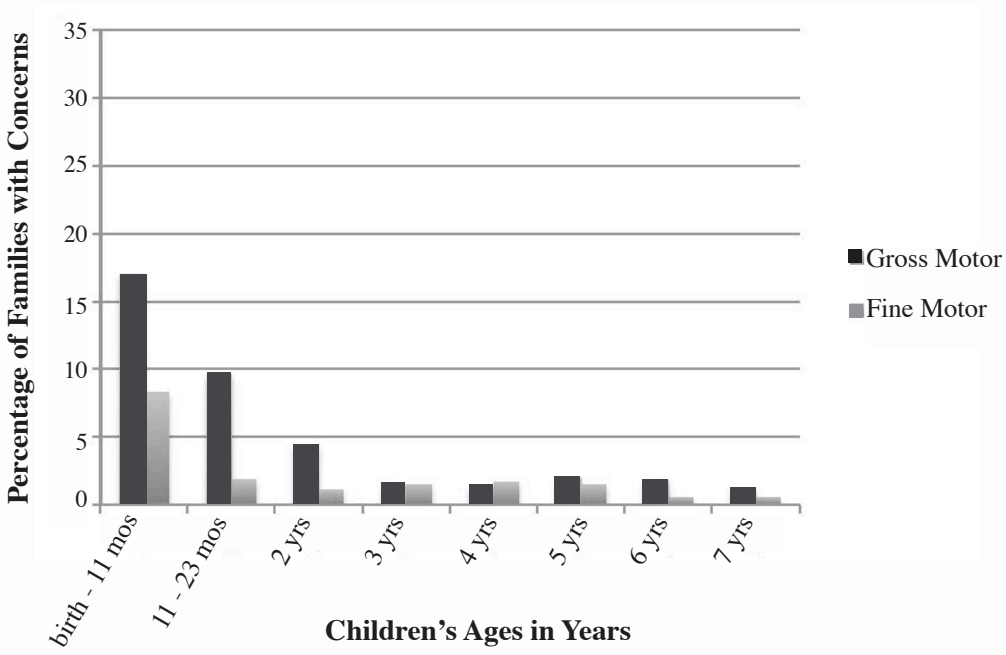
Figure 2-11. Frequency of Parents' Concerns about Expressive Language as Compared to Receptive Language Concerns by Age



Fine Motor versus Gross Motor Concerns by Age

Gross motor concens were most frequent in the 0 – 11 month age range and waned substantially during subsequent years. Fine motor concerns were most frequent in the first year of life but stabilized in frequency after age 1. Gross motor concerns are not predictive of problems until age 3 and beyond. Fine Motor concerns predict problems at age 4 ½ years and older.

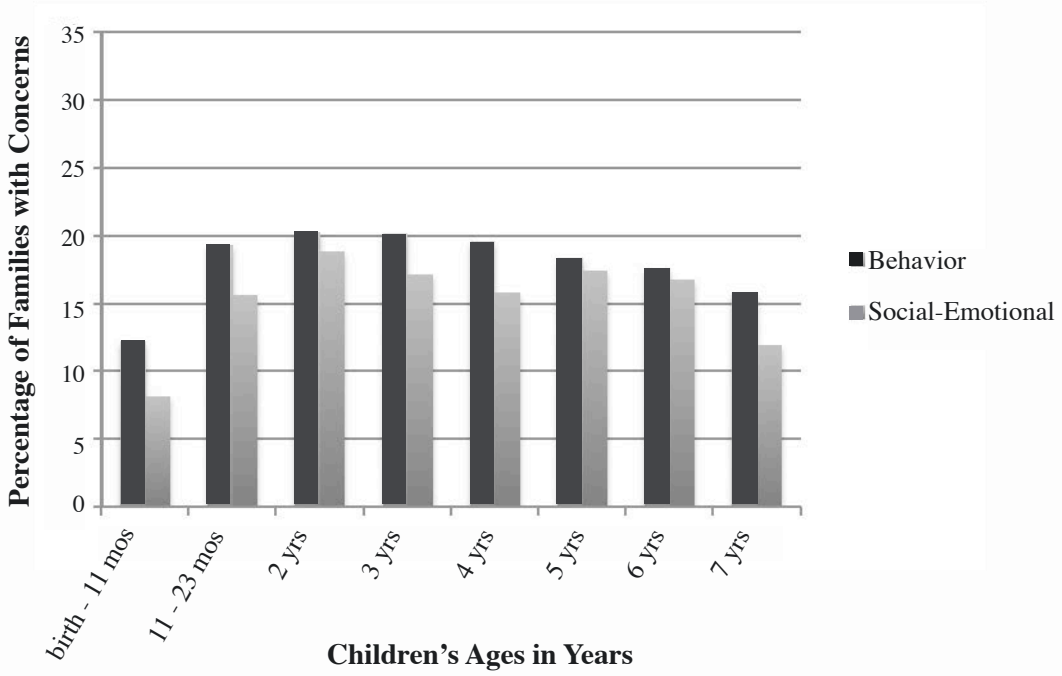
Figure 2-12. Fine Motor Versus Gross Motor Concerns by Age



Behavior versus Social-Emotional Concerns by Age

Parents' concerns about behavior were infrequent in the 0 – 11 month age range and increased substantially during the 12 – 23 month level. The frequency of behavior concerns remained high through 5 years of age and waned slightly in years 6 and 7. Behavior concerns do not predict developmental problems although they often accompany concerns that are predictive. Social emotional concerns were less common in the 0-11 month age range than at older ages. Such concerns are predictive of problems in the 0 – 17 month age range but not thereafter. With younger children, parents often comment on difficulties with relatedness and shared interests which may be symptomatic of speech-expressive language problems, intellectual delays or austism spectrum discorder. With older children, social-emotional concerns are more likely to focus on more typical temperament issues (e.g., "shy", "bossy"). Nevertheless, the persistence of behavior and social emotional concerns after age 4 ½ suggests the need for mental health evaluations.

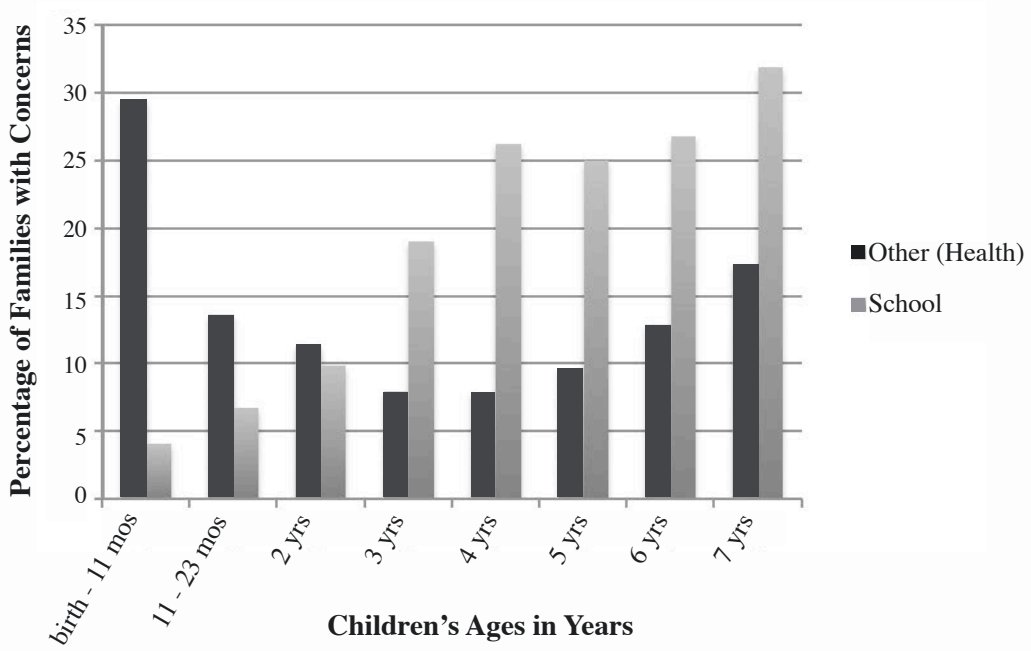
Figure 2-13. Behavior versus Social-Emotional Concerns by Age



School versus Other (Health) Concerns Age

Health concerns were common in the first year of life and waned substantially until age 6 where they began to increase. Health concerns are predictive of problems throughout the age range but generally suggest the need for intervention, health-related concerns (e.g., vision, hearing, diet, sleep habits, asthma). Nevertheless, chronic health problems have a known adverse impact on quality of life and school performance, and often co-occur with developmental concerns. School concerns were infrequent in the 0 – 11 month age range but increased consistently in subsequent years. Concerns about school skills in the youngest age groups often reflected challenges finding day care or expulsion from daycare, the latter almost always accompanied by behavior and social-emotional concerns. In subsequent years, the content of school-related concerns tended to focus on actual skill deficits. Concerns about school are predictive of problems in children 4 ½ years and older.

Figure 2-14. School versus Other (Health) Concerns



Year by Year: Frequency of Categories of Concerns

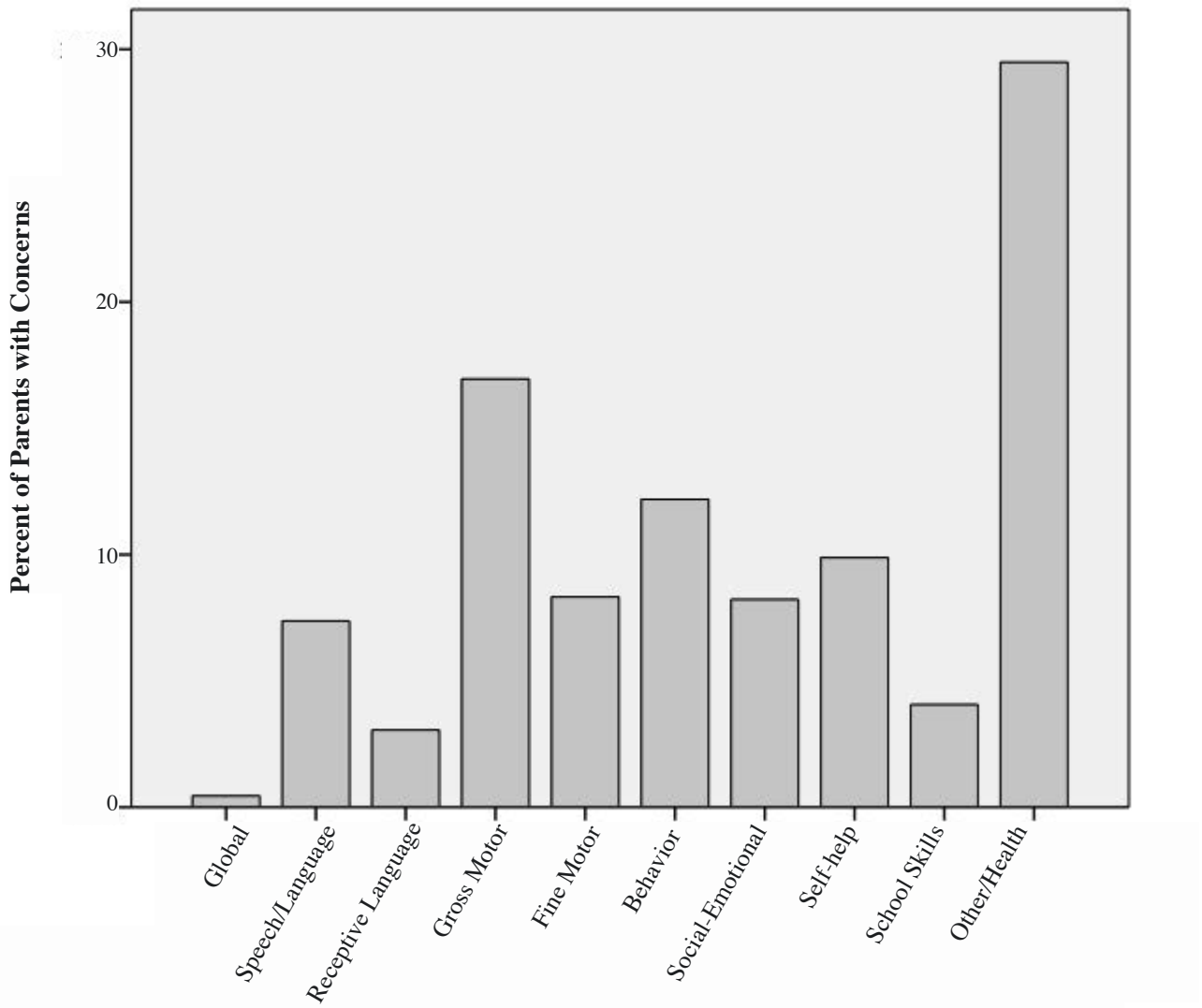
The subsequent discussion describes year by year performance in greater detail. Information on age-related trends in the type and frequency of parents' concerns should help clinicians best to prepare for the types of concerns they are likely to encounter at each well-visit (or other age-specific encounters).

Birth to 11 months

Of the 15,523 birth to eleven-month-old children, parents raised an average of 0.24 concerns (range 0 – 8). Most (85.3%, N= 11,529) did not have concerns. The remaining 14.7% (N = 1994) raised one or more concerns as shown in Figure 2-15 below.

Among parents who raised concerns, predominant were "other/health" concerns (usually health related issues focused on such topics as sleeping, eating, etc.) raised by 29.5%. Gross motor concerns were raised by 17% of parents with concerns, followed by behavior (12.2%), self-help (9.9%), fine motor (8.3%), social-emotional (8.2%), speech/expressive language (7.4%), school issues (4.1%), receptive language (3.1%) and global/cognitive (0.1%).

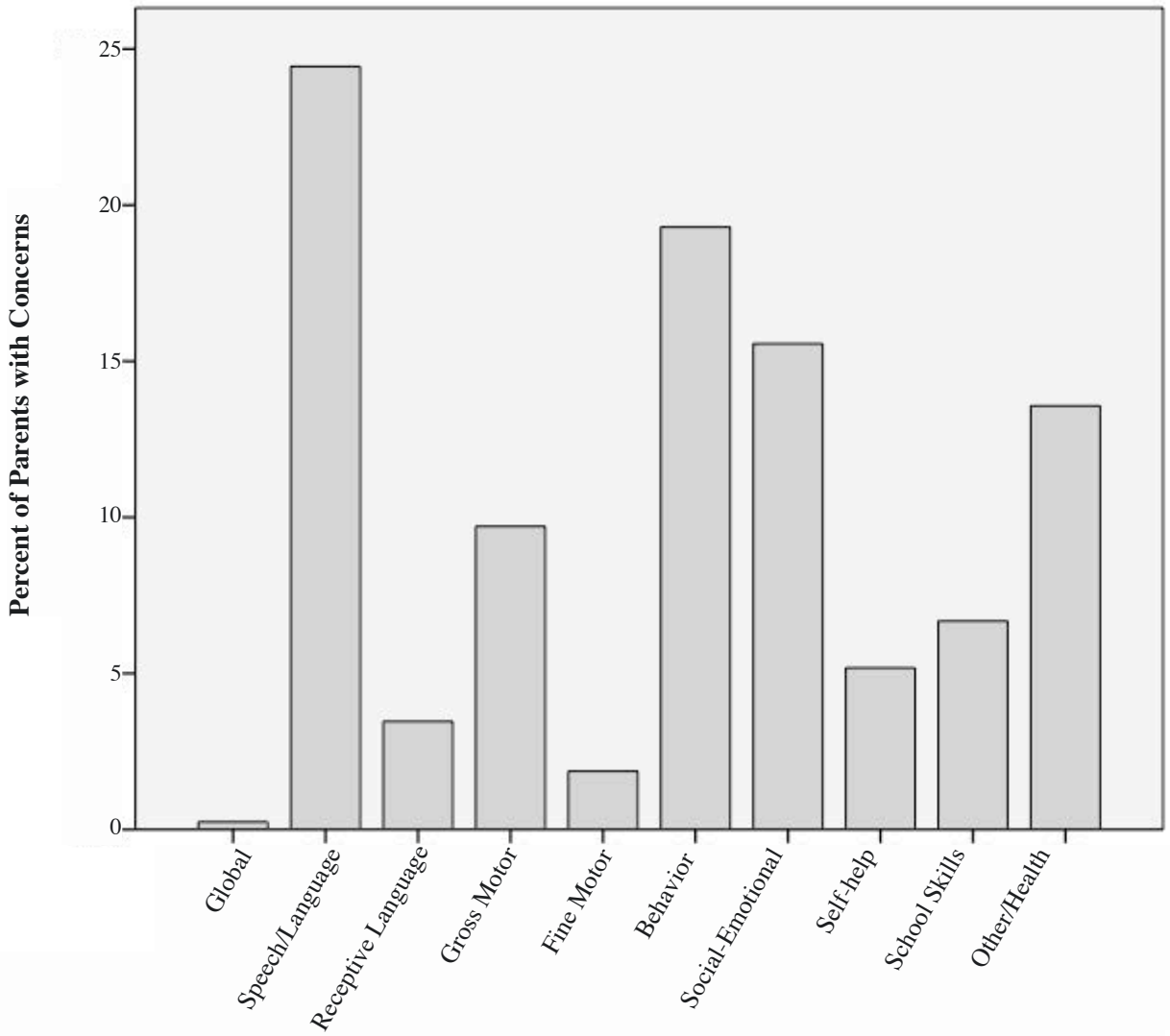
Figure 2-15. Frequency of Concern Categories Raised by Parents of 0-11-Month-Olds Among the 14.7% of Families with Concerns



One-year-olds (12 – 23 months)

Of the 12,829, one-year-old children whose parents were administered *PEDS* , the average number of concerns raised was 0.431 (range 0 – 9). Most (74.5% N= 9,564) did not have concerns. The remaining 25.5% (N = 3265) raised one or more concerns as shown in Figure 2-16 below. In contrast with younger children, speech-language concerns were predominant (24.4%) followed by concerns about behavior (19.3%), social emotional (15.3%), other/health (13.6%), gross motor (9.7%), school skills (6.7%), self-help (5.2%), receptive language (2.9%), fine motor (0.5%) and global (0.2%).

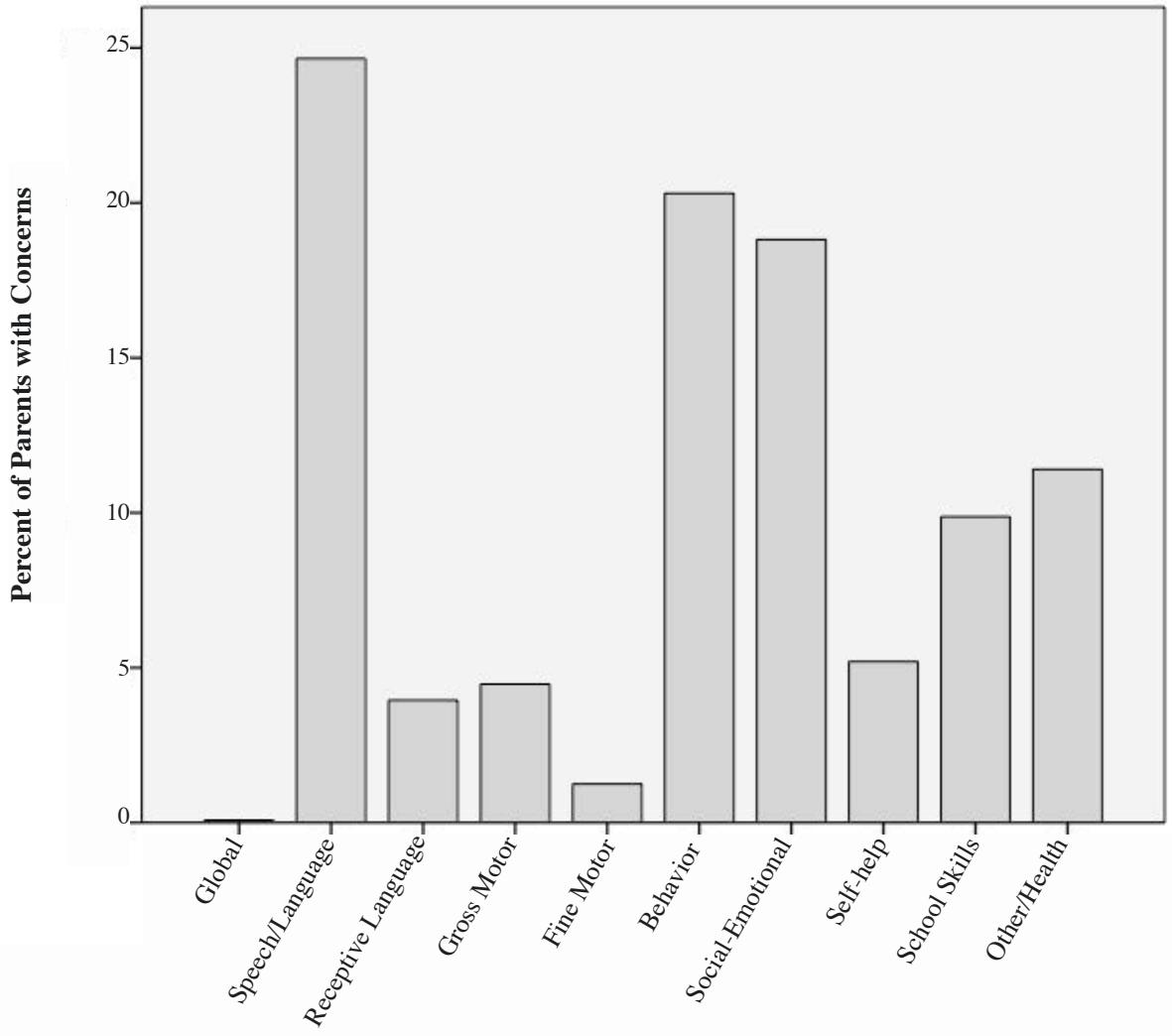
Figure 2-16. Frequency of Concern Categories Raised by Parents of One-Year-Olds Among the 25.5% with Concerns



Two-year-olds (24 – 35 months)

Of the 7,769 two-year-old children whose parents were administered *PEDS*, the average number of concerns raised was 0.61 (range 0 – 9). Most (68.1% N= 5,287) did not have concerns. The remaining 31.9% (N = 2,482) raised one or more concerns as shown in Figure 2-17 below. Speech-language concerns predominated (24.7%) followed by concerns about behavior (20.3%), social emotional (18.8%), other/health (11.4%), school skills (9.9), self-help (5.2%) gross motor (4.5%), receptive language (3.9%), fine motor (1.2%) and global (0.1%).

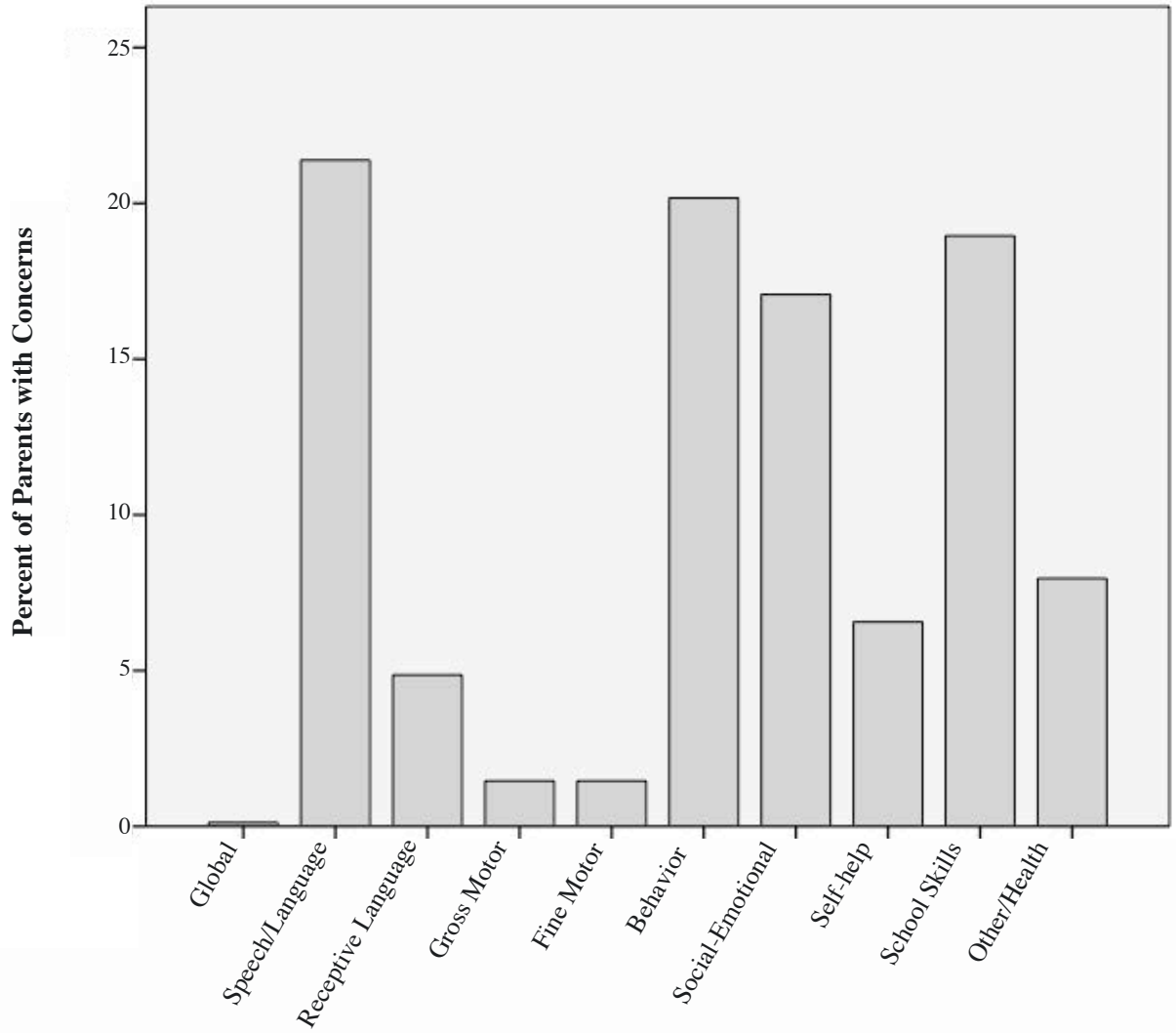
Figure 2-17. Frequency of Concern Categories Raised by Parents of 2-Year-Olds Among the 31.9% with Concerns



Three-year-olds (36 – 47 months)

Of the 4,125 three- year-olds whose parents were administered *PEDS*, the average number of concerns raised was 0.9 (range 0 – 9). More than half of parents (60.1% N= 2479) did not have concerns. The remaining 39.9% (N = 1646) raised one or more concerns as shown in Figure 2-18 below. Speech-language concerns were the most common (21.4%) followed closely by concerns about behavior (20.2%), social emotional (17.1%), and school skills (19%). Concerns about other/health were raised by 8%, self-help concerns by 6.6%, receptive language (4.9%), gross motor (1.5%), fine motor (1.5%) and global (0.1%).

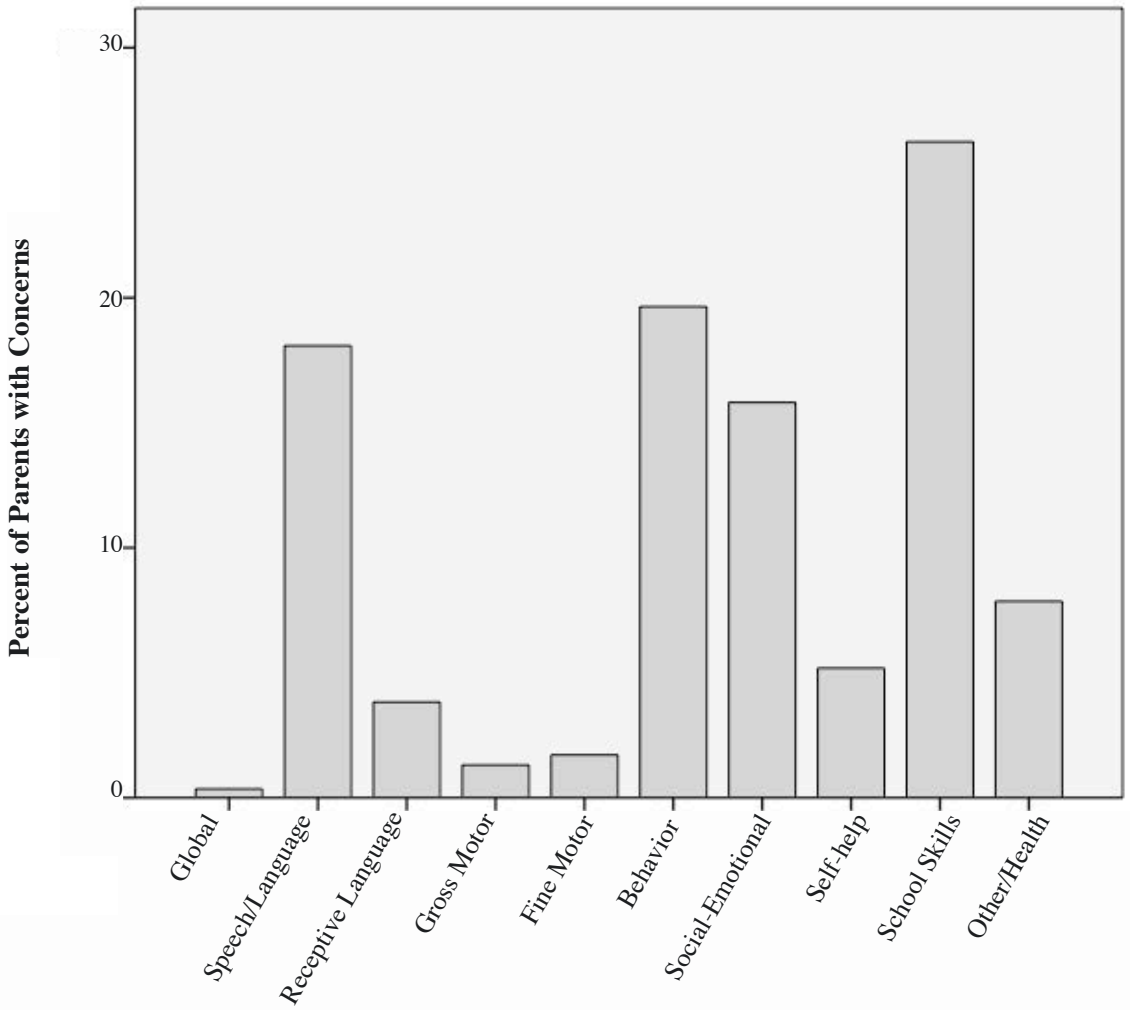
Figure 2-18. Frequency of Concern Categories Raised by Parents of 3-Year-Olds Among the 31.9% with Concerns



Four-Year-Olds (48 – 59 months)

Of the 4,092 four-year-olds whose parents were administered *PEDS*, the average number of concerns raised was 0.91 (range 0 – 9). More than half of parents (59.1%, N= 2196) did not have concerns. The remaining 40.9% (N = 1906) raised one or more concerns as shown in Figure 2-19 below. Concerns about school skills took precedence (26.2%) followed by concerns about behavior (19.6%), speech language (18.1%) and social emotional (15.8%). Concerns about other/health were raised by 7.9%, self-help concerns by 5.2%, receptive language (3.8%), fine motor (1.7%) gross motor (1.3%), and global (0.4%).

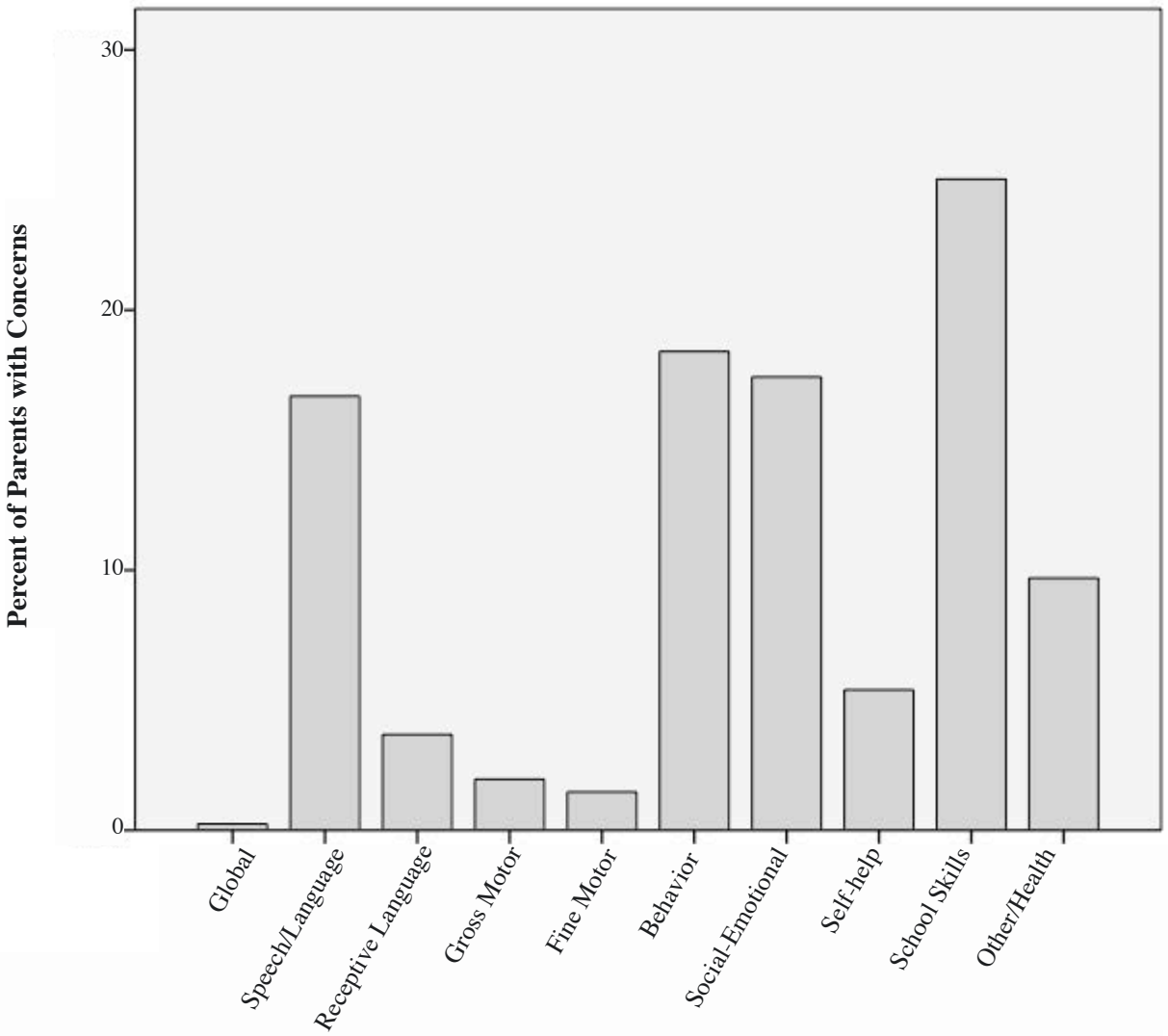
Figure 2-19. Frequency of Concern Categories Raised by Parents of 4-Year-Olds Among the 40.9% who Raised Concerns



Five-Year-Olds (60 - 71 months)

Of the 2178 five-year-olds whose parents were administered *PEDS*, the average number of concerns raised was 0.88 (range 0 – 9). More than half of parents (62.6%, N= 1363) did not have concerns. The remaining 37.4% (N = 815) raised one or more concerns as shown in Figure 2-20 below. Concerns about school skills remained prominent (25%) followed by concerns about behavior (18.4%), social-emotional (17.4%) and speech language (16.7%). Concerns about other/health were raised by 9.7%, self-help concerns by 5.4%, receptive language (3.7%), gross motor (2%), fine motor (1.5%) and global (0.2%).

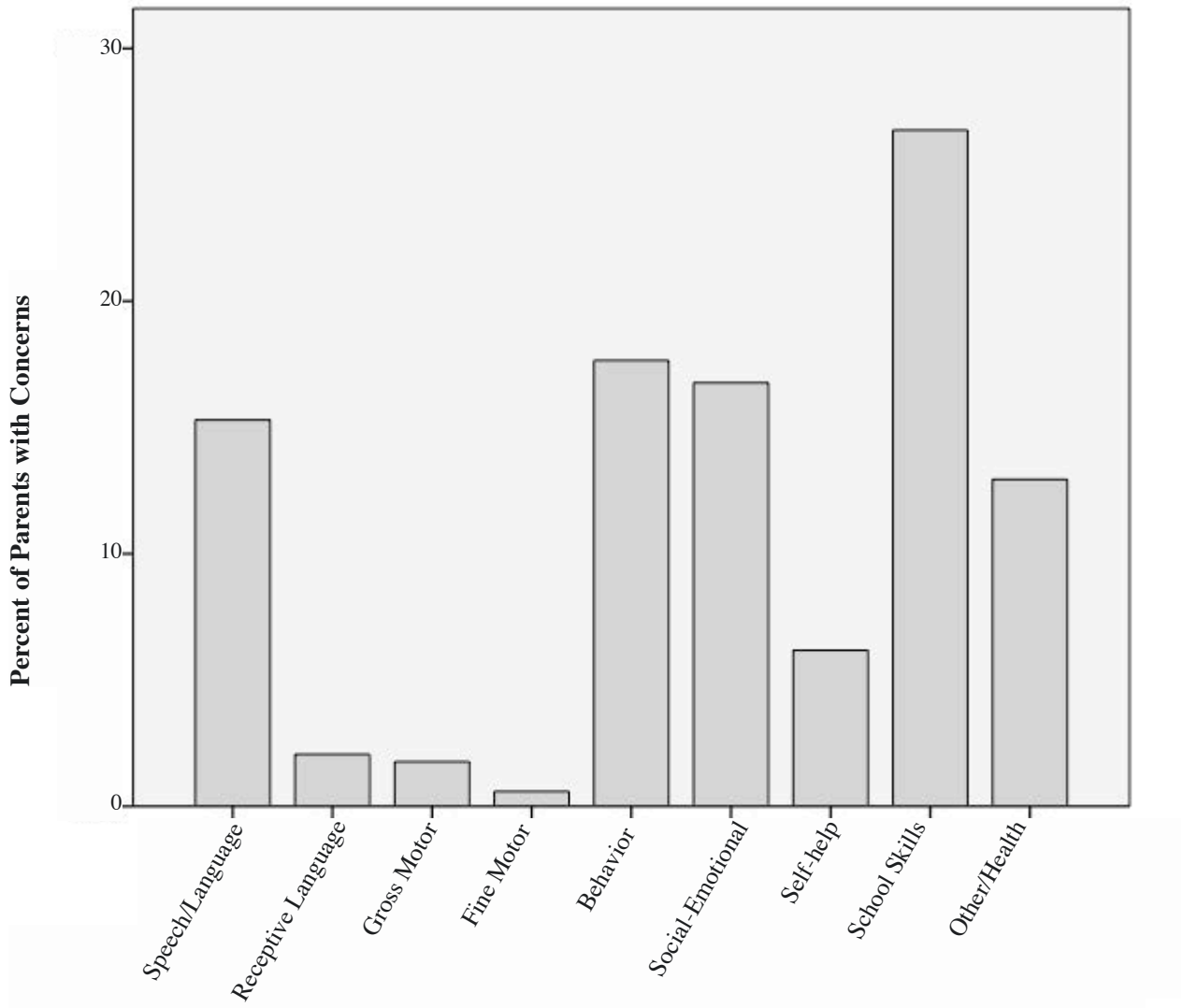
Figure 2-20. Frequency of Concern Categories Raised by Parents of 5-Year-Olds Among the 37.5% of Parents who Raised Concerns



Six-Year-Olds (72 – 83 months)

Of the 994 six-year-olds whose parents were administered *PEDS*, the average number of concerns raised was 0.82 (range 0 – 9). More than half of parents (65.8%, N= 654) did not have concerns. The remaining 34.2% (N = 340) raised one or more concerns as shown in Figure 2-21 below. Concerns about school skills were the most common (26.8%) followed by concerns about behavior (17.6%), social-emotional (16.8%) and speech language (15.3%). Concerns about other/health were raised by 12.9%, self-help concerns by 6.2%, receptive language (2.1%), gross motor (1.8%), fine motor (0.6%). No parent in this age range expressed global/cognitive concerns.

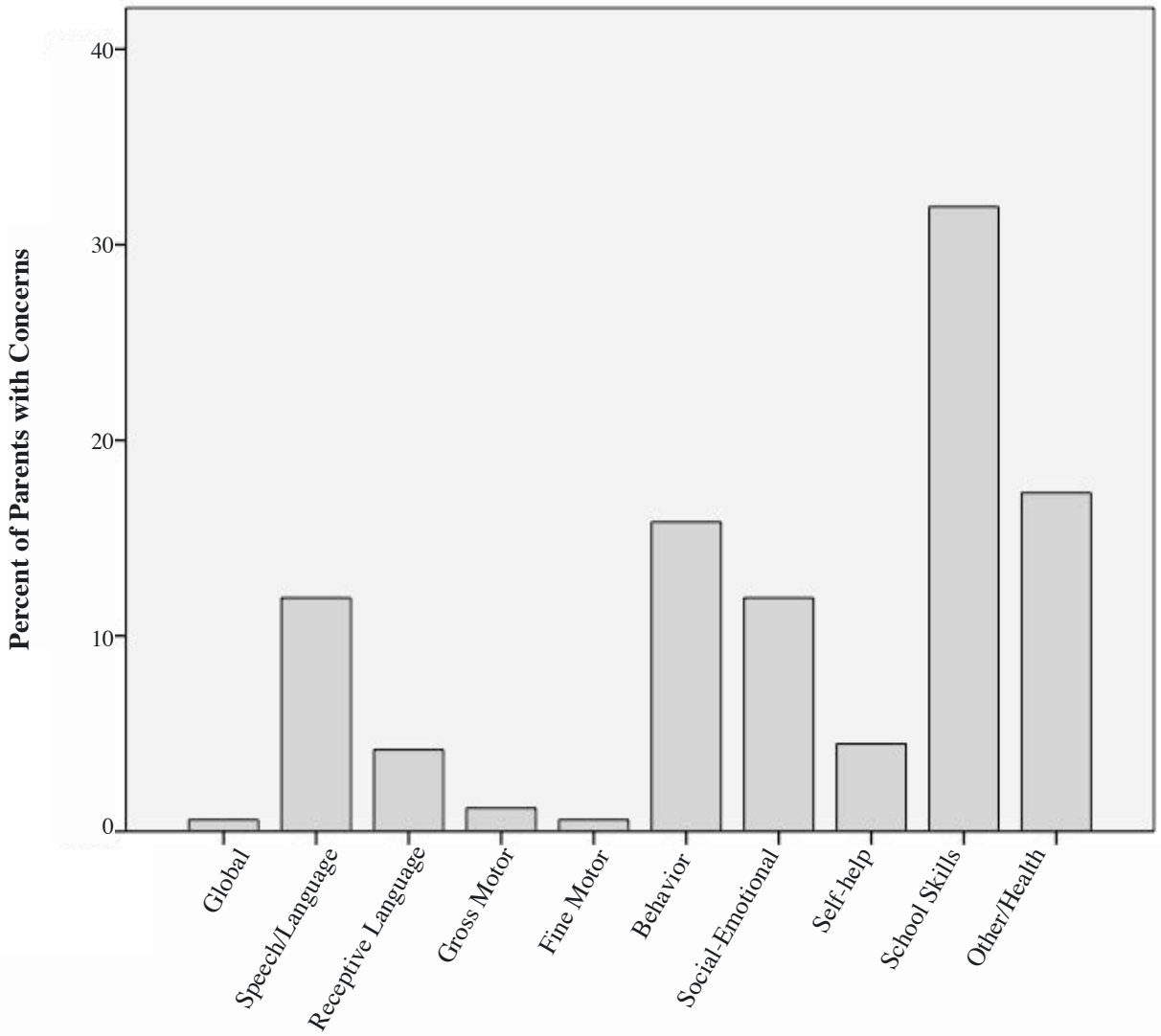
Figure 2-21. Frequency of Concern Categories Raised by Parents of 6-Year-Olds of the 34.2% who Raised Concerns



Seven-Year-Olds (84 – 95 months)

Of the 913 seven-year-olds whose parents were administered *PEDS*, the average number of concerns raised was 0.9 (range 0 – 9). More than half of parents (63.3%, N= 578) did not have concerns. The remaining 36.7% (N = 335) raised one or more concerns as shown in Figure 2-22 below. Concerns about school skills were the most common (31.9%) followed by concerns about behavior (15.8%), other/health (17.3%),social-emotional (11.9%) and speech language (11.9%). Concerns about self-help skills were raised by 4.5%, receptive language (4.2%), gross motor (1.2%), fine motor (0.6%) and global/cognitive (0.6%).

Figure 2-22. Frequency of Concern Categories Raised by Parents of 7-Year-Olds of the 36.7% who Raised Concerns



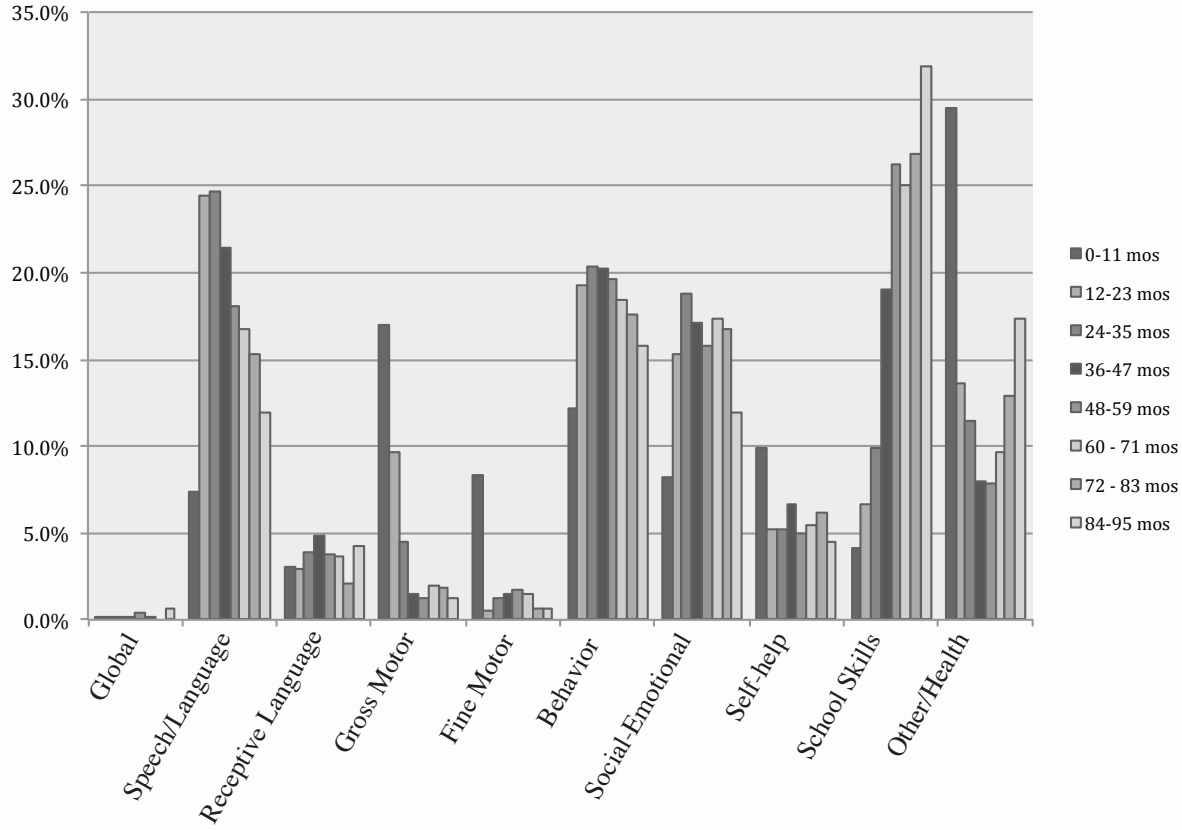
Numbers of Concerns Raised in Relation to Children's Age

Table 2-25 shows measures of central tendency of concerns according to children's age (in years). There is a clear progression of increasing numbers of concerns, the older the child. These differences were significant [$F(7) = 79.88$, $p < .0001$].

Table 2-25. Frequency of Concerns by Children's Age (in years)

AgeGroup	Mean	Median	N	Std. Deviation
0 - 11 mos	1.59	1	1994	1.100
12 - 23 mos	1.69	1	3265	1.176
24 - 35 mos	1.91	1	2482	1.326
36 - 47 mos	2.26	2	1646	1.649
48 - 59 mos	2.25	2	1986	1.625
60 - 71 mos	2.35	2	815	1.732
72 - 83 mos	2.40	2	340	1.592
84 - 95 mos	2.45	2	335	1.659
Total	**1.96**	**1**	**12863**	**1.431**

Figure 2-23. Overall Comparison of Concern Categories by Age



Levels of Risk: *PEDS* Paths by age

Description of *PEDS* Paths

Extensive validation research (described in the chapters on Validation and Accuracy) showed that certain concerns, the frequency of those concerns when intersected by children's ages, combine to predict developmental status. *PEDS* generates five distinct paths to which risk levels are assigned:

A. **Path A** is high risk and involves two or more predictive concerns (to which providers are encouraged to refer for further evaluation).

B. **Path B** is moderate risk and involves only one predictive concern (to which providers are directed to screen further before making a referral decision and to monitor development vigilantly) Path B is divided into:

   1. Health-related concerns to which providers are encouraged to respond with health screens and guidance.
   2. Developmental concerns to which providers are encouraged to respond with developmental-behavioral screens.

C. **Path C** is low risk but includes parents who held non-Path A and B concerns (to which clinicians are encouraged to respond with parenting advice and follow-up on its effectiveness). Path C is divided by age:

   1. For children who are less than 4 ½ years, providers are encouraged to counsel parents and monitor progress.
   2. For children 4 ½ years and older, providers are encouraged to refer for mental health evaluations (since Path C becomes predictive of problematic well-being at older ages).

D. **Path D** reflects moderate risk and is designated by clinicians when they suspect problems but parents do not raise concerns, communicate effectively (or sensically), or when parents have literacy barriers that prevent reading and responding to test questions. *Path D is not used in PEDS Online because providers are encouraged to add their concerns before scoring and because the site rejects communication and literacy barriers* (e.g., when a parent fails to write anything on a printed *PEDS* Response Form). In such cases, clinicians are prompted to readminister *PEDS* by interview (and are also prompted to administer a measure such as the *PEDS:DM*, hands-on).

E. **Path E** is low risk and no concerns (to which providers are prompted to offer reassurance that development is on-track and to rescreen at the next well-visit or check-point).

Shown below in Table 2-26 are the mean and median ages (in months) for *PEDS* Path results. The age range throughout is 0 – 95 months. There is an obvious trend toward higher risk, the older the child, i.e., "development develops and developmental problems do too." Age differences in risk levels were enormously signicant significant [F(3) = 812.522, p < .0001]. Following Table 2-26 is a breakdown of *PEDS* Paths by years of age.

Table 2-26. Children's Age according to *PEDS* Paths*

PEDS Path	Mean age (in months)	Median age (in months)	Std. Error of Mean	N	Percent of Sample	Std. Deviation
A (high risk)	42.49	43	.466	2149	4.5%	21.607
B (moderate risk)	30.60	24	.247	6473	13.7%	19.908
C (low risk but concerned)	29.42	24	.315	4241	9.0%	20.499
E (low risk and not-concerned)	23.51	18	.108	34370	72.8%	20.023
Total	**25.87**	**19**	**.095**	**47233**	**100%**	**20.636**

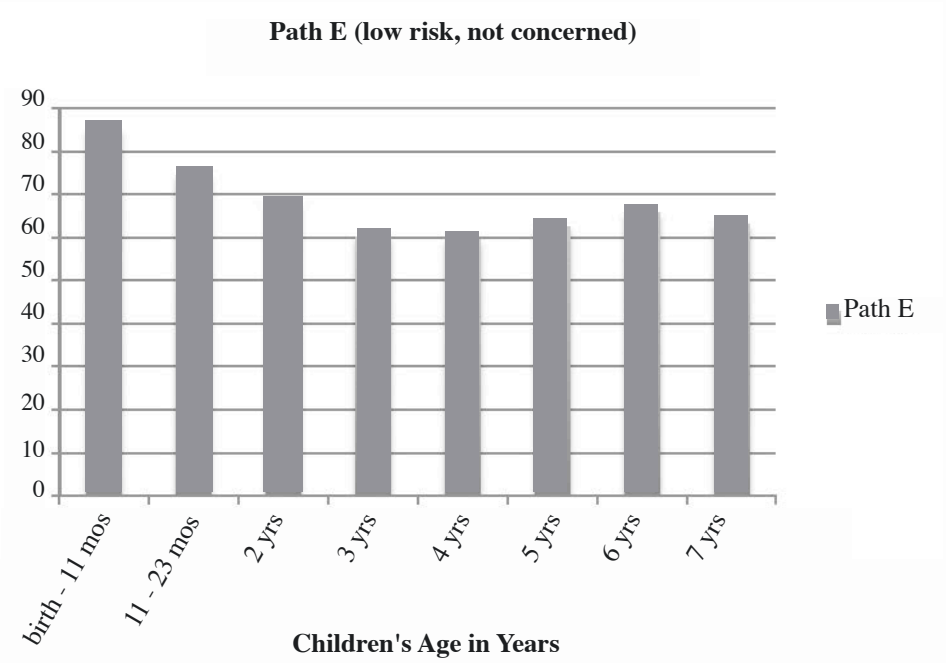
* *Path D is not used in PEDS Online because providers are encouraged to add their concerns before scoring and because the site rejects communication and literacy barriers*

PEDS Paths by Age

Path E (No Concerns and Low Risk) by Year of Age

In the following graph, the frequency of Path E (low risk, not concerned) is grouped by year of age. Overall, 73% of children are not found to have risk on *PEDS*. But, there are fewer children without risk as they increase in age.

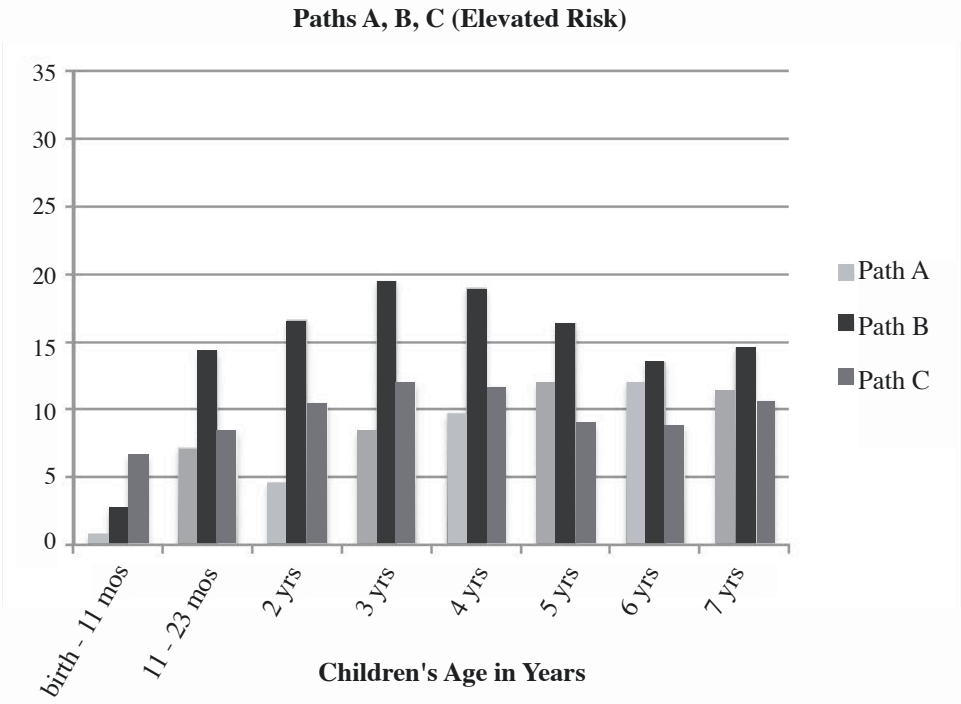
Figure 2-24. Absence of Risk by Year of Age



Elevated Risk: *PEDS* Paths A, B, C by years of age

In the following graph, the percentage of risk levels are broken out by year of age. [Again, these are Path A = high risk, Path B = moderate risk, and Path C = low risk, but concerned (although children on Path C who are > 4 ½ years old, have an elevated risk for mental health problems)]. As shown, Path A and Path B scores generally increased at each year of age, tapering slightly at age 6 and 7: a clear statement about the need for continued screening. Tapered at older ages may reflect enrollment in early intervention/special education, its effectiveness, and/or parents satisfied with services (who tend not to raise ongoing concerns). Path C increased until 4 years of age, remained common through age 5 and tapering only slightly at ages 6 and 7. This may reflect the impact of ADHD and emergence of other mental health problems.

Figure 2-25. Presence of Risk: Frequencies of *PEDS* Paths A,B, and C by Year of Age



COMMENT ABOUT PARENTS' CONCERNS AND PEDS PATHS BY CHILDREN'S AGES

Parents concerns increase in frequency as their children get older. This makes sense because the prevalence of developmental-behavioral problems increases significantly with age. The types of concerns raised also varies by age: Parents of children 0 – 11 months tend not to have many concerns but when they do, these tend to focus on children's health, motor, self-help, behavioral and social-emotional skills. Motor and health concerns wane substantially the older the child (although health issues rise again once children reach kindergarten age and beyond). Expressive language, behavioral and social-emotional concerns increase with age, waning slightly after four years of age. School-related issues increase systematically the older the child.

The above is broad information but may be helpful to clinicians working with children at specific ages—enabling them to focus on the changing types of information and referrals they will need as children grow. Future research should view the content of parents' concerns at different ages because content within domain concerns will surely change with age (e.g., sitting up in the first year of life versus stair-climbing in later years). A refined sense of specific worries by type of concern and age is particularly informative for helping providers anticipate, prepare for, and best address parents' concerns.

PEDS and Children's Gender

Types and Frequency of Concerns by Gender

There were no significant differences in the types of concerns parents raised when describing their sons versus daughters. ($p < .06$). Trends in concerns were that parents tended to have more behavioral concerns about boys than girls (6% versus 2%) as well as more social-emotional concerns (8% versus 5%). Nevertheless, the sheer numbers of concerns raised varied significantly: Parents of boys raised an average of 1 concern, while parents of girls raised on average, only 0.5 concerns [$F(1) = 8.638$, $p < .003$].

PEDS Paths by Gender

Male children were more likely to receive a Path A result than were females (11% versus 6%), a Path B result (15% versus 10%) or a Path C result (11% versus 5%). As a consequence, they were less likely to receive a Path E result, i.e., no concerns (64% versus 79%). These differences were significant ($\chi^2 = 1.417$, $p < .003$).

Comment on Gender-related performance.

Male children are more likely to receive a diagnosis of developmental-behavioral disabilities and to have biological conditions associated with disabilities.[7] So, it is not surprising that parents worry more about their sons. Worrisome is the finding that when presented with problematic screening results, parents of boys are more likely to follow through with a referral than are parents of girls.[8] This finding suggests clinicians need to carefully monitor referrals made when girls do poorly on screening measures and encourage parents to keep appointments.

PEDS' Performance Across Various Populations

Standardization on a nationally representative population is requisite psychometric reporting for test construction. But for the many providers who work with populations differing from the nation as a whole, it is reasonable to expect answers to such questions as: Do more children score on Path A in clinics serving Medicaid populations? Are there cultural differences associated with the types of concerns parents' raise? Do highly educated parents have more concerns than parents with less education? In this section, answers to some of these questions are explored.

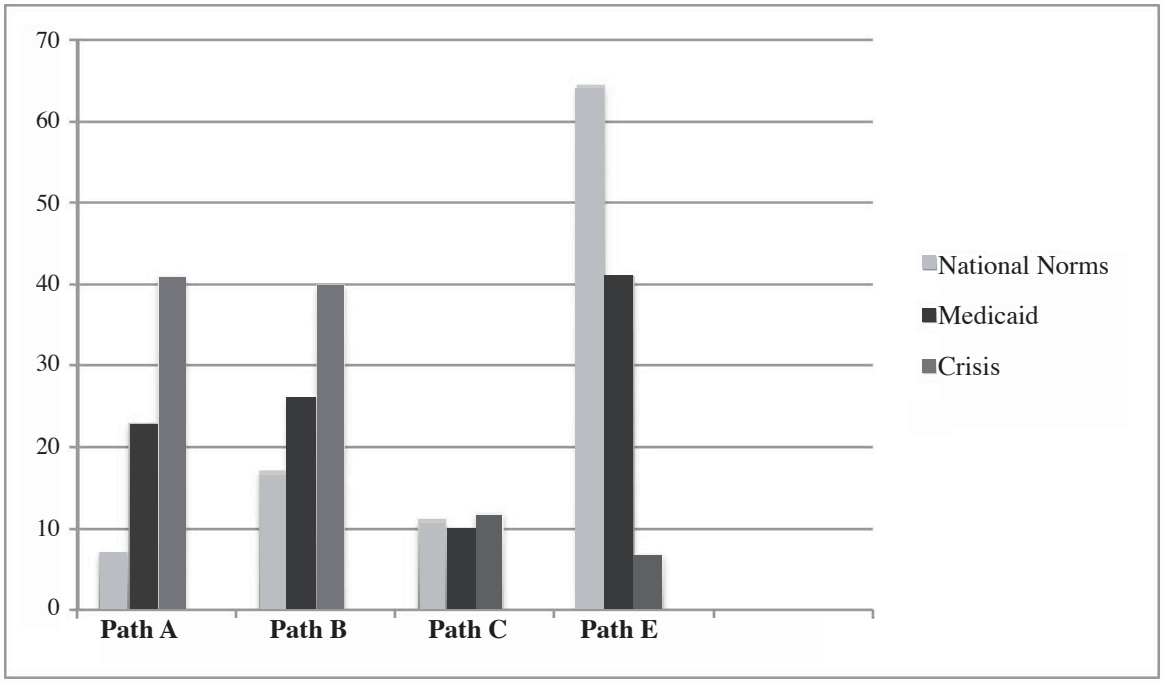
Differences in Performance between Males and Females

In this study of 263 children [whose mean age was 48 months (range = 18 – 72 months] of whom 47% (N = 124) were boys, both parents and day care teachers (who independently completed *PEDS*) expressed far more concerns about boys than girls. More boys than girls were classified as being at high risk (Path A) on *PEDS*; 12% of boys vs. 7% of girls. Similarly more boys than girls were classified as at medium risk (Path B); 23% of boys vs. 14% of girls. Both parents and teachers reported more concerns about boys' skills with expressive language, receptive language and self-help domains. Teachers reported more concerns than did parents about male students' gross motor and social-emotional skills. Gender differences in performance on *PEDS* are consistent with research on gender differences in young children.[9,10]

PEDS with Impoverished Families and Those in Crisis: Psychosocial risk and Developmental-Behavioral Status

Figure 2-26 is from a study published recently in which *PEDS* standardization (using the current 2012 data) are compared to a Medicaid clinic (serving families who were 80% African American and 15% Latino)[11] and to a non-emergent crisis call-in clinic (211LA). Results are reported on children averaging 36 months of age for all three groups. Clearly visible are significant differences in performance based on patient mix. Medicaid families were far more likely to have children who received high or moderate risk paths on *PEDS* (A and B). In the non-emergent crisis call center, families had even higher risk of developmental-behavioral problems. Bottom line, in contrast with *PEDS* normative sample, parents in both the Medicaid and crisis center groups had more concerns but also more concerns predictive of risk for developmental-behavioral problems.

Figure 2-26. Comparison of *PEDS* National Norms (2012) to a Medicaid Clinic and a Crisis Call Center (211LA)



A Comment on Psychosocial Risk

Children in poverty or children whose parents are in the midst of crises, are understandably at higher risk for developmental-behavioral problems surely due, in large part, to the presence of psychosocial risk factors. Risk factors include parents with less than a high school education, who are not married, have more than 3 children to care for, don't speak English, are depressed, abuse substances, engage in domestic violence, lack extended families to provide social support and advice, are jobless, homeless, or don't know to read and converse much with their children.[12,13] Four or more such factors conspire to generate below average development in the preschool years, leading to subsequent academic problems including in-grade retention during elementary school, and are subsequently associated with high school drop-out, teen pregnancy, unemployment and criminality.

While powerful, psychosocial risk factors are imperfect predictors of developmental-behavioral status because

some children are resilient and overcome their challenges. Such children are likely to have parents who engage them, encourage language and school skills, and promote success and well-being. For this reason, we cannot rely on risk factors alone to predict developmental-behavioral problems. But, we do need to identify risk factors (and absence of resilience factors) and intervene with them whenever possible.[14]

Nevertheless, it is natural to wonder whether families with enormous life stresses have time to even notice problems in their children. Such an assumption is clearly false. As shown in the above findings, heavily burdened families do notice their children's difficulties and want help. In another example, a study in Tanzania in which parents were administered PEDS in the midst of a malarial outbreak, found parents to be extremely worried about their children's development, as well they should be given the adverse effects of malaria on cognitive skills: More than 80% of parents raised concerns.[15] *But what is criticial for clinicians to know is that parents with psychosocial risk factors are much less likely to spontaneously raise concerns about their children's development and behavior. Many such families are not aware that developmental-behavioral issues are a part of health care or that clinicians are interested in their concerns.*[16] *So… "if you don't ask, they won't tell" is the take-home message about working with psychosocially challenged families.*[17,18]

PEDS with Parents' of Differing Educational Levels

Do educational levels make a difference in the frequency of concerns on *PEDS*? In the following analysis, frequency and type of concerns are compared by parents' level of education. Children's risk rates, i.e., *PEDS* paths are similarly compared. Because older children tend to have higher levels of risk, children's ages across varying levels of parental education were tested and were not significantly different ($p < .28$).

Types and Frequency of Concerns by Parents' Level of Education

Parents were grouped by educational attainment as follows:

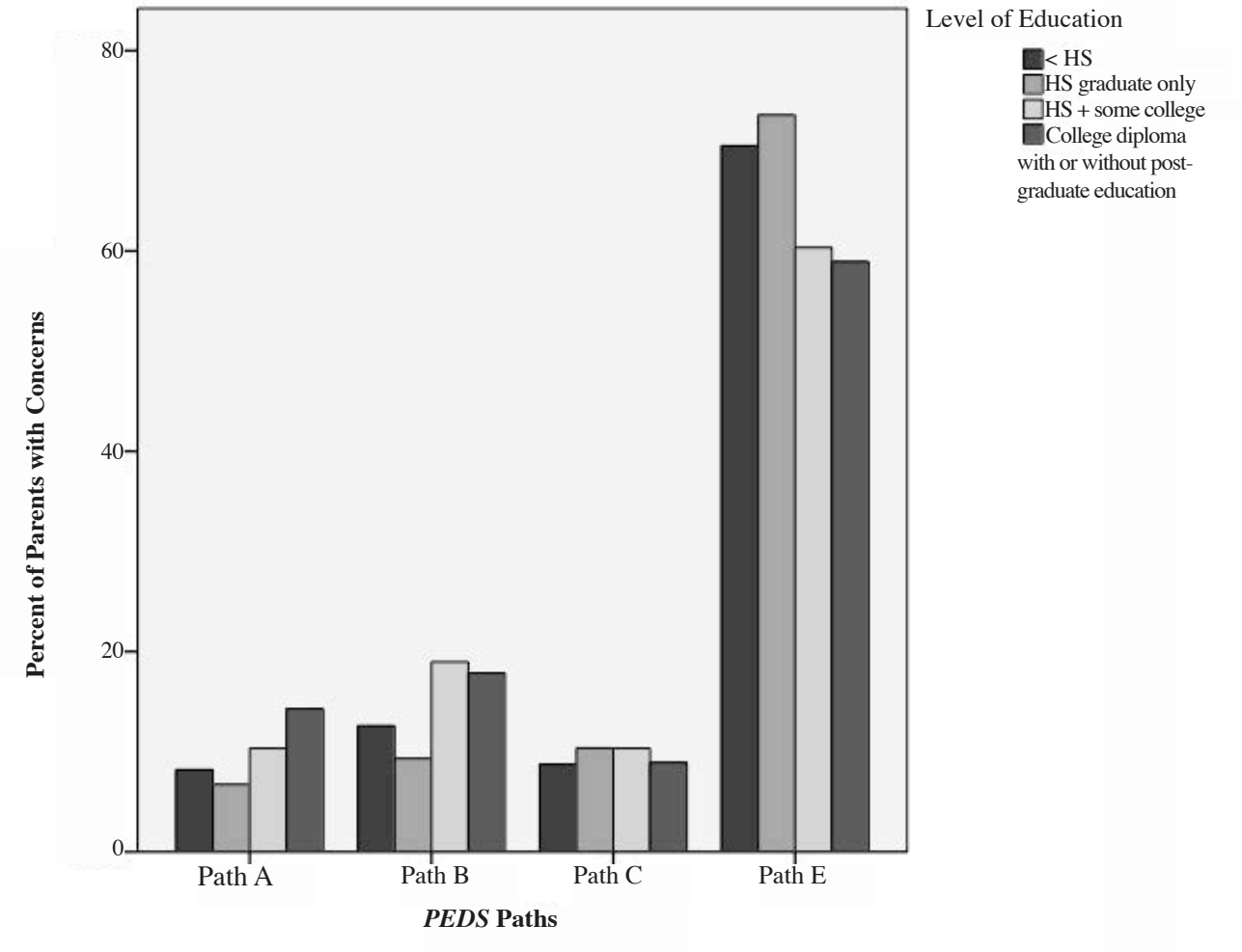
1. Did not complete high school;
2. Completed high school only;
3. Attended but did not graduate from college;
4. Graduated from college (including those who completed graduate degrees).

In comparing categories of concerns according to level of education, there were no significant differences among the four groups ($p<.97$). This means that parents despite differences in educational levels were equally likely to raise the same types of concerns. Nevertheless, in viewing sheer numbers of concerns broken out by education levels, differences were significant [$F(3) = 5.244$, $p < .001$]. Parents who had graduated from college (or beyond) raised more concerns (mean = 1.5) than parents who had less education (range of means = 0.6 – 1.0).

PEDS Paths: Risk Levels by Parents' Education

So did differences in frequency of concerns according to parents level of education generate differences in children's risk status, i.e., *PEDS* Paths? Only marginally [$\chi^2 = 8.244$, $p < .04$ (An alpha of at least $p <.0001$ is needed to avoid Type I error given the size of this sample)]. In viewing *PEDS* Paths by level of education, highly educated parents were slightly more likely than less educated parents to have a child on Path A (12% versus 7%), Path B (18% versus 11%), equally likely to have a child on Path C (10% each) and less likely to have a child on Path D/E (60% versus 72%).

Figure 2-27. *PEDS* Paths by Parents' Level of Education



COMMENT ON PEDS AND PARENTS' LEVELS OF EDUCATION

By using PEDS, we ensure that families with limited education and those in poverty i.e., who have low socio-economic status (SES) have "a level playing field" and thus have the necessary facilitation to share their worries with providers. By asking about concerns we also help all families think about development as a range of domains and thus pay careful attention to each aspect of children's development. It may take more than one administration of PEDS to elicit concerns in families with low SES but the second time through PEDS, they are usually quite prepared to share concerns about children's development.

In working with parents whose education is limited, it is important to know that PEDS is written at the mid-4th grade level, meaning that about 90% of Medicaid families should be able to read, understand and respond.[19] (A general index of a parent's reading level uses this formula: highest grade completed minus 5 grade levels). Nevertheless, about 10% of parents will have difficulty when presented with a written PEDS Response Form (even if in the language they most commonly speak). So if using PEDS in writing it is important to know that parents with limited literacy may engage in 'face-saving' in order to hide their reading and writing challenges. In such cases, it is not uncommon to receive completed PEDS Response Forms in which no words are written and only "yes", "no" or "a little" have been circled. In such cases PEDS cannot be scored. It must be readministered by interview. Clinicians using PEDS in print need to refer often to the Brief Guide. Those using PEDS ONLINE are prompted for a written comment before scoring and clinicians are given clear directions to elicit comments from parents when nothing is written on the Response Form (e.g., if using the .pdfs provided by PEDS ONLINE in waiting or exam rooms).

Parents with high levels of education tend to have more worries than families with less education. But even though their children are marginally more likely to receive high or moderate risk scores on PEDS, their specific concerns tend to focus on health issues that can be readily addressed by health care providers—meaning that what generally remains are moderate risk concerns for which additional screening is needed (e.g., with the PEDS:DM). Thus clinicians working with highly educated parents, indeed with all parents, need to be prepared to offer additional screening but also (given acceptable performance on a second screen) viable information on parenting and age-appropriate activities that focus on language and other skills essential for school success.

Clinicians would also do well to identify reputable sources of internet information for parents and offer a list of these to parents (whether highly educated or not). Educated parents do tend to rummage the internet and despite their education, may have difficulty discerning websites providing quality information from those that are questionable. This can be an enormous problem when a child is diagnosed with a developmental disability, most especially it seems with autism spectrum disorder for which there are many unproven medical interventions (although many viable educational programs). On the pedstest.com website are links to viable sources such as the American Academy of Pediatrics' Section on Developmental-Behavioral Pediatrics, KidsHealth, etc. along with a downloadable handout on information sources to post in exam rooms or give to parents.

PEDS and Ethnicity

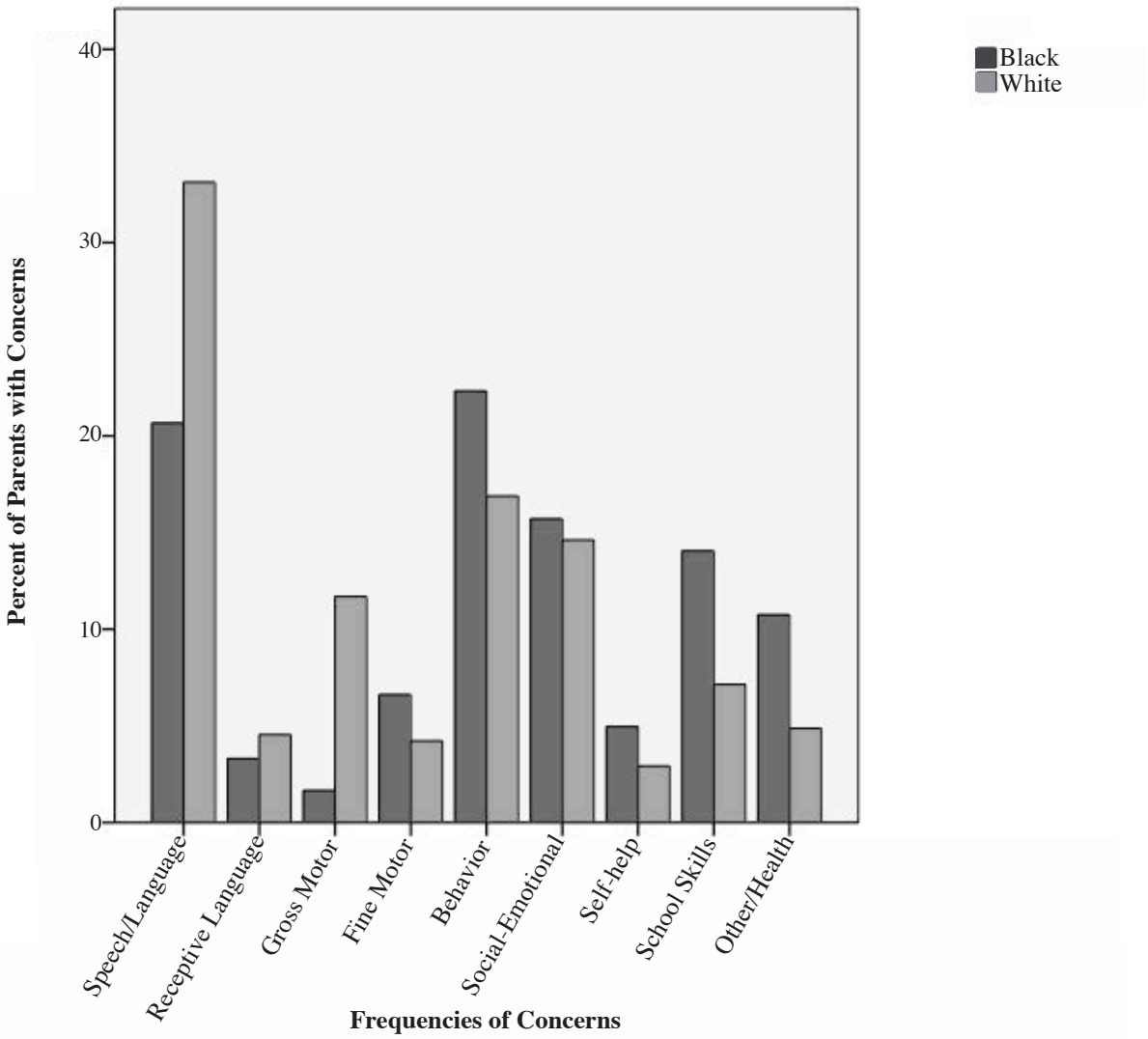
PEDS with African American Families

In the following analysis of 1554 children, a site (greater Baltimore, MD) in which 84% of families were black (N = 419) was compared to a site (greater Dallas, TX) in which 85% of families were white (N = 1135). Both communities were comparable in terms of languages other than English spoken at home (0.04% versus 0.06%). Poverty rates varied substantially (40% in the black community versus 12% white). Parents in the black community were also less likely to have graduated from high school (70% versus 86%) or to have obtained a bachelors degree (15% verus 27%). The black community had children who averaged 31 months of age while the white community had somewhat younger children who averaged 24 months of age.

Types and Frequency of Concerns in African American versus white families

After adjusting (via analysis of co-variance) for group differences in children's ages, blacks were marginally more likely to have concerns [$F(8) = 2.50$, $p < .01$]. In comparing the numbers of concerns raised between groups, black parents tended to raise more concerns (mean = 2.2) than did whites (mean = 1.6) [$F(1) = 11.75$, $p < .001$]. As shown in Figure 2-28, among those in both groups who raised concerns, blacks were far more likely than whites to have concerns about children's skills in the domains of fine motor (7% versus 4%), behavior (22% versus 17%), school (14% versus 7%), and other/health (11% versus 5%). Blacks were significantly less likely than whites to have concerns about expressive language (21% versus 33%) and gross motor skills (2% versus 12%). Blacks and whites had similar rates of concerns about receptive language (3% versus 4%), social emotional (16% versus 15%), self-help (5% versus 3%), and neither group raised any global/cognitive concerns), approximately [χ^2 (8)= 2.74, $p < .001$].

Figure 2-28. Differences in Frequencies of Concerns Between Black and White Families who Raised any Concerns

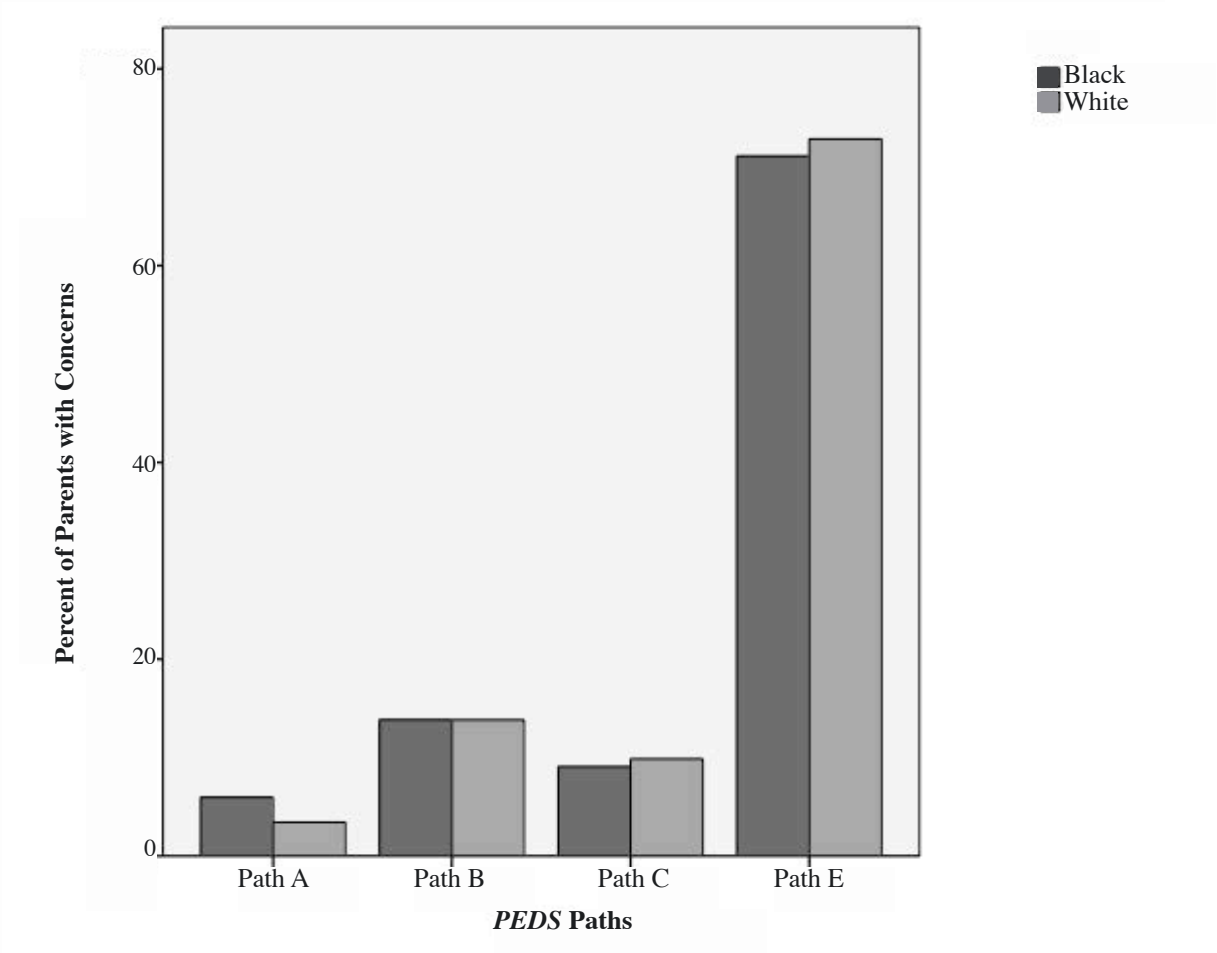


*All parents with concerns raised 2 or more concerns. No parents raised global/cognitive concerns.

PEDS Paths in African Americans Compared to white families

So, did variations in concerns between blacks and whites generate substantial differences in detection rates on *PEDS?* No! As shown in Figure 2–29, black families were more likely than whites to incur a Path A (high risk) result (6% verus 3%). Both groups had identical frequencies for Path B (moderate risk) (14%) and similar rates for Path C (low risk but concerned) (9% versus 10%) and for Path E (no risk, no concerns) (71% versus 73%).

Figure 2-29. Differences in *PEDS* Paths Between Black and White Families



Comment on PEDS with African American Families

These analyses confirm that PEDS works reasonably well at detecting children in African American families. Nevertheless, in considering that blacks tend to have higher levels of psychosocial risk (e.g., greater poverty, lower high school graduation rates) it is reasonable to wonder why there weren't more black families with moderate risk results on PEDS. Lower rates of concerns about expressive language may explain this (because Path B is most often generated by a single expressive language concern). Therefore, it seems invaluable to provide black families with information on milestones in speech-language development and for providers to periodically add a milestones-focused measure such as the PEDS:DM to PEDS.

Comparison of *PEDS* with American Indian Versus White Families

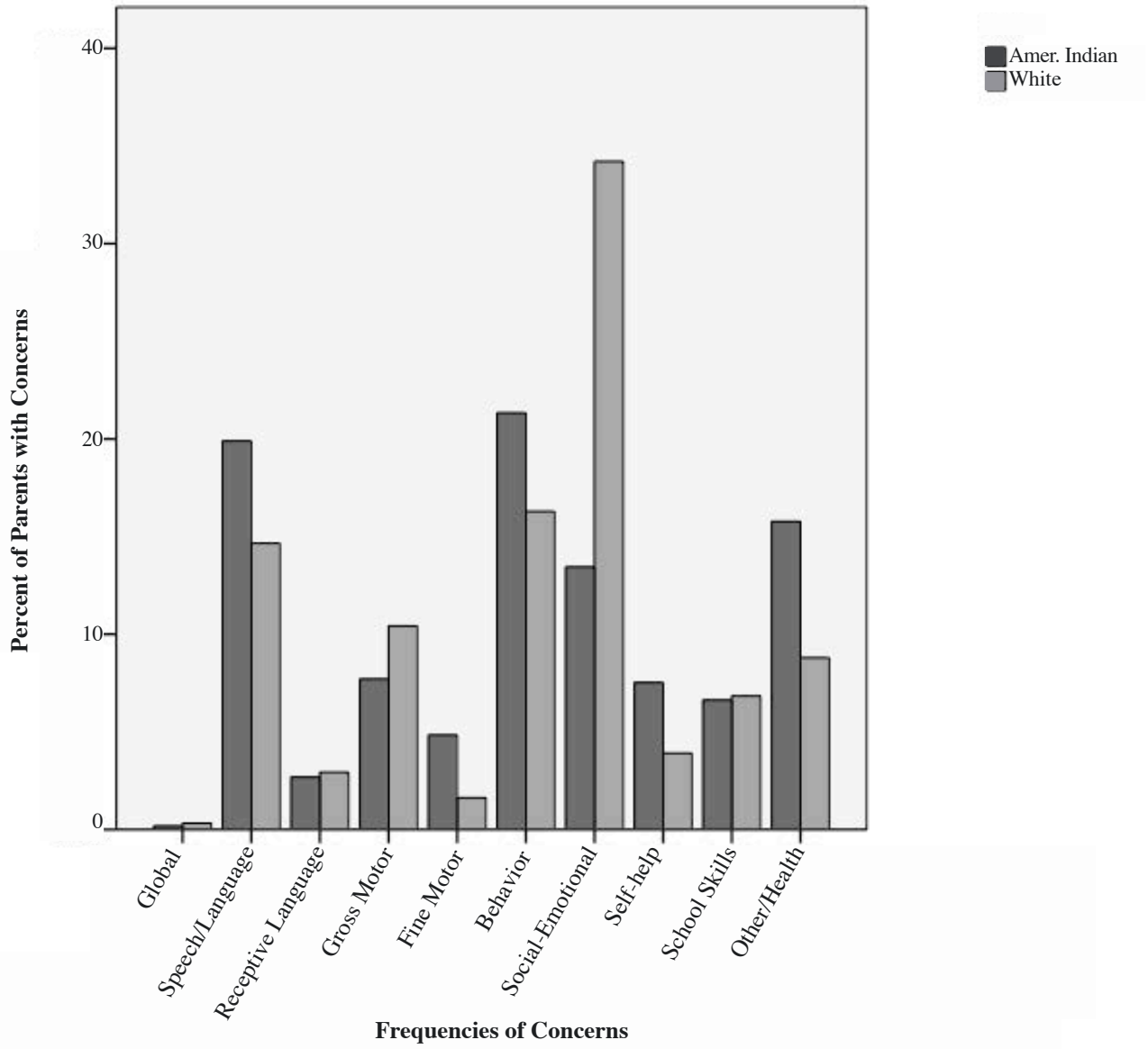
This analysis of 2,565 children compared an Indian Health Service site in rural Arizona (N = 1032) to a site in rural Pennsylvania in which no American Indian families resided (N = 1533). The two groups were similar in terms of ability to speak English well (91% for American Indians and 88% in the white group). American Indian children were slightly older on average than whites (20 months versus 18 months). American Indian parents were less likely than white parents to have completed high school (64% verus 72%), and were more likely to have income below federal poverty guidelines (63% versus 35%).

Categories and Frequency of Concerns in American Indians versus whites

Given that American Indians had more psychosocial risk factors (less educated and more empoverished) and given that parents with risk factors tend to have more concerns and elevated risk rates on *PEDS*, we'd expect that American Indian parents would have more concerns than white families. This was not the case: The frequency of concerns was similar between groups (mean = 0.6 concerns in American Indian families versus a mean of 0.7 in white families [F (2563) = 3.076, (NS)].

Neverthless, there were substantial differences in the types of concerns raised between the two groups [χ^2 (10) = 7. 452, p < .0001]. As shown in Figure 2-28, whites were more likely than American Indians to have concerns about expressive language (17% versus 12%), fine motor (4% verus 2%), self-help (4% versus 2%), and health concerns (6% versus 3%). American Indians, in turn were more likely than whites to raise concerns about social-emotional development (13% versus 7%). Other worries were not significantly different between groups, i.e., concerns about receptive language, gross motor, behavior, school and global/cognitive skills.

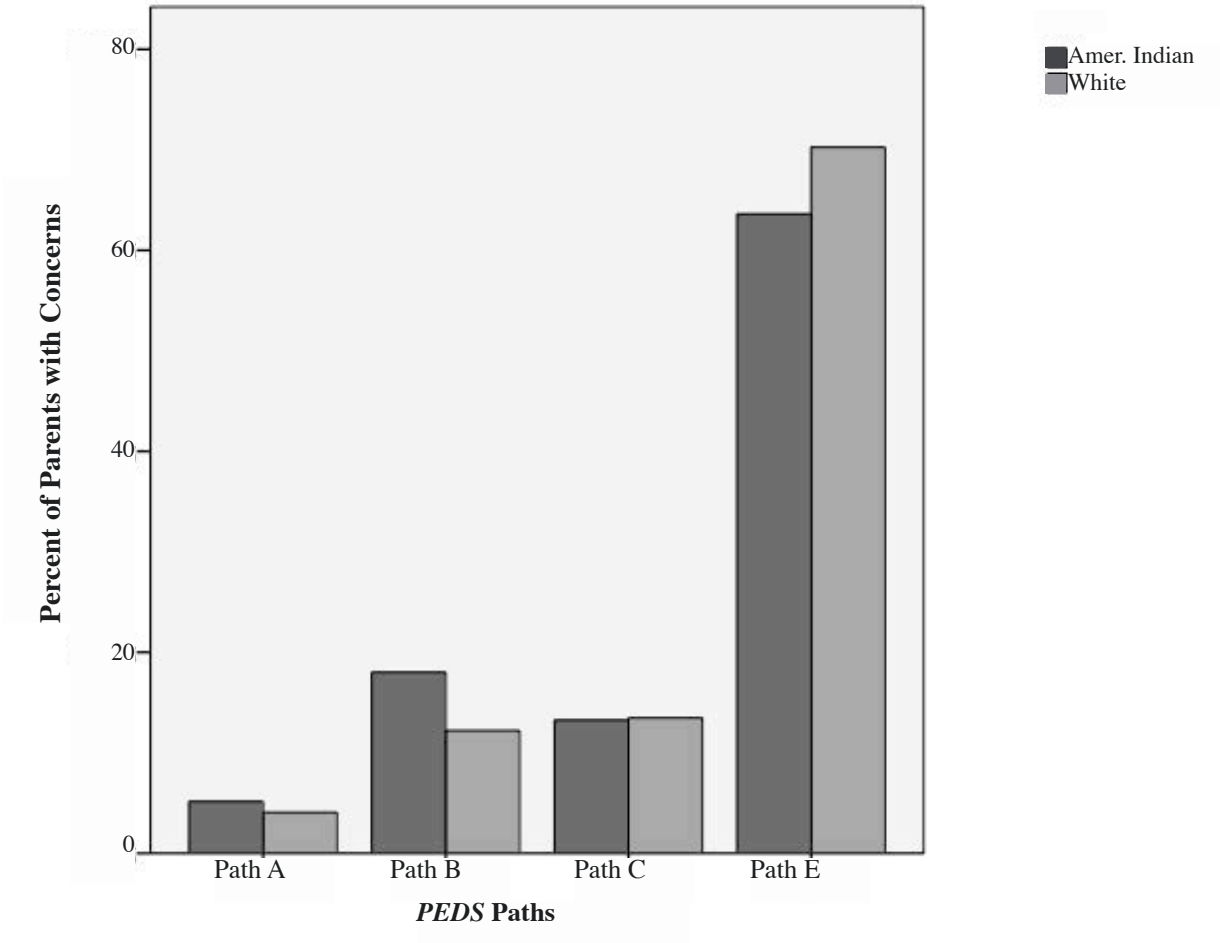
Figure 2-30. Frequencies of Concerns Between American Indians and Whites who Raised any Concerns



PEDS Paths in American Indians compared to white Families

So, do differences in types of concerns, render differences in risk rates on *PEDS*? Yes! Although American Indians were as likely as whites to land on Path A (high risk), (5% versus 4%), and Path C (low risk but concerned) (12% versus 13%), they were substantially less likely than whites to land on Path B (moderate risk for which follow-up screening is needed (12% versus 18%), and were more likely to land on Path E (no concerns, no risk) (70% versus 63%). Figure 2-29 illustrates the differences in risk rates by *PEDS* Paths. The differences between groups was significant [χ^2 (3) = 1.89, p < .0001].

Figure 2-31. Comparison of *PEDS* Paths Between American Indians and Whites



*Comment on PEDS with American Indians**

The above findings mean that American Indians may be less likely to come under the needed scrutiny of additional screening tests (per Path B recommendations) when their children may need a more careful look at developmental progress. And given what is known about families at psychosocial risk, it is expected that American Indian families would have much higher rates than whites on Paths A, B, and C. So, what explains differences in PEDS performance with American Indian families and what should professionals do about it? In this particular tribal nation, children "are expected to recognize seniority and show respect for age, regardless of sex; to promote group solidarity; and to respect the role, function, and opinion of every member of the band" (http://universalium.academic.ru/288637/Southwest_Indian). This suggests that social-emotional development, especially ability to get along with others, is highly valued and thus particularly salient to parents. But ability to get along with others well also places demands on cognitive, motor, and language skills that may be subsumed within social-emotional concerns.

Here are some suggestions for working with American Indian families:

1. *Providers should carefully probe the social-emotional concerns American Indians raise. It may be that imbedded within are descriptors of expressive language or other predictive concerns.*

2. *American Indian families would appear to benefit from more information about expressive and receptive language milestones and related age-appropriate parent-child interactions in order to build skills in language and other domains necessary for school success (and for better understanding of social-interactions).*

3. *Providers need to make sure they add their own observations and concerns before scoring PEDS.*

4. *Use of a second screen (e.g., PEDS:DM) is a wise addition to PEDS when parents of American Indian children do not raise concerns (Path E) and also with those whose parents raise Path C concerns (which are mostly social-emotional and/or behavior).*

** the above findings and recommendations were reported to the Indian Health Service and staff providers agreed on the advisability of adding the PEDS:DM to PEDS when using PEDS Online.*

PEDS In Translation

The following section covers how *PEDS* translations are developed and concludes with an analysis of how *PEDS* works with Spanish- speaking families in America. Sample sizes for the many other languages in which *PEDS* is administered were too small for analysis but we describe several studies that have tested translations especially in other nations. Research on *PEDS* with other language groups is welcomed and we keep current, on *www.pedstest.com*, completed studies of *PEDS*.

Translations of *PEDS*: Lessons learned the hard way

The original Spanish translation of *PEDS* (used in the original standardization study) was created on the East coast of the United States where most Spanish speakers were of Cuban, Puerto Rican, and Dominican descent. Problems arose when the original translation was used on the West coast where countries of origin were more likely to include Mexico and nations within Central and South America. One provider called to say that he was having to explain the meaning of *PEDS*' questions each time he administered the measure in Spanish! Wrong and wrong! So, I posted a note on the Ambulatory Pediatric Association discussion list asking for advice. More than 20 clinicians agreed to comment and we collectively agreed that the original wording ("Tiene preocupaciones …." should be changed to "Le preocupa…"). Several providers agreed to try out the new translation with their staff and families. The consensus was that the new version was far more effective wih Spanish-speakers of various national origins. So, *PEDS* staff then trashed (recycled actually) the existing Spanish forms, and printed new ones with the improved translation.

The above is an expensive mistake both for a publisher but even more so for the clinicians who struggled with the wording and who had to take extra time with families just because of problems with the translation. This is also an avoidable mistake but only if translations are carefully constructed, i.e., vetted within language groups and culutures. Translating and then back-translating are clearly not enough. Translations have to be tried out to make sure they work across all dialects within a specific language (wherever possible).

Here are a few more tales of woe regarding our initial translation challenges; before we learned that culturally vetted translations are essential:

1. In our first attempt at a Somali version of *PEDS*, the translator, who was a long-time expatriot, did not realize that the word "concerns" had become a political slogan used by warlords. Families did not respond well, understandably—only about 2% answered *PEDS* questions. Meanwhile, from *PEDS* above norming studies, we know that 40% to 50% of parents raise concerns. One parent finally asked if the provider was "*spying on our families back home?*" Yikes! Many attempts to improve wording resulted in questions that back translate into "Do you have feelings about your child's …..". While such phrasing would lead to major over-identification in English, they worked well with Somali families who began raising concerns at frequencies with which English speakers do.

2. Similarly, we found difficulties with our first efforts (in 2001) at a Chinese translation where the word "concerns" was interpreted to mean, "Do you care about your child?" (described by Kiing et al, 2012).[20] Obviously parents "care" and so the response rates for the high risk *PEDS* paths were excessive. So, after working with many different Chinese-English speakers, the back translation reads, "Are you worried about your child's….?". This phrasing, having been tested in the original pilot studies for *PEDS*, does not work at all well in English since parents aren't sure they are "worried" at least not when initially noticing problems. The word "concerns" which is used throughout the English translation works far better in English at getting parents to talk with providers. But "worries" works far better with Chinese speakers. On top of all this, the Chinese language increasingly uses what is known as "simplified Chinese" rather than the more complex, elegant characters known as "traditional Chinese". This trend required us to change the *PEDS* script to the more commonly recognized characters.

Other studies used variations of *PEDS* wording in English (e.g., as suggested by the American Academy of Pediatrics in its 2006 policy statement on early detection). This wording breaks up the first *PEDS'* question, "Do you have concerns about your child's learning, development, and behavior", into seemingly more digestible bits, "…..Development? ….Learning? ….Behavior?". *PEDS'* wording deliberately paired the more familiar terms "learning" and "behavior" with the less well understood term "development" because it appears to be understood by only 50% of parents.[21] So, it isn't surprising that a study of the AAP's questions had troubling findings. Parents tended to respond only with concerns about behavior and not with developmental concerns.[22] Further, *PEDS* uses 10 questions in order to help parents think about development the way professionals do, as a range of domains. For example, a parent may express on the first *PEDS* question, concerns about behavior but when asked to think about and comment on other developmental areas, often raises additional concerns about receptive or expressive language, i.e., some of the possible contributors to behavioral noncompliance.

Ongoing issues with translations

Languages change and change rapidly, as we can surmise by thinking about American English slang terms used, say, in the 1960's. Few people now use "*groovy*", "*hip*", or "*beatnik*" (although "*cool*" remains, well, "*cool*"). Spanish in America now has its own emerging dialect. For example, when referring to children in most Spanish speaking countries, the phrase "*niños y niñas*" is used, while American Spanish uses the more efficient "*chicos*". But that vocabulary choice does not work well for new immigrants from other Spanish speaking countries or with Spanish translations outside of America. In vivo trials of translations are much needed to make sure wording works for all speakers of a language.

Clearly, translations need to avoid colloquialisms and slang that may fade across years and decades. Translations need to be reviewed periodically to make sure they are still working. Languages morph with time especially languages spoken in a foreign country. To that end *PEDS* has a translation team that includes a linguistic anthropologist and an ESL (English as a Second Language) instructor. These professionals connect providers working with the same language so that all can vet translations and decide on the best approach. So, if you need a new translation or have trouble with an existing one (there are ~ 21 translations of *PEDS* available), please contact research@pedstest.org for assistance. For more guidance on translations see the International Test Commission's website: *www.intest.org.*

One of the translations we are currently debating is actually English but English when spoken by Americans of Chinese descent. The legacy of "concerns" meaning "care" in Chinese seems to persist into English—meaning that too many concerns are reported by English speaking Americans of Chinese descent, at least in studies of *Survey PEDS* (which uses 12 closed-ended questions within telephone interviews (e.g., California First Five, the National Survey of Early Childhood Health). In contrast, English speaking Australians of Aboriginal descent, seem to be struggling with the word "concerns" which may be less familiar to them—in a culture where the word "worries" (as in "No worries") is a common and nonthreatening phrase. Ongoing research on the quality of translations, even in English, is needed and encouraged!

A Comment about working with translation services

From the above discussion, it should be clear that translations of PEDS are hard-won and carefully tested for effectiveness. For this reason, if a translation service is required to support families who do not speak (or read) English, please make sure translators receive and use copies of our translations and don't just make up new wording. If you are using PEDS in print, we can license our translations (see www.pedstest.com for more information). If you use PEDS Online, we provide .pdfs of all translations as part of the Online License Agreement.

How do Translations of *PEDS* Work in Practice?

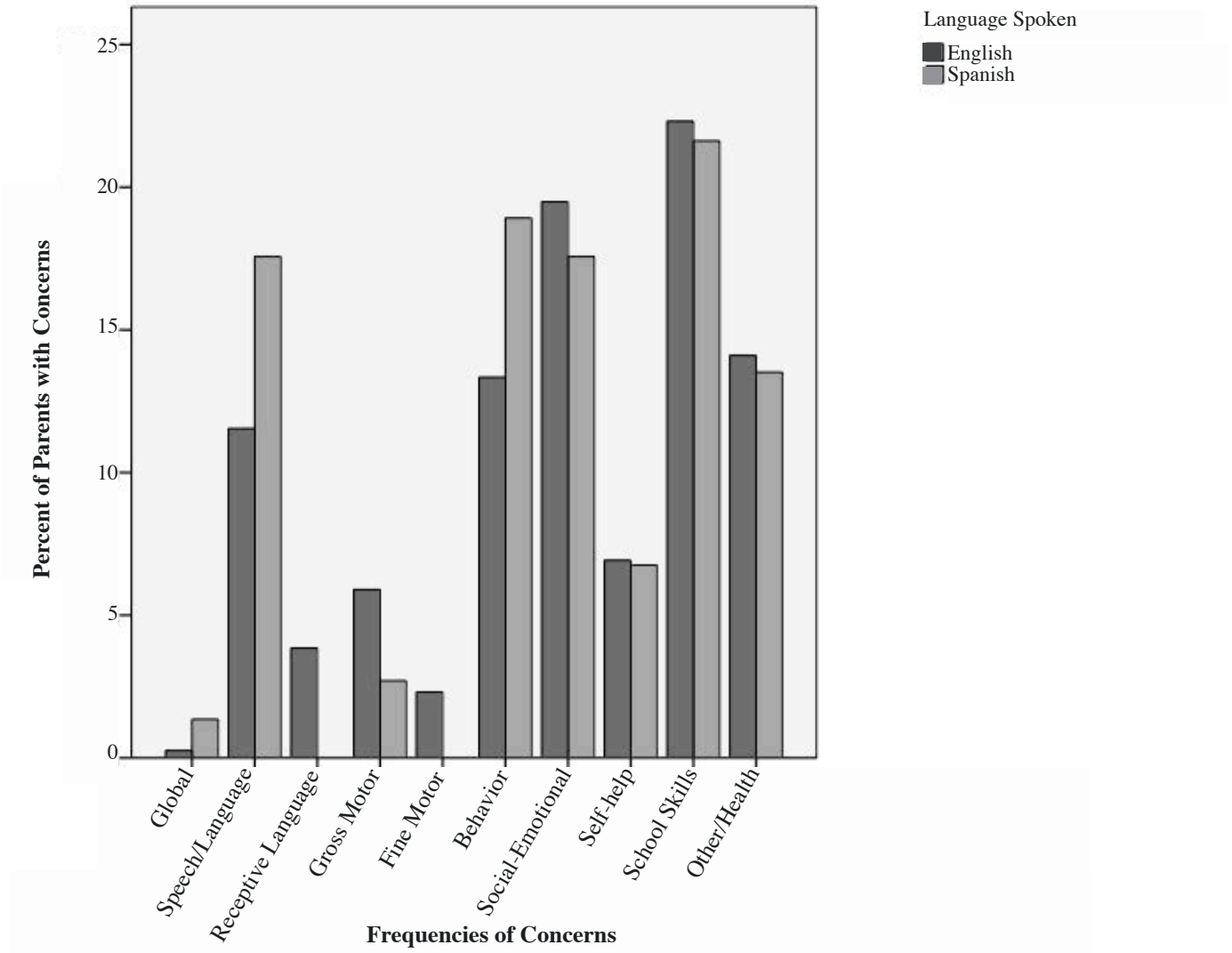
In the following analysis two groups of families, one Spanish-speaking and the other English-speaking were compared in terms of types of concerns and risk levels on *PEDS*. Because the *PEDS Online* database did not indicate when measures were administered in Spanish versus English until May, 2011, data from May through August, 2011 was used for the following analysis. Within this time frame, *PEDS* was administered in Spanish to 171 families across 8 clinics in California (N = 76), Texas (N = 87) and Florida (N = 6). English-speaking families (N = 1026) attending the same 8 clinics served as the comparison sample.

Spanish-speaking families had children who were slightly older (mean = 38 months, sd = 20.69) than children in English-speaking families (mean = 32 months, sd = 20.44). Levels of education varied substantially between groups: Spanish-speaking parents were far more likely to have dropped out of high school than were English-speaking families (71% versus 33%), and were less likely to have completed at least some college courses (25% versus 56%), or to have completed a college or post-graduate program (4% versus 11%). Although information on poverty levels was not available, the known and close association between education levels and income, makes it probable that Spanish speakers were far more likely to have less earning power.

Frequency and Categories of Concerns in Spanish- versus English Speakers

As shown in Figure 2-32, Spanish-speaking families were somewhat more likely to have concerns about global/cognitive (0.6% versus 0.1%), expressive language (8% versus 4%), behavior (8% versus 5%), school skills (9% versus 8%), and other/health (6% versus 3%). English-speaking families were slightly more likely to have concerns about receptive language (1.5% versus 0%), gross motor (2% versus 1%), and fine motor (1% versus 0%). Differences in types and frequency of concerns were significant between groups [χ^2 (10) = 5.288, $p < .0001$]. Spanish parents also had significantly more concerns (mean = 1.2) than did white families (mean = 0.5) even after accounting for differences in children's [$F(1) = 45.974$ $p < .0001$]. A recent paper by Cox and colleagues at Harvard University[23] also found substantial differences in the concerns of Spanish- versus English-speaking families: Spanish-speaking parents were far more likely to have health concerns ($p < .001$) and also more likely to have behavioral concerns ($p < .002$).

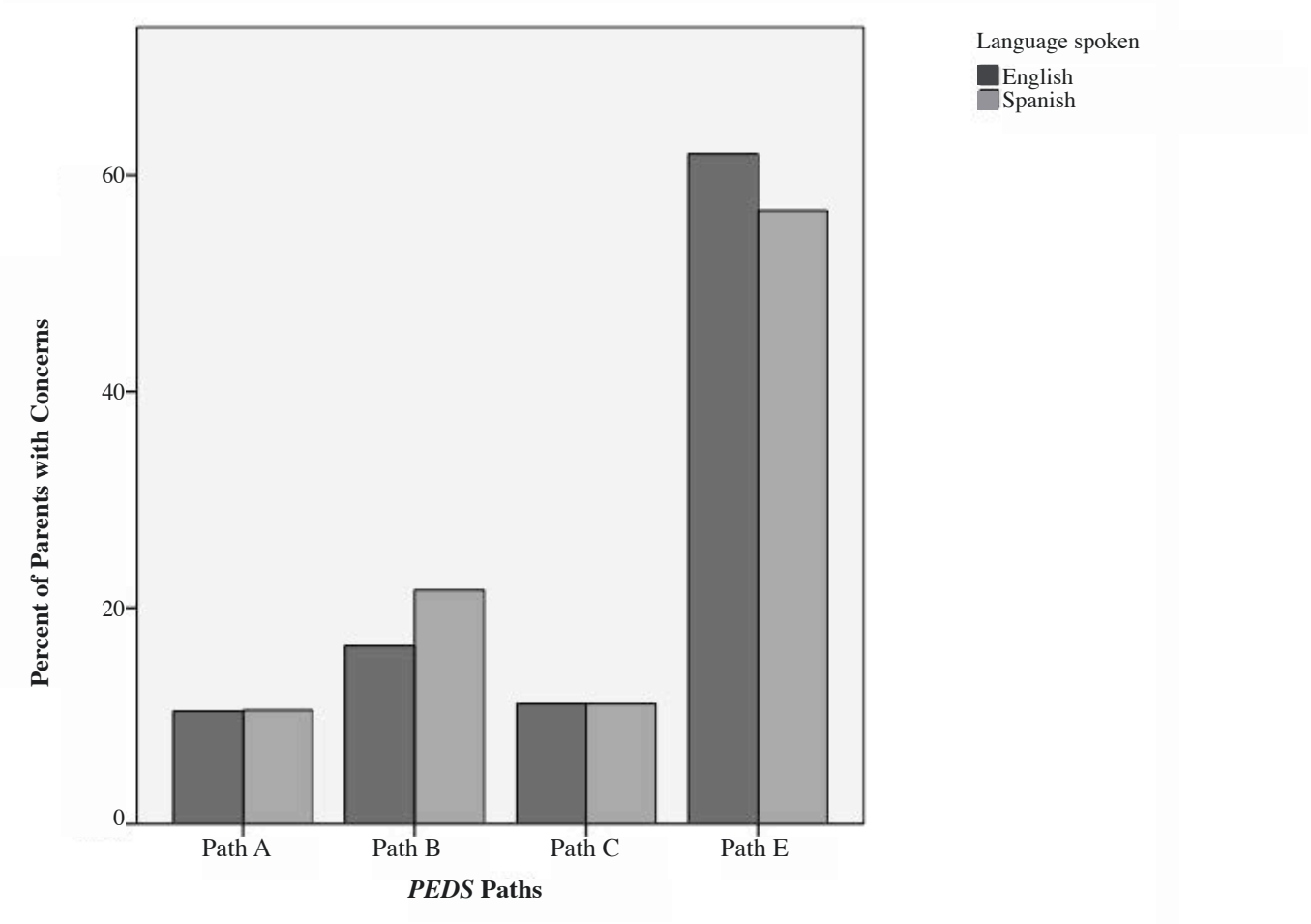
Figure 2-32. Frequencies of Concerns Between Spanish-speaking and English-speaking Families



Comparison of *PEDS* Paths between Spanish- and English-speakers

As shown in Figure 2-33, there were differences in frequencies on *PEDS* Paths between Spanish- and English-speaking families. Although equally likely to receive a Path A score as English-speaking families (10.5% versus 10.4%) or a Path C score (11% versus 11%), Spanish-speaking families were more likely to receive a Path B (moderate risk) score (22% versus 6%) and thus less likely to receive a Path E (low risk) score (57% versus 62%).

Figure 2-33. Comparison of *PEDS* Paths Between Spanish- and English-speaking Families



COMMENT ON PEDS IN SPANISH

The above results illustrate that PEDS is effective with Spanish-speaking families at eliciting their concerns and assigning risk levels to children. Given higher rates of psychosocial risk in Spanish-speaking families and association of risk with higher rates of parental concerns corroborates the effectiveness of PEDS in Spanish. This finding was also visible in a recent study comparing undocumented adults to those holding green cards or who were naturalized citizens.[24] As Ortega et al noted, "Mexican children with undocumented parents have greater parent-reported developmental risk than Mexican and white children whose parents are US citizens or otherwise legally documented. More research is needed to understand the roles of immigration stress and home environments on the developmental risks of children in households with undocumented parents."[24]

PEDS In Healthcare versus Educational Settings

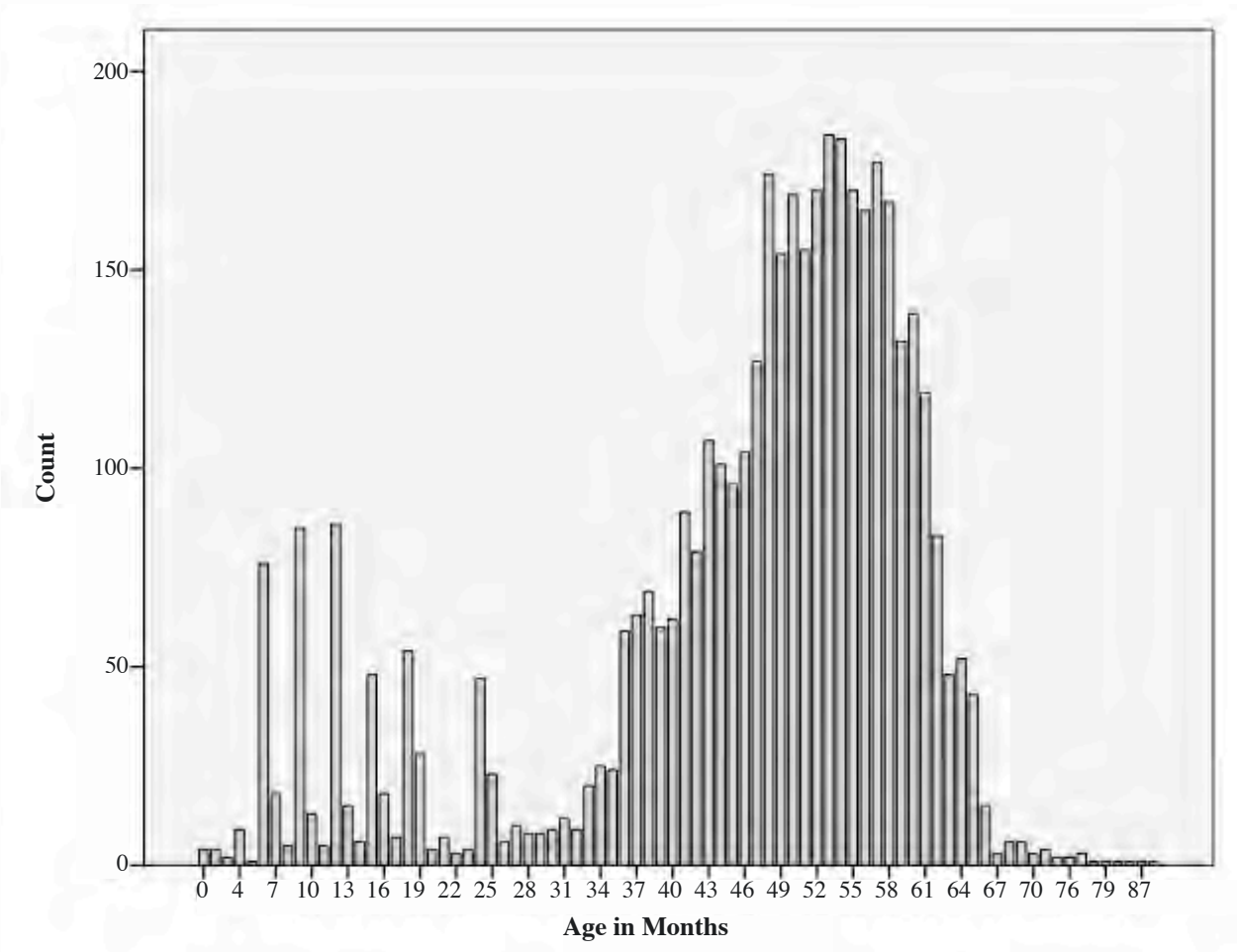
This section provides information on *PEDS* when used exclusively in healthcare versus educational settings. The goal is to help various types providers know what to expect across different types of services.

Education Settings: Ages and Poverty Rates

In the standardization sample, 4,253 children were administered *PEDS* in educational settings (9% of the total sample). Their mean age was 46 months. The remaining children, 43,057 were administered *PEDS* in healthcare settings (91% of the sample) and their mean age was 24 months. Age differences between the two groups were obviously significant. Children seen in educational settings were substantially poorer than primary care sites (28% poverty rates versus 20%) [$F(1) = 1170.24$, $p < .0001$].

Although the overall sample may simply reflect which types of clinicians chose to use *PEDS*, educational settings typically work with older children than do primary care settings. The specific education sites using *PEDS* were often focused on pre-kindergarten intake and to a lesser extent in Early Head Start/Head Start—which may also explain the preponderance of children seen between 4 to 6 years of age. Figure 2-34 shows the pattern of children's ages when seen in educational settings while Figure 2-35 shows the pattern of children's ages when seen in healthcare settings.

Figure 2-34. Children's Ages when Administered *PEDS* in Educational Settings

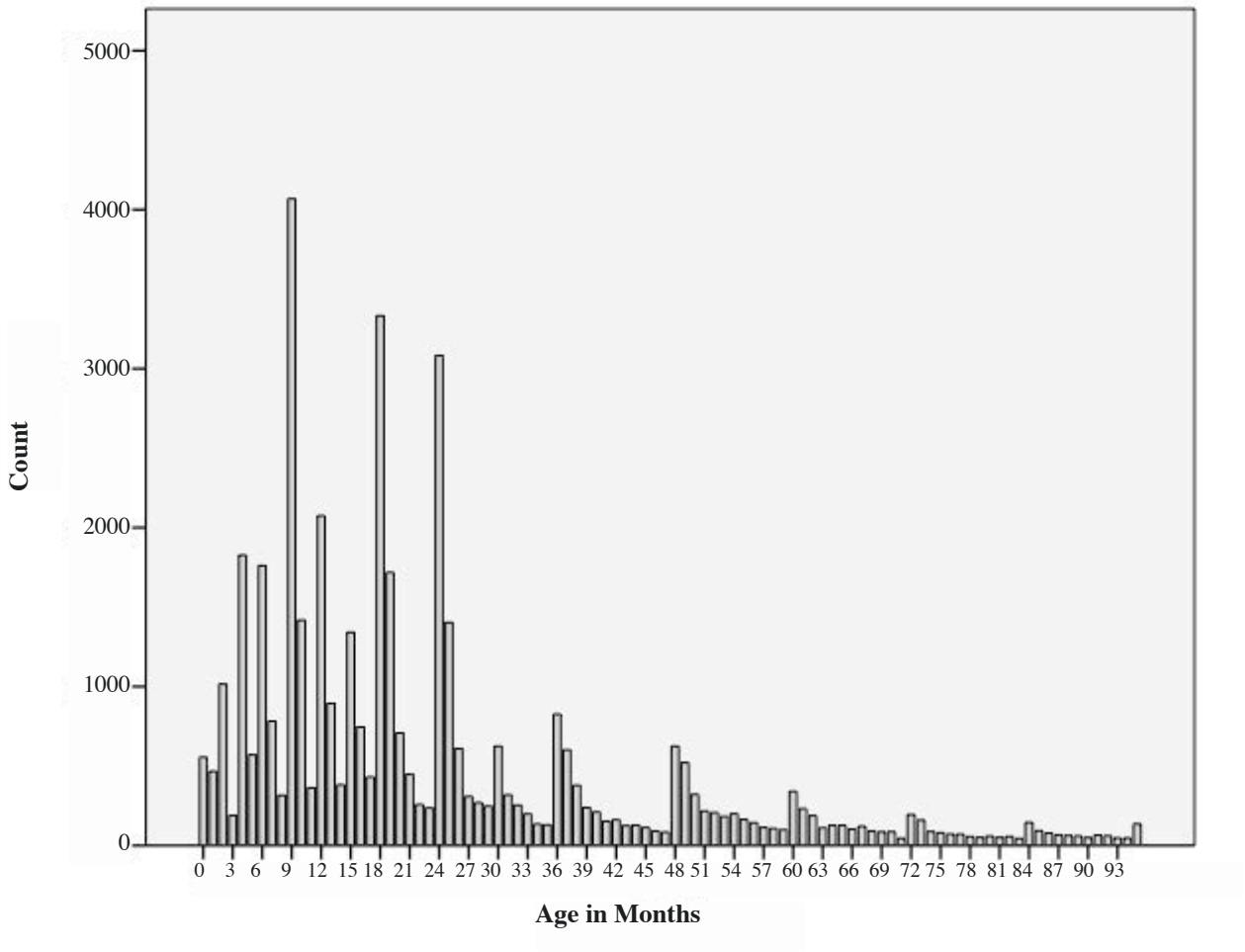


Primary Care: Ages of Children and poverty rates

Of the 43,057 families seen for consecutive health supervision visits where *PEDS* was administered, the mean age of children was 24 months, and the median age was 18 months. Seventy-five percent (75%) of children were less than 31 months of age and 90% were less than 4 ½ years of age. Families seen in primary care were less likely to have incomes at or below federal poverty levels than were parents seen in educational settings (20% versus 28% at education sites) [F(1) = 2876.88, p < .0001].

There were clearly spikes in well-visits attendance at the ages recommended by the American Academy of Pediatrics (as seen in Figure 2-35). But, as confirmed in this study and by prior research, attendance dwindles substantially after 9 months and begins to be virtually asymptotic after 36 months.[25]

Figure 2-35. Ages of Children Seen in Primary Care



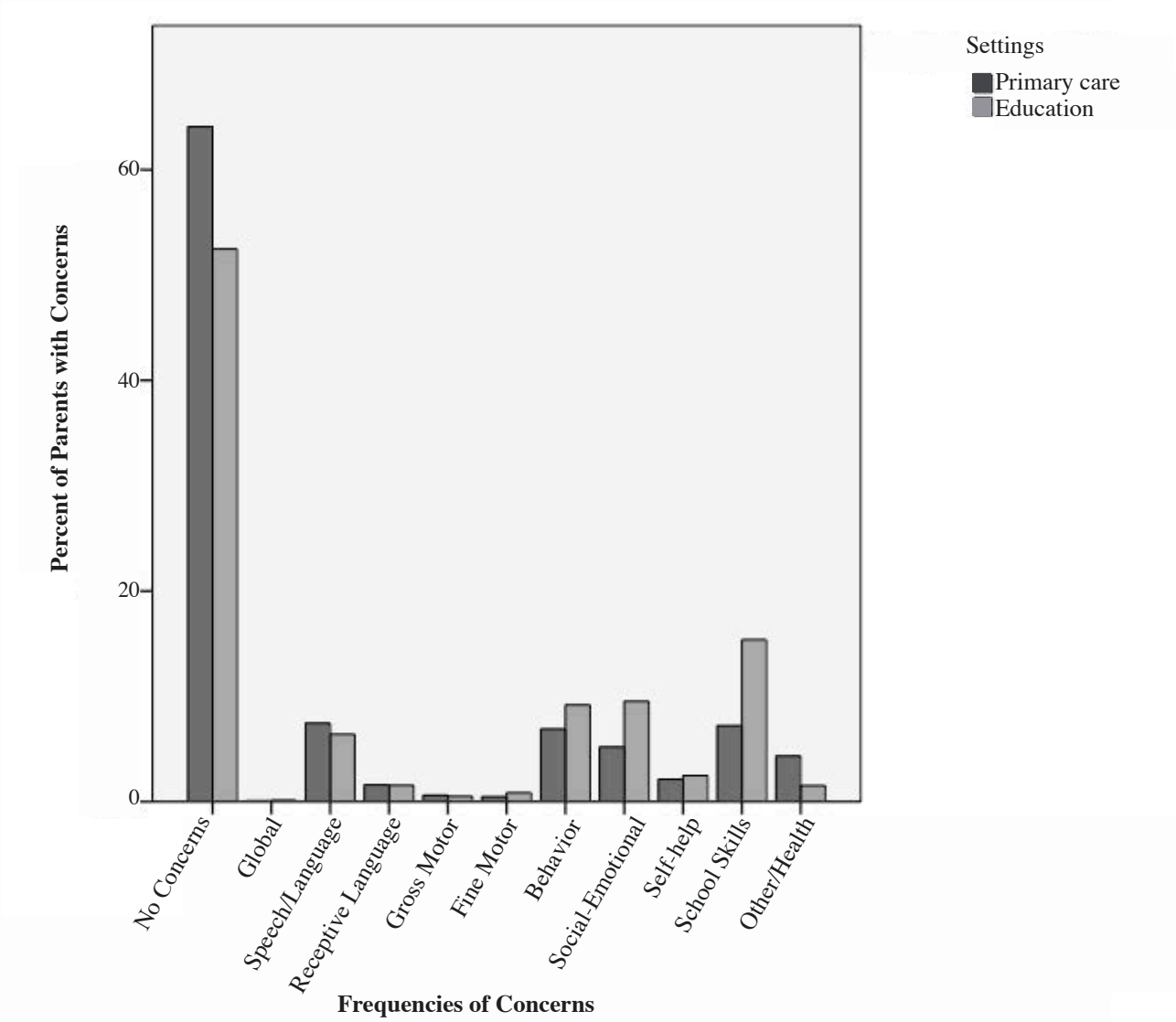
Comment on Age Differences between Primary Care and Education settings

In comparing sheer numbers screened in primary care versus educational services, it is clear that primary care sites worked with the majority of young children. Education settings, in constrast, see mostly older and poorer children but only a fraction of all children. But striking is the huge gap when preschoolers, in particular, don't encounter any professional who can detect and address problems. And this gap occurs in the age range where developmental problems are developing in readily measureable ways and when parents have increasing numbers of concerns. This finding may explain why early intervention enrollment rates are lower than they should be—children tend not to present to either educators or health care providers in the preschool years. That's quite problematic for the task of assuring that we intervene early and do our best to prevent school failure.

Types of concerns raised in primary care versus educational settings

To minimize the known influence of children's ages on parents' concerns, the following analyses focus on children 3 years and older seen in either primary care (N = 9,562) or educational settings (N = 3,550). In comparing groups (and after adusting via analysis of covariance for poverty, a factor that generally elevates the frequency of concerns) parents were less likely to raise concerns to healthcare providers than they were to educators (36% versus 48%) [$F(1) = 211.55$, $p < .0001$]. As shown in Figure 2-36, there were also differences in the types of concerns raised: Parents seen in healthcare settings raised concerns about behavior somewhat less often than in education sites (7% versus 9%) and were substantially less likely to raise concerns about social-emotional skills (5% versus 10%) and school skills (7% versus 15%). Parents raised other/health concerns more often to healthcare providers than to educators (4% versus 2%). The remaining types of concerns were comparable in frequency between settings.

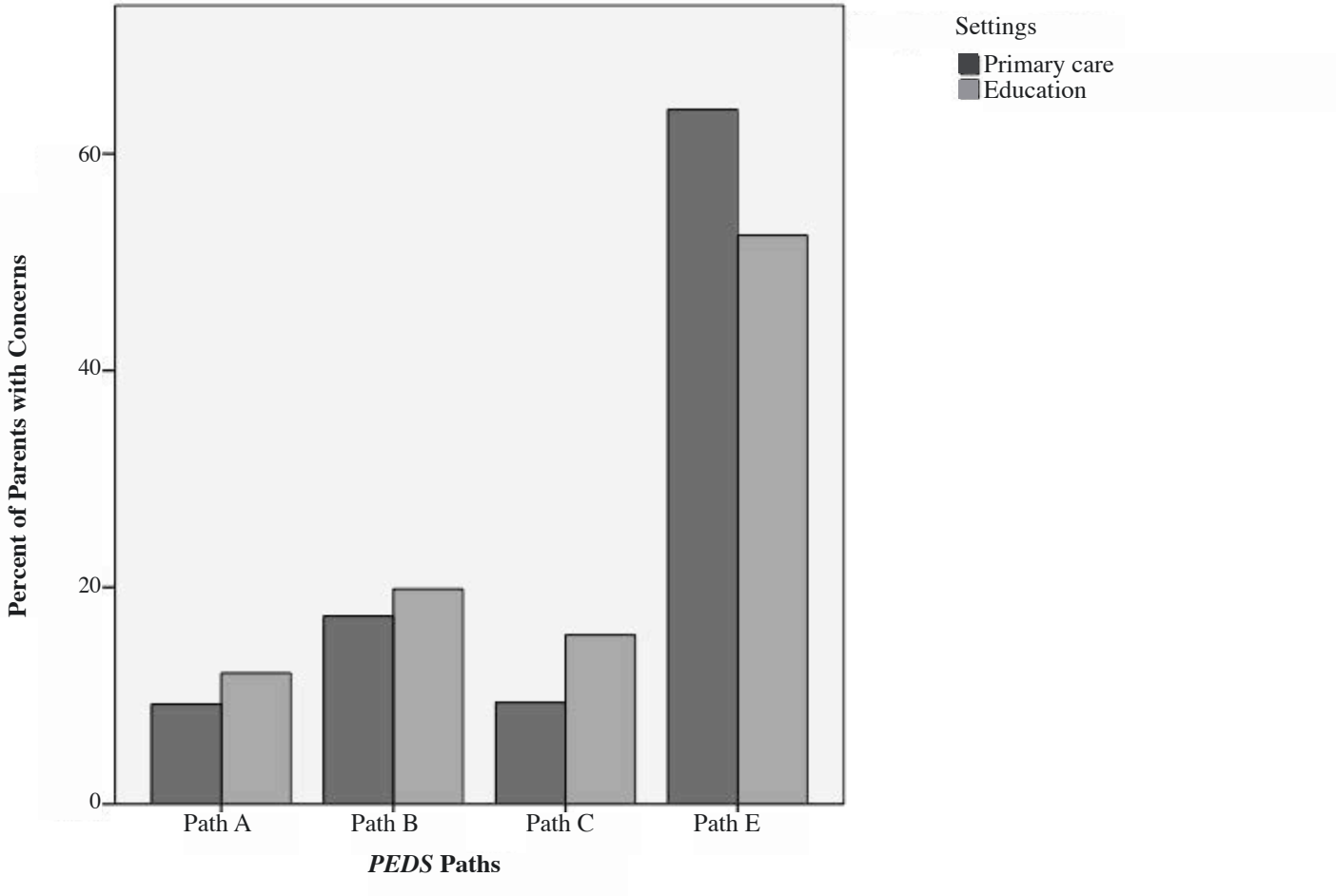
Figure 2-36. Frequencies of Concerns Raised by Parents of Children 3 Years and Older within Primary Care versus Educational Settings



Differences in Risk Levels on *PEDS* between primary care and education settings

Surely related to the differences in frequency and types of concerns raised in different settings (combined with differences in poverty levels), children were far more likely to receive high, moderate, or low-risk but concerned scores in education settings (Paths A, B, and C) [χ^2 (3) = 1.784, p < .0001], as shown in Figure 2-37. Parents administered *PEDS* in education settings received Path A (high risk) scores more often than in healthcare settings (12% versus 9%), received Path B (moderate risk scores) more often (20% versus 17%), or Path C scores (low risk but concerned with elevated risk for mental health problems in older children (16% versus 9%).

Figure 2-37. Comparison of *PEDS* Paths Between Primary Care and Educational Settings



Comment

At first glance, it might be reasonable to conclude that parents sometimes decline to talk with healthcare providers except about issues they consider relevant to providers' expertise, i.e., health issues. Although that may be the case, around 60% of children 3 years and older are engaged in day care or preschool (the latest available data on enrollment rates is from 2006 www.childtrendsdatabank.org, accessed August 2011). Thus many parents have, we hope, another professional to turn to for assistance with developmental-behavioral concerns.

Additional Information On *PEDS* in Primary Care

PEDS, well-visit uptake, and Improvements in Parenting Skills

Families attendance at well visits occurs in inverse proportion to the age of the child. Parents with psychosocial risk factors are even less likely than parents without psychsocial challenges to come for well-visits. The burdens of transportation, problems with child-care arrangements and other woes make getting to visits particularly difficult. But does the content of visits, and use *PEDS* in particular, encourage families to return for recommended visits? One study suggested it does: Blue Cross-Blue Shield of Tennessee manages much of Tennessee's Medicaid recepients and found that parents were 16% more likely to return for subsequent well-visits when *PEDS* was used.[26]

A 16% increase in well-visit attendance isn't exactly resounding but it is a definite improvement especially for families who are poor and whose children have higher risk levels. The finding implies that if we elicit and address parents' unique concerns, we make visits more relevant, more focused on issues of interest to families, and as a consequence, families with elevated psychosocial risk are more likely to come back.[26]

Even more exhilarating is the finding that when families' concerns are elicited and addressed, parents are more likely to engage in positive disciplinary practices (e.g., less likely to spank, more likely to praise and use 'time-out').[27] One researcher/clinician hypothesized that improved communication between parents and providers reduces parenting stress and promotes positive parenting because parents learn to view providers as helpful collaborators in child-rearing issues (*Dr. Franklin Trimm, personal communication, 2002*).

Meanwhile, there are deterrants to continued participation in well-visits. Needless to say, poverty is the big one. Not all families are aware of Medicaid and the States' Children's Health Insurance Program (S-CHIP). Immigrant families may be wary of enrolling, especially if they are illegal entrants to the US. Waxing and waning economic well-being in families is a challenge for those funded by Medicaid/S-CHIP. Parents who earn even temporarily just a few dollars above poverty limits are dismissed from coverage. The reapplication process is inordinately time-consuming and surely many families simply give up. The fact that families seen in education settings were substantially poorer than those seen in healthcare seems to speak to the economic challenges of paying for ongoing healthcare.

Another potential deterrent to the use of *PEDS* as an approach to encouraging families to come back for well-child visits is that some third party payers interpreted the American Academy of Pediatrics policy statement on early detection[14] that emphasized formal screening at 9, 18, 24, and 30 months, to mean that reimbursement for screening (and screening itself) is not needed with older children. In fact the AAP policy states that screening at these specific ages is intended to establish, "a pattern and practice of attention to development that can and should continue well beyond 3 years of age.[14 (p. 406)] Wise this is, because the older the child, the more likely there are to be developmental problems. The AAP is working hard to dispel the notion that we can stop screening at 24- 30 months, and is advocating with private payers, lobbying Congress, etc. More information on reimbursement issues and clinic-level advocacy is provided below.

How can primary care providers encourage parents to keep coming for annual well-visits—most especially those with older children and those with lower SES, Here are some suggestions:

(a) Consider an appointment reminder system: Automated calls are used heavily in family practice and internal medicine and are clearly effective at getting adults to come in for care. Such a system should work well in pediatric primary care.

(b) In the absence of automated call reminders, providers can mail appointment reminders and include a *PEDS* Response Form.

(c) Via text messaging or other reminder mechanisms, providers can direct parents to a clinic website with a link to *PEDS Online* (parents will not see results. Instead these are sent directly to the relevant clinic). A clinic website should also house links to provider approved websites for parenting issues. A number of quality resource links can be found at *www.pedstest.com.*

(d) Families in poverty will benefit from clinic level assistance in applying for and maintaining Medicaid/S-CHIP coverage.

(e) To circumvent literacy issues, providers should consider administering *PEDS* as an interview, to make sure parents have fully expressed their concerns.

(f) Providers should ensure they have the skills and resources need to fully address the concerns of parents with young children (e.g., how to find information handouts, referral services).

(g) Providers should make appointments for families requiring referral.

(h) Healthcare professionals should follow-up on parents' concerns (e.g., call them back in six or so weeks to see how recommended advice or services helped and whether other courses of action are needed.

(i) Providers also need encouragement including getting paid for what they do. The website for *PEDS Tools*, *www.pedstest.com*, includes current information on billing and coding for reimbursement.

Well-visit Appointment Length, Administration time and Implementation Issues

Clinicians who consider adopting *PEDS* (or any other screen) often balk at the mere thought of yet another procedure within already busy well-visits: At first glance, adding a screen to the work load would seem to just increase visit length—even while payors demand shorter visits and greater efficiency. That perception is understandable. But the reality is surprisingly different. Using *PEDS* actually shaves an average of 3 minutes off slated appointment time frames.[28,29] Why and how? Schonwald and colleagues at Harvard have used *PEDS* in print for many years, and speculated that the time-savings is due to a reduction in those odious "oh by the way" concerns that so disrupt and lengthen encounters.[28,29] This hypothsis makes sense because eliciting parents' concerns before the visit enables a better focus the visit on the issues at hand—even enabling clincians to walk into an encounter optimally prepared—with parenting information, referral suggestions, or prepardness to complete a second screen (e.g., *PEDS:Developmental Milestones* or M-CHAT).

PEDS in print takes 1 – 2 minutes to score (assuming parents have completed it on their own and otherwise 3 – 5 minutes to administer and score if an interview is needed). Still, that will leave clinicians with the additional and time-consuming need, in about 20% of cases, to locate referral resources, dictate a referral letter, and find ICD-9/10 and procedure codes for optimizing billing.

So what are the options for reducing the time clinicians spend on routine clerical tasks in favor of helping families with their concerns, i.e., using *PEDS* to focus encounters and effectively collaborate with families? Here are broad thoughts on efficient and efficacious implementation of *PEDS*:

1. If using *PEDS* in print, encourage parents to fill out the Response Form on their own [e.g., in waiting, exam rooms, or by mail (e.g., with an appointment reminder and/or a self-addressed stamped enveloped)];

2. If families have limited literacy (e.g., don't write anything on the *PEDS* Response) let office staff conduct *PEDS* by interview and also score (additional rationale for this recommendation is discussed below in the section on reimbursement);

3. Even if starting with written copies of the *PEDS* Response Forms it is wise to use *PEDS Online*. *PEDS Online* saves prodigious amounts of staff and clinician time because it provides scoring, generates referral letters, parent summary reports, and provides suggested ICD-9/10 and procedure codes when needed. *PEDS Online* also provides live links to parenting information and referral resources, and comes with photocopiable *PEDS* of the Response Form in all languages

4. Even more optimal is to use *PEDS Online's* parent portal (wherein parents can complete screens from home, their child's school, public library or via office computers) with results sent directly to providers (but are not visible to parents). More than 80% of empoverished families report internet access and so most will be able to complete measures online. [30]

PEDS and Reimbursement Issues

With appropriate billing and coding (and with efficient implementation methods, i.e., use of information from parents) validated screens garner quite reasonable reimbursement that more than covers practice expense and material costs—if not provide a profit for clinics. Through Medicaid, reimbursement averages about $8.00 per screen across States, with private payers often reimbursing at closer to $20 per screen. But there is no reimbursement, i.e., relative value units (RVUs) for provider time within Medicaid or private insurance. This means that most aspects of screening in primary care should become a staff function. Clinicians, in contrast, are expected to interpret results and address concerns as a part of the well-visit payment. So, engaging staff in the value of early detection and implementation of screening within clinics is needed. Because billing and coding (and the needed modifiers) is volatile, we house the *how-tos* on *www.pedstest.com*.

Survey PEDS

Survey PEDS is used in the Promoting Healthy Development Survey, National Survey of Children's Health, National Survey on Early Childhood Health (NSECH), California Health Interview Survey (CHIS), and the California First Five Survey. *Survey PEDS* eliminates all open-ended response options and instead uses 12 multiple choice questions (the two extra questions focus on vision, hearing, health and the global cognitive concerns, that would, if using clinical *PEDS*, be scored from parents' verbal comments).

Norming and scoring of *Survey PEDS* (in English only) was established by researchers who created the Promoting Healthy Developmental *Survey* (PHDS)[27] with advice from *PEDS* researchers. Survey *PEDS* studies appear on the research pages on *www.pedstest.com*.

These and other papers established *Survey PEDS* as a national evaluation method for capturing parents' satisfaction with and access to healthcare, whether parents' perceive providers as addressing their concerns, engaging in early detection, making referrals, etc.[31] In general, *Survey PEDS* functions as an effective needs assessment tool.

Issues with *Survey PEDS*

While helpful in population-focused needs assessment and public health mapping studies, *Survey PEDS* cannot be used in clinical care because it does not elicit parents' actual concerns. Parents' verbatim comments are essential for focusing an encounter, i.e., choosing parent education materials, creating a follow-up plan and a problem checklist, identifying the types of referrals needed, and managing visit length by reducing the ever problematic, "oh by the way" concerns.

Although rates of risk in *Survey PEDS* parallel those in clinical *PEDS*, it is well-established that parents don't always answer the question asked. Cox and colleagues found that 24% of the time, parents' answers did not match the intent of the question.[23] This means that in a closed-ended survey, we don't actually know what the parent is thinking and response errors can place a child on a lower risk path than he or she should be.

Existing research on *Survey PEDS* showed that Spanish speakers have suspiciously low rates of risk. *Survey PEDS* used a different translation than clinical *PEDS* ("le inquieta…" rather than "le preocupa…" and so translation problems seem explanatory—something PHDS/NSCH researchers are rectifying with assistance from *PEDS* researchers (*Stephen Blumberg, National Center for Health Statistics, CDC, personal communication, August, 2011*). *Survey PEDS* in Chinese is plagued by the same excessive rates of concerns found in the original Chinese translation of clinical *PEDS*. Hopefully, the new translation used in clinical *PEDS* will be adapted into *Survey PEDS*, along with trials of a modified English version using "worries" for families of Chinese descent who still seem overly worried given the shared meaning of "concerns" and "care".

Comment on Survey PEDS

Clinical PEDS is preferable to Survey PEDS, particularly when used via PEDS Online (in which parents actual comments are elicited but categorized correctly and with the thoroughly tested translations provided). Clinical PEDS has been used effectively in telephone surveys and using the 10 open-ended questions requires less than two minutes.[32] Use of PEDS Online renders richer and more accurate results, enabling a qualitative and quantitative view of parents' concerns and children's developmental-behavioral status.

International Studies on *PEDS*

There have been numerous studies of *PEDS* in other countries. A side-by-side comparison of *PEDS* in the US versus *PEDS* when used in other countries is not possible due to wide variations in sampling (e.g., differences in parents' levels of education, poverty rates, access to healthcare, let alone languages).

Many international studies began by determining feasibility (e.g., did parents or providers find *PEDS* useful? Was *PEDS* readable? How well could parents' complete it on their own? Did *PEDS* open channels of communication and enable providers to engage parents in services?). Because answers were uniformly positive, international researchers continued with norming studies. All international studies sampled the age ranges for which *PEDS* is normed and most compared results to the *PEDS* 2002 norming studies. Details on studies by nation/region are described below followed by a summary of findings and recommendations.

Middle East

Ongoing studies in Israel (with *PEDS* administered in Hebrew) and another focused on Palestinian refugees in Lebanon (with *PEDS* administered in Arabic), showed dramatically fewer parental concerns about children's behavior than is seen in the US (*data and personal communication from Lobel, 2011; Tan, 2007*). This phenomena makes sense given cultural differences, at least in certain parts of the Middle East, in child-rearing attitudes: Families in Israel and Lebanon seem quite tolerant of children behaving like children! And it isn't that parents didn't comment on behavioral issues such as attentional problems, hyperactivity, or temper tantrums. They did indeed, but were less likely than US families to note that they were concerned about such behavior.

But, the Middle East is hardly a uniform culture. Colleagues in Jordan, Saudi Arabia and elsewhere, provided us preliminary reports suggesting that behavioral issues were at least equal to those in the US. We continue to await additional information from different nations and will provide prompt updates on *www.pedstest.com* as we receive them.

Africa

East Africa

In Tanzania, parents had far more concerns than any other nation, i.e., 4 times the number of children receiving a high risk score on *PEDS* as compared to the original US norming study. The context of this study is important to note: Conducted in the midst of a malaria outbreak, parents were uniformly worried about their children's health and the potential impact of malaria on their development.[15]

South Africa

Both *PEDS*, *PEDS:Developmental Milestones (Assessment Level)* and the ASQ were administered in English to 133 graduates of the neonatal intensive care nursery when they were 6 months of age. Because this study did not report *PEDS* results apart from the combination of *PEDS* and *PEDS:DM* and because it is more of a validation study than a standardization study, this research is discussed in more detail in Chapter 4 (Validation). Nevertheless, *PEDS* in combination with the *PEDS:DM* was found to be more effective in identifying communication delays than was the ASQ although both sets of tools were equally likely to identify overall delays.

Asia, India, and the South Pacific

Thailand

In Thailand, *PEDS* was used with 216 0 – 72 month-old children seen in outpatient hospital clinics. The frequencies of *PEDS* Paths were not reported (only the abstract was written in English) but the authors commented, *"….significant concerns of parents about their children's development are the* [source of] *critical information for referral* [and, sic...] *further management. In other words, parents concerns could have far more advantage than the (Denver-II)."*[33] This means that researchers found parents' verbatim comments clinically useful; more so than a simple pass/fail score. Studies in Thailand are ongoing for both *PEDS* and the *PEDS:DM*.

Taiwan and Indonesia

In Taiwan and in Indonesia, *PEDS* was validated against diagnostic measures. Specific categories of concerns were not reported except within a comment that behavioral concerns were the most frequent (and least predictive) of concurrent test results consistent with US studies.[34,35] This paper is discussed in detail in Chapter 5: *PEDS* Accuracy.

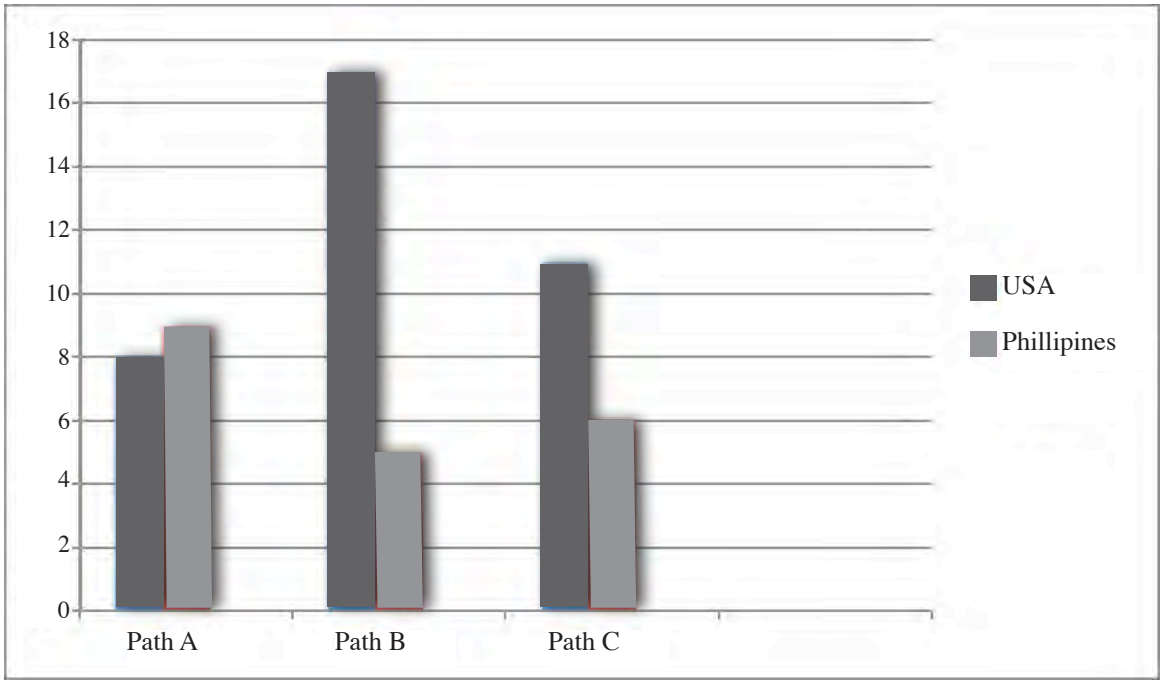
Singapore

A study in Singapore conducted in 2002, provided translations for *PEDS* in two different languages and then compared rates on *PEDS* paths when administered in Malay (N=569), English (N = 864), and Chinese (N = 383). Children of Malay-speaking parents were somewhat less likely to receive a Path A (high risk) score on *PEDS* (18% versus 29%), and more likely to receive a Path B (moderate risk score (13% versus 8%) or a Path C score (11% versus 8%). Overall Malay speaking parents had fewer concerns (58% versus 54%). When Malay and English speaking parents were compared to Chinese-speaking parents, the latter had marked performance differences, i.e., 86% received Path A scores). This study is described in detail by King et al[20] who argue that "culture matters". This is irrefutable, but quality "translations matter" too. So by changing the Chinese translation to use a word more synonymous with "worries" than "concerns" (which can be interpreted as "care"), rates on *PEDS* Paths became equivalent across language backgrounds.

Phillipines

Using translations into Visayan, researchers from the Phillipine Society for Developmental-Behavioral Pediatrics, trialed *PEDS* on 421 children to determine detection rates (and the effectiveness of translations). Despite similarity in Path A rates, children were somewhat younger in the US subsample (which was selected to reflect the same age range as the Phillipine sample: mean age 44 months in the US versus 50 months in the Phillipines). Proportional sampling would have been more optimal, because mean age differences may explain the differences especially in Path B (more common in younger versus older children). In contrast, Path C may reflect cultural differences in child-rearing practices, greater tolerance for children's behavior, and differences in curricular demands once children enter school. In any case, the findings suggest that risk rates on *PEDS* likely differ across nations and that separate standardization is needed. Even so, Phillipine studies found similar trajectories as US studies across age ranges: The older the child, the more frequent were parental concerns, and as with US studies, behavioral issues rise dramatically at 2 years of age and older.

Figure 2-38. Comparison of *PEDS* Paths Between the Phillipines and the US for Parents who Raised Concerns



India

In India, a study of *PEDS* was conducted with children (N = 79, age range 24 – 60 months) receiving outpatient care in tertiary hospital out-patient clinics. Parental concerns were abundant, surely as a consequence of sampling an at-risk population and one that was generally older (and probably more likely to have health problems) than in the 2012 US sample. In some ways, frequencies of concerns found in India's sample paralled percentages found in the US (2002 study), but with higher rates of each: Behavior concerns were the most common (40% in India versus 32% in the US), followed by social emotional concerns (22% versus 19%), and global/cognitive (6% versus 4%). In other ways, the two samples differed substantially: Parents in India had much higher rates of health concerns (17% India versus 5% US) while US parents were more likely to have expressive language language concerns (18% India versus 24% US).[36] Again, unique standardization seems needed.

Europe

There are numerous but still ongoing studies in various European nations (e.g., The Netherlands, Iceland, Germany, Portugal, etc.). Results will be reported on *www.pedstest.com* when studies are completed. Completed and ongoing studies and reports include:

Galicia, Spain

Researchers in Galicia, Spain published a study of 6 – 24-month-olds attending Galician pre-primary schools (N = 1089) whose parents completed *PEDS*. Information about parents' levels of education or poverty were not described in the paper making it difficult to compare results with the US sample (2002). Galician families received Path A scores less often than US parents (8% versus 11%), Path B (22% versus 23%), Path C (22% versus 20%), Path D (the path designated when hand-scoring *PEDS* for parents who had difficulty completing forms on their own, had mental health problems, etc.) was 1% versus 3%, and Path E (46% versus 43%).[37] *PEDS* Paths in the Galicia study followed the general trajectory of US findings (using the more age-comparable 2002 sample) but at slightly lower rates.

Iceland

Studies in Iceland are ongoing but positive enough to have included *PEDS* in the national healthcare electronic record. Both *PEDS* and the Brigance

Screens were translated into Icelandic and adapted for the culture (e.g., on the Brigance, images of people, stoves, refrigerators and milk cartons all needed to be adapted to ensure familiarity to Icelandic children. And, because there are no snakes in Iceland, we included "worms" as a correct response for the snakes vocabularly question). Updates on the Icelandic experience will be added to the research pages on *www.pedstest.com*.

Great Britain

Many studies in the National Health Service of Great Britain are in progress. One completed study was conducted within England's Sure Start (a program serving children at risk and much like Head Start in the US). Subjects were 1615 parents of children between 22 and 27 months of age. High rates of poverty probably explain some of the differences in the British sample as compared to the US (2002): Path A (7% versus 5%), Path B (17% versus 17%), Path C (18% versus 10%) and Path E (58% versus 68%). [Data from the National Evaluation of the Sure Start Programme, *www.sphsu.mrc.ac.uk/research-programmes/mh/ness/*].

The Milton-Keynes Public Health Trust in England has used *PEDS* for almost a decade: Health visitors administer the measure by interview in families' homes and return to administer an assessment level battery when screening suggests a problem. The pilot study found *PEDS* beneficial in identifying developmental-behavioral problems, in promoting communication between parents and providers, parental and provider satisfaction with care, and in establishing a clear pathway of follow-up care.[38] Preliminary results from an ongoing study of 76 two-year-old children at risk for developmental-behavioral problems found 26 (34%) to be high risk on *PEDS* as well as on the Schedule of Growing Skills (SOGS) a lengthy assessment level measure. Interesting were the findings that 22 of the 26 had been tested with the SOGS at 1 year of age and found to be typically developing, but *PEDS* identified at 1 year of age many of these children as high or moderate risk.

Australia

Victoria

Australian researchers have conducted numerous studies on *PEDS*. In a study based in day care center[10] 262 families participated whose children were between 18 months and 69 months of age. Results were compared to the 2002 *PEDS* standardization study. Overall, Australian families were less likely to have any type of concern than were US families (48% versus 43%) and thus less likely to score on any of the elevated risk Paths than were Americans: Path A (High Risk) (9% Australia, 11% US), Path B (moderate risk) (19% Australia and 23% US); Path C (low risk), concerned with subsequent risk for mental health problems (24% Australia versus 20% US) and Path E (low risk), no concerns (48% Australia versus 43% US). Types of concerns were lower for expressive language (21% versus 24%, receptive language (6% versus 8%), gross motor 5% versus 8%) school skills 9% versus 12%) and other/health (3% versus 5%). Rates were similar for global/cognitive and fine motor, Australian families had slightly more concerns about behavior (34% versus 32%), social-emotional (21% versus 19%) and self-help (11% versus 19%).

The study also had day care teachers complete *PEDS*. Teachers were less likely to have concerns in any area than were Australian parents. *PEDS* has not been normed soley on teacher or provider report (but rather on a combination of the two) but it seems predicatible that children, even those with deficits, behave better and demonstrate a larger complement of skills when surrounded by appropriate role models.

A replication study in another Victorian city, Wondonga (N = 246) found similar performance patterns, i.e., fewer concerns among Australian than American parents. The researchers also studied age differences in parents' concerns, and although rates of concerns are lower than in the US, the patterns are similar: Concern regarding expressive language and behavior increased with the age of the child. Expressive language concerns increased with age and peaked between 18 months up to 3 years, with 32.7% of parents reporting concerns. Expressive language concerns then decreased slowly with the increase in age of the child with 23.2% of parents reporting concerns with children ≥ 4.5 years of age. The Chi-Square Test for Independence revealed a significant difference in parent reported concerns for expressive language between age groups (p= 0.003).

Behavioral concerns also increased with the age of the child and peaked with 34.1% of parents reporting concern with children ≥ 4.5 years of age. There was a significant difference in parent reported concerns for behavior between younger versus older age groups (p=0.023).[39]

Western Australia and Queensland

Australia's Aboriginal Health Service and its researchers, especially in Western Australia and Queensland, used *PEDS* (and other screens) in various communities, many of them rural. A summary of these studies is presented below:

Cultural and language challenges abound: More than 100 different indigenous languages exist and unlike similar populations in North America, only about three are written down. Many indigenous families speak a combination of languages. The culture embraces the notion that "it takes a village" to raise a child and so aunts, uncles, and grandparents play a major role in child-rearing. At the same time, "kids rule", meaning that concerns about children's behavior are less frequent than in the US, and… if children don't want to go to school, their refusal is acceptable. As a consequence, many children are ill-prepared for curricular demands (which may explain high rates of absenteeism as children face academic challenges). In turn, this leads to limited high school graduation rates and high rates of poverty. Health problems in adults are legion and seem to stem from intolerance of a western style diet (high in sugar and refined flour). Adults in indigenous communities still fear the history of the "Lost Generation" in which children were forcibly removed from their homes and thus lost knowledge of their culture. Thus providers must gain the confidence of families of Aboriginal descent. When rapport is established, parents are more likely to express concerns. The word "concerns", prominent in *PEDS*, may be a challenge and studies are needed to determine whether "concerns" should be replaced with the more common Australian word, "worries" (as often heard in the phrase, "No worries").

Establishing an effective screening tool inevitably leads to advocacy for early prevention services (e.g., an equivalent to the US Early Head Start and Head Start programs). Most young indigenous children fail screening tests such as the *PEDS:DM* or Brigance Screens. Community-wide intervention is clearly needed to ensure promotion of early development, and thus early detection leads to increased likelihood of school success (Aboriginal Health Service (*www.aboriginal.health.wa.gov.au*).

Canada

Via Toronto's Department of Public Health (Ontario), randomized telephone dialing was used to identify families with children in the appropriate age range and then administer *PEDS* via interview (in English). Children (N = 221) ranged in age from birth to 6 years. Perhaps because families weren't seeking services (or because healthcare services are more readily available) rates on the elevated risk *PEDS* paths were lower than in the US: Path A (9% versus 11%), Path B (21% versus 23%), Path C (10% versus 20%) and Path E (61% versus 43%).[32]

In a separate study in Calgary (Alberta), parents were followed over time (when their children were 6, 12 and 18 months). In this study, parents were more likely to be educated (82% held college degrees and beyond versus 26% in the US). Parents in Calgary were less likely to be poor (5% in Calgary versus 24% in the US), and were equally likely to be depressed (5% - 8% in Calgary versus 5.4% - 9% in the US (*http://www.cdc.gov/prams/ppd.htm*).

Six-month-olds (N = 372) were more likely than US children (N = 1837) to receive a Path A score (4% versus 1%), a Path B Score (15% verus 6%), a Path C score (16% versus 6%) and less likely to receive a Path E score (66% versus 87%). At 12 months, children in Calgary (N = 334), were still more likely than those in the US (N = 2159) to receive a Path A score (5% versus 1%), Path B score (15% versus 11%), Path C score (14% versus 8%) and less likely to receive a Path E Score (66% versus 80%). At 18 months Candian children (N = 327), were marginally more likely than US children (N = 3376) to have Path A scores (4% versus 3%), but still more likely to have Path B scores (22% versus 17%), Path C (11% versus 8%) and continued to be less likely to have Path E scores (63% versus 72%). (Calgary data courtesy of Leew et al.)[40] These comparisons illustrate that highly educated parents tend to have more concerns in Canada than in the US.

Ongoing Studies In Other Nations

There are ongoing studies in Haiti, Fiji, Portugal,

Brazil, Hungary, Turkey and many other nations. Updates will be found on *www.pedstest.com*.

It is tempting to think that in nations with universal healthcare, there might be lower rates of parental concerns—given better access to professionals who can provide guidance on child-rearing [apart from samples where families are in extreme poverty (e.g., Australia's First Nation, England's Sure Start) or almost exclusively college educated, i.e., the worried well (Calgary)].[40] That may be, but this still remains an hypothesis requiring further research with samples matched across nations on critical variables such as parents' level of education, poverty rates, and children's ages. Nevertheless, it is clear that when parents face psychosocial risks including health challenges, concerns about their children tend to rise substantially wherever in the world they reside.

Summary of International Studies and Recommendations for Clinicians and Researchers

Availability of early education programs varies substantially within and across nations. Rural and impoverished children may have limited access to preschool programs and so will perform less well on milestones-type screens. Because early school services may be less available and unprepared children less likely to confront difficulties in preschool, parents may well have fewer concerns about developmental domains associated with school success (e.g., language, fine motor, school performance). Such parents may focus instead on how well children meet other life tasks (e.g., self-help, social-emotional development).

Overall, researchers should expect (once translations have been thoroughly tested) differences in the types and frequencies of concerns on *PEDS* when used in other cultures. Cultural norms matter (e.g., as seen in the paucity of behavioral concerns in Israel and Lebanon). Curricular demands and their universality matter too. For example, in Portugal, children are taught to read when they start 1st grade, whereas in the US, 6-year-olds are expected to have a substantial sight-word vocabulary and knowledge of all letter sounds before starting 1st grade. Thus parents in other nations may have fewer concerns about school skills prior to age six than they might in the America. Culture matters (and quality translations do too), but the need for unique standardization in each nation is clear.

COMMENT ON SERVICE AVAILABILITY ACROSS NATIONS

Challenges in finding services even when available seems to be world-wide even in "developed nations":

(a) The US is fortunate to have, under the Individuals with Disabilities Act (IDEA), something of a "one-stop shop", i.e., a toll free number for each State for early intervention and follow-up evaluations. For older children, special education directors in the school of zone are identifiable and accessible. Nevertheless, IDEA across States does not always provide monitoring services for children at risk (e.g., false positives on screens but high likelihood of future academic problems due to elevated psychosocial risk factors) is not uniform. Some States' IDEA programs are prohibited from referring non-qualifying children to private services (e.g., quality day care/preschool or private therapies). Head Start and Early Head Start are widely available but not for those above federal poverty levels—meaning that many low-income children cannot attend. This leaves providers needing abundant knowledge of local service options.

(b) Canada, in contrast, has many services (varying, as in the US, by province/State), but Canada lacks an "umbrella", meaning that providers are much challenged when making referrals given the absence of a single toll-free number to identify services (a province-by-province directory of programs sounds much needed);

(c) Australia has universal screening at four years of age and is slated to soon begin three-year-old screening as well. Australia has family resource programs devoted to parent-training but there are challenges)similar to Canada's in terms of finding resources) due to the lack a universal early intervention program.

(d) Great Britain has relatively easy access to services (via local and regional council websites) but its Sure Start program has faced budget cuts and loss of services [for which parents are currently suing their funding source, the Exchequer (the US's IRS equivalent)]. But in contrast with the IRS, the Exchequier directly funds Sure Start and has, until recent economic down-turns, ensured a stable source of funding in a way that the US does not do for Head Start).

(e) In developing nations, some early detection initiatives foundered due to a dearth of early intervention/prevention services. Neverthless, application of screening tools in such nations can at least serve as needs assessment and a viable foundation for service advocacy.

Comparison of the 2002 Versus the 2013 Standardization Studies

The 2013 sample is substantially younger than the 2002 study. The 2002 study included children with a mean age of 46 months, while children in the 2013 study had a mean age of 26 months. Because younger children have lower risk for developmental-behavioral problems, a sample comparable to the 2002 study was created from the 2013 study sample (N = 20,408, mean age 45 months) in order to view similarities and differences across the two standardization studies:

(a) In the 2013 subsample 1 out of 8 children (12%) were at high risk for developmental-behavioral problems (Path A). This is slightly but not significantly lower than the 1 out of 10 (10%) found to be at risk in the 2002 sample.

(b) In the 2013 subsample, 18% of children were at moderate risk (Path B). This rate is slightly but not significantly lower than the 2002 sample where 23% were at moderate risk.

(c) In the 2013 subsample, 11% scored on Path C (low risk but concerned, and with increased likelihood of mental health problems after 4 ½ years of age). In contrast the 2002 sample revealed that 20% of children landed on Path C. These differences are significant but hopefully reflect increased attention on the part of providers to parents' behavioral and social-emotional worries. Other factors at play may be improvements in parents' access to children-rearing information (e.g., via internet sites such as *www.kidshealth.com*), or diminution in family size (which should enable parents to better attend, in positive ways, to children's behavior and social-emotional development—a process known to reduce problematic behavior).

(d) In the 2013 subsample, 63% of families had no concerns. This contrasts significantly with the 2002 sample in which only 43% lacked concerns. Initiatives such as the American Academy of Pediatrics' Bright Futures initiative may have encouraged providers to carefully address concerns raised in earlier years—resulting in fewer concerns the older the child. Programs such as Reach Out and Read (*www.reachoutandread.org*) provide brief and effective intervention in primary care and so may reduce the frequency of developmental problems.

Hypotheses for Future Research

The comparative analysis (above) showing changes in the frequency and types of concerns parents raise, provides several hypotheses worthy of future investigation:

1. If providers using *PEDS* are better able to vigilantly and promptly address parents' concerns, do the children they serve have fewer problems in the long-run?

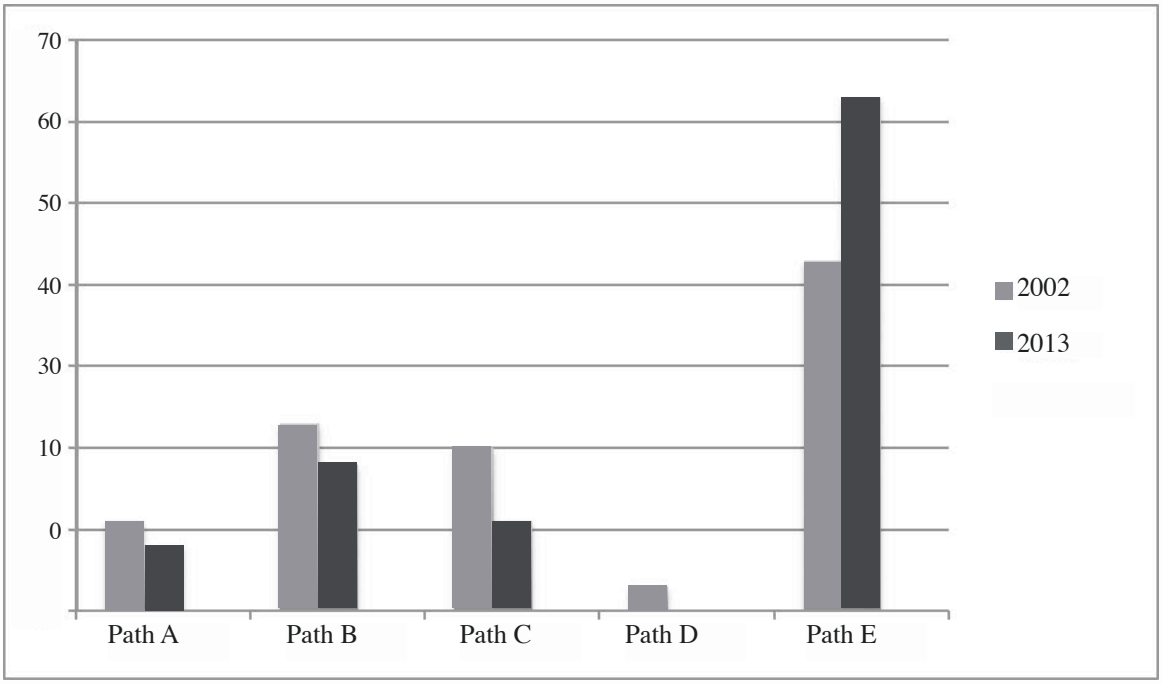
2. If providers encourage parents to independently seek information on child-rearing, does this reduce behavioral and social-emotional challenges?

3.If providers refer promptly when problems are present and get families to needed services, how much does this reduce the liklihood of long-term problems?

4. Is there a combination of the above, that leads to fewer problems?

5. Are providers who opt to use *PEDS* more willing than other providers to offer parenting advice and/or refer children for services when indicated? Do their patients and families have better outcomes as a consequence?

Figure 2-39. Comparison of *PEDS* Paths Between 2002 and 2013*



*Not rendered by *PEDS ONLINE*

COMMENT ON COMPARISONS BETWEEN STANDARDIZATION STUDIES

Early intervention takes many forms and includes, not only programs under the Individuals with Disabilities Education Act but also quality day care, preschool, Head Start, parent training, and parenting advice. Given what we know about early intervention's effectiveness, it makes sense that any form of swift attention to the various problems parents raise should have a positive impact on developmental-behavioral outcomes. Researchers are encouraged to study the above questions and whether there are long-term differences in children's outcomes in settings where PEDS is used.

Summary of *PEDS* 2013 psychometric data

Standardization Summary

- *PEDS* was restandardized in 2012 on a nationally representative sample of 47,531 families in 16 US states and Canada, representing the major geographic regions of the US.
- Sites included rural and urban/suburban areas in proportion to prevalence.
- Parents' levels of education were similar to US Census Bureau 2010 indicators (e.g., 16% had not completed high school while 28% had completed college).
- Ethnicities were represented at percentages between US Census Bureau indicators for 2010 and projections for 2020, and included white (not Hispanic), black, American Indian, Asian, Hawaiian/Pacific Islander, Hispanic, etc.
- Six percent of families were administered *PEDS* in Spanish (in keeping with Census Bureau indicators for those not speaking English well).
- Children's gender and poverty rates also matched Census information.
- Children ranged in age from 0 – 11 months (20%, N = 13,523) to 8 years (2%, N = 913), i.e., a much younger sample than in *PEDS* original norming studies.
- 91% of children and families participated in general pediatric clinics with the remainder participating from public schools (kindergarten intake), day care/preschool programs, developmental-behavioral pediatric clinics, and non-emergent crisis call centers.
- The frequency of parents' concerns and risk on *PEDS* rises, as expected, with children's age, and with psychosocial risk factors. Hispanics and blacks were more likely to have concerns as well as higher risk *PEDS'* paths.
- Educated families are more likely to receive Path C scores (i.e., to be the "worried well" in need of professional advice).
- Native Americans were more likely to have social-emotional and behavioral concerns as compared to other ethnicities, probably in keeping with the tribal custom of respect for elders.
- *PEDS* has been translated into 21 languages and standardized separately in many other nations and languages. In many international studies, different constellations of concerns and thus assignation of *PEDS* Paths have been established. For example, self-help concerns are of greater concerns to parents and also more predictive of overall problems than in the US.
- *Survey PEDS* (used in the National Survey of Child Health, First Five California, the Promoting Healthy Development Survey, etc.) depends only on 12 closed-ended questions and is scored from "yes", "no", or "a little" responses. Results are problematic (due to poor quality translations but also due to the fact that 24% to 32% of families across clinical *PEDS* do not answer the questions according to their intended content). Although risk rates on *Survey PEDS* are similar to clinical *PEDS*, assignation to *PEDS* Paths is strikingly different. As a consequence *Survey PEDS* may not be used for clinical care with individual children.

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Chapter III
The Reliability of PEDS

Critical Concepts in Screening and Test Construction Reliability

- TEST-RETEST reliability illustrates that virtually identical results are obtained if the measure is re-administered to the same subject after a short interval (e.g., if *PEDS* is administered several days to several weeks later to the same parent, do they still have the same concerns?).One to two weeks is the typical time frame.
- INTER-RATER or INTER-EXAMINER reliability tells whether the same score is obtained if two different examiners administer the test to the same child/families (e.g., if parents are interviewed by different examiners within a short time frame; whether two different examiners come up with the same results). One to two weeks is the typical time frame.
- STABILITY demonstrates that scores are consistent over long intervals (e.g., 3 months to 6 years). Standards for stability coefficients are not well established (which is understandable given the rapid changes in young children's skills). But significant correlations between performance at Time 1 and Time 2 suggest that measures tap enduring issues in probable need of attention.
- INTERNAL CONSISTENCY demonstrates that related items "hang together" and consistently measure the same domain. For example, if motor items are highly correlated with language items, directions for motor tasks may demand too much receptive language and thus penalize a child with good motor ability but poor language comprehension. Internal consistency also shows which items are so highly correlated with other items that duplication is present and thus item(s) can be safely removed. High correlations among unrelated tasks are problematic. Low correlations across domains are desirable—with consideration for the fact that subdomains (e.g., fine motor and gross motor, versus expressive language and receptive language) likely share variance. Internal consistency analyses also illustrate routine and thus predictable measurement error.
- FIDELITY addresses whether parents' or children's responses match the intended content of questions (e.g., in the case of *PEDS*, how well do parents' comments match the question asked). Fidelity studies also address how well clinicians deploy a measure according to test instructions.

Original Reliability Studies (1997-2002)

Test-Retest Reliability

In order to assess whether parents' concerns have stability over time, 20% of parents in the *PEDS*' pilot studies (N = 100) were re-interviewed by a second examiner two weeks later. Because the original interviews had been conducted during general pediatric encounters, i.e., well-child or return visits, it was not feasible to have parents return to the clinic for an interview. Instead, parents were contacted by telephone and re-interviewed by the original interviewer. Even though the research setting was altered, parents' concerns remained highly consistent. Again agreement ranged from 80% to 100% with an average of 88%. The findings illustrate that performance on *PEDS* is consistent across readministration by the same examiner, despite changes in settings, i.e., face-to-face versus telephone interview.

Inter-rater Reliability (Elicitation of Concerns)

How consistent is performance on *PEDS* when administered across a short time frame by two different interviewers, i.e., do different examiners obtain the same results? This question was assessed by having a different examiner re-interview 20% of parents (of the 200 participating in the pilot studies) and then comparing results from the two interviews. Although it would have been more desirable to re-interview parents on the same day, this assessment was conducted two weeks later and over the telephone instead of face-to-face. Nevertheless, agreement ranged from 80% to 100% and produced an average of 88%. This shows that parents comments on *PEDS* can be reliably elicited by different examiners (in different settings, i.e., face-to-face versus over the telephone).

Inter-rater Reliability (Categorization of Concerns)

Do different examiners agree on categorization of concerns? To assess this, 20% of the protocols from the first 100 parents participating in the pilot studies of *PEDS*, were submitted to a second researcher along with a list of developmental domains.[1] Each examiner was blinded to the other categorized comments. Agreement ranged from 80% to 100% across categories, with an average of 95%. This illustrates that different examiners can reliably categorize parents' comments on *PEDS*.

Internal Consistency (Relationships Among Items)

Do responses to *PEDS* questions measure unique dimensions of development? In the following studies, the internal consistency of *PEDS* was viewed for each category of comments based on responses to the open-ended questions. Next responses on the probe or closed-ended questions were compared with responses to the open-ended questions. For these analyses, the other/health category was subdivided into medical concerns versus other concerns (meaning non-medical issues—typical family challenges such as divorce, domestic violence, homelessness, etc.). Table 3-1 shows the relationship among categories based on actual comments. Table 3-2 shows inter-correlations between combined responses (both open-and closed-ended questions) for each kind of concern. The patterns of inter-correlations reveal desired trends. Most concerns have a limited relationship with the other concerns. Those concerns that are correlated share legitimate and logical overlap (e.g., fine and gross motor skills; self-help and motor skills; expressive and receptive language skills, etc.). The results suggests that each *PEDS* item is essential for assessing the range of parental concerns and that none are redundant or could be eliminated without decreasing the overall value of the measure.

Internal Consistency Across Items

Coefficient alpha was then produced for *PEDS* items as a whole. Coefficient alpha reflects the extent to which a measure samples a homogenous versus heterogeneous construct. The alpha produced by *PEDS* was moderately high ($\alpha = .81$). This suggests that parents' responses to each item make unique contributions to *PEDS* results as a whole. This also means that only a very small amount of variance in parents' concerns is attributable to measurement error.

Table 3-1. Internal Consistency (Item-intercorrelations) Between Open- and Closed-Ended Questions

	Expressive	Receptive	Self-help	Behavior	Social	Gross Motor	Fine Motor	School	Global	Medical	Other
OPEN-ENDED QUESTIONS											
Expressive	—	.17	.12	.03	.09	.22	.14	.09	.07	.14	.16
Receptive	.17	—	.32	.28	.14	.32	.24	.22	.25	.37	.18
Self-help	.12	.32	—	.09	.30	.32	.24	.13	.16	.17	.11
Behavior	.04	.28	.08	—	.17	.10	.11	.19	.16	.14	.06
Social	.09	.14	.30	.17	—	.23	.16	.13	.16	.11	.06
Gross Motor	.22	.33	.32	.10	.24	—	.56	.22	.25	.28	.19
Fine Motor	.14	.24	.24	.11	.16	.56	—	.16	.18	.20	.13
School	.09	.21	.13	.19	.13	.22	.15	—	.16	.10	.10
Global	.07	.25	.16	.16	.16	.25	.18	.16	—	.21	.13
Medical	.14	.37	.17	.14	.11	.28	.20	.10	.21	—	.15
Other	.17	.18	.11	.06	.06	.19	.13	.10	.13	.15	—
CLOSED-ENDED QUESTIONS											
Expressive	.44	.19	.11	.06	.06	.12	.15	.10	.12	.11	.04
Receptive	.11	.37	.16	.17	.00	.12	.13	.30	.10	.21	.05
Self-help	.07	.32	.18	.16	.12	.10	.11	.29	.12	.14	.05
Behavior	.01	.17	.10	.31	.10	.02	.02	.17	.12	.09	.02
Social	.05	.15	.06	.16	.16	.15	.04	.21	.12	.14	.02
Gross Motor	.07	.24	.18	.10	.10	.23	.16	.18	.08	.20	.00
Fine Motor	.01	.30	.17	.13	.10	.18	.12	.19	.12	.13	.02
School	.04	.20	.07	.20	.04	.09	.14	.32	.17	.08	.02
Medical	.02	.01	.01	.02	.01	.00	.01	.01	.01	.01	.01
Other	.20	.16	.22	.14	.09	.17	.19	.08	.11	.18	.23

Table 3-2. Internal Consistency (item-intercorrelations) between Categories of Responses Derived from a Combination of Open- and Closed-ended *PEDS* Questions

	Expressive	Receptive	Self-help	Behavior	Social	Gross Motor	Fine Motor	School	Medical	Other
					PROBE QUESTIONS					
Expressive	—	.37	.32	.12	.22	.29	.26	.36	.03	.28
Receptive	.37	—	.68	.28	.40	.54	.51	.40	.02	.18
Self-help	.32	.68	—	.34	.50	.53	.53	.42	.02	.17
Behavior	.14	.28	.34	—	.45	.27	.30	.23	.04	.21
Social	.22	.40	.50	.44	—	.56	.50	.40	.02	.17
Gross Motor	.28	.54	.53	.27	.56	—	.72	.47	.02	.18
Fine Motor	.26	.51	.53	.29	.50	.72	—	.50	.01	.17
School	.36	.40	.42	.23	.40	.47	.50	—	.02	.11
Medical	.03	.02	.02	.04	.02	.02	.01	.02	—	.01
Other	.28	.18	.17	.21	.17	.18	.17	.11	.01	—

2013 Reliability Studies

Test-Retest Reliability

In this study, 193 parents (whose children were between 1 through 91 months of age) were re-administered *PEDS* in print within 8 days (range= 0 – 32 days). Office staff entered comments into *PEDS ONLINE* for scoring. Agreement between administrations (meaning whether parents' comments rendered the same *PEDS* Paths the same way at Time 1 versus Time 2) was 94% (182/193). Errors mostly involved a change from Path B to Path A (from moderate risk to high risk but for either path there is a recommendation for at least some level of additional professional scrutiny).

Inter-Rater Reliability (for Categorization of Concerns)

In this study, 355 parents with at least one concern and whose children were between 6 and 30 months of age, were administered *PEDS* by interview (with results entered into *PEDS ONLINE* for scoring). The goal was to determine the agreement between an expert coder in comparison with the text-based scoring analyzer that generates results for *PEDS ONLINE*. The expert coders reviewed the results for both the accuracy of categorizing concerns and also for the accuracy of assignment to *PEDS* Paths. Of the 355 cases, concerns were correctly assigned in 95% of cases. The remaining 5% (N =18) had errors. Of these, 2 cases involved failure to assign the gross motor category, 3 were over assignation of the global/cognitive category, 5 were omissions in the behavior category (and over-assignment to the social-emotional category, 3 were under-assignation of the other/health category, etc.

One of the interesting aspects of *PEDS ONLINE* is that cases and concerns can be isolated to identify which phrases needed adding or altering. For example in this study, the other/health category (where parents usually describe concerns about eating, sleeping, hearing, specific health conditions, etc.) was missing the words "appetite" and "napping" and "arthritis" which is why the scoring analyzer did not render correctly the other/health category. In three cases these terms were added into the scoring analyzer and the results were re-run to make sure category assignments were correct. (*PEDS* researchers troll cases on the site on a regular basis to identify any new terms essential for correct scoring.) Although errors are clearly uncommon, most involve specific health conditions (e.g., "retinopathy" that are then fed into the online scoring engine). But, the fact

that providers see actual comments on *PEDS*, means they can still address health issues based on parents' verbatim comments and the child's health history.[1]

Inter-rater Reliability (for assignment to *PEDS'* Paths)

Because correct categorization of parents concerns is critical to determining *PEDS* Paths, this same sample was scrutinized for accuracy of Path assignment (prior to feeding new words into the scoring analyzer). In 97% of cases (N = 345 out of 355), the Path assigned by *PEDS Online* was deemed accurate by the expert coder.

Inter-rater Reliability (parents versus teachers)

Although *PEDS* was not standardized on teachers' concerns, Coughlan,Wake et al[2] asked teachers of 262 children enrolled in day care to complete *PEDS*. At the same time, the researchers asked parents to independently complete *PEDS* (blinded to teachers' concerns). Parents were significantly more likely than teachers to have concerns about expressive language, receptive language, gross motor, behavior, social-emotional, self help and school skills ($p < .01$ - .03). Both parents and teachers had 2 – 3 times more concerns about boys than girls, especially with language, social-emotional, and self-help skills. Overall agreement between the concerns of parents and teachers was high (>75%) for all domains except behaviour (64.9%). Coughlan et al[1] noted …. *"parents and carers see a different range of behaviour and abilities across differing situations…".* It is surely the case that children benefit from the role models that a classroom setting provides, are more likely to behave appropriately at school than they are at home.

Stability (Older Children)

Wake, Gerner et al[3], studied changes in parents' responses to *PEDS* when administered again two years later. Two groups were randomly selected from an original sample of 1591 children administered *PEDS* when they were approximately 6 years of age, i.e., when entering elementary school (Time 1): a) 173 were children whose parents had raised concerns predictive of developmental problems, and; b) 129 were children whose parents had not raised predictive concerns (case controls). Both groups were comparable in terms of parents' level of education and language spoken at home. *PEDS* was re-administered two years later, i.e., Time 2 - when all child subjects were approximately 8 years of age. Parents who raised any predictive concern at Time 1 were five times more likely than case controls to hold predictive concerns two years later, including expressive language, receptive language, fine motor, gross motor, school skills, global/cognitive, and other/health concerns ($p < .001$). Parents with concerns at Time 1 were also significantly more likely to have concerns at Time 2 about their child's behavior, social-emotional responses, and self-help skills ($p < .01$). Although the Wake et al[3] study did not account for any specific interventions instituted during the two-year duration of the study, the results indicate that parents' concerns persist over time and thus have substantial stability.

Stability (Younger Children)

How stable over time are the concerns of parents of young children? In this study by Leew et al[4], 327 Canadian parents attending public health clinics completed *PEDS* three times across a 12 month time frame (when their children were 6, 12, and 18 months of age). Attrition was minimal (12% overall). All parents were administered *PEDS* by interview and answers scored via *PEDS Online*). Six percent of families did not speak English and sowere administered *PEDS* in other languages. Eighteen percent had not graduated from high school, 25% completed at least some college courses, 43% completed college, and 13% completed graduate school (rendering a sample with higher levels of education than US prevalence). Parents were also administered measures of depression/anxiety. Across the study's duration, parents received advice and/or referrals when needed.

Dynamic changes are expected in children's development across the 6 – 18 month age range and so we should surely expect changes in the type and frequency of parents' concerns. Such was the case in this study: When children reached 18 months of age, parents raised twice as many concerns about expressive language than they'd raised at 6 or 12 months. So, in the face of the changing nature of development and brief interventions from primary care, how stable are concerns over time?

Comparing 6 to 12 months

- 37% of parents had one or more concerns at 6 months (N = 126/334)
- 45% of parents with concerns at 6 months (57/126) continued to have one or more concerns at 12 months (also meaning that 55% no longer held concerns presumably because developmental differences resolved or because parents' worries had been effectively addressed)
- 16% of parents who did not have concerns when their children were 6 months old, raised concerns at 12 months of age (N = 55/334)

Comparing 12 to 18 months

- Of parents with concerns at 12 months and who remained in the study, 60% continued to hold concerns at 18 months (N = 66/109)
- New concerns were raised by 17% of parents whose children were 18 months old (N = 54/326) and overall, 37% of parents with 18-month-olds held concerns (N = 120/326)

Comparing 6 to 18 months

- Of parents (who were administered *PEDS* at both 6 and 18 months) and whose concerns were predictive of problems at 6 months (Path A or B), 40% continued to have predictive concerns at 18 months (N = 25/62)
- Of those with non-predictive concerns at 6 months (Path C) 28% had predictive concerns by 18 months (N = 15/54), and 18% (N = 10/54) continued to score on Path C
- Of those without concerns at 6 months, 30% (N = 63/211) held predictive concerns by 18 months.
- Of those with any concern at 6 months, 48% had concerns at 18 months (N = 56/116)

To summarize, almost half of all parents had ongoing concerns. Although the type of concern often changed with time, predictive concerns were stable between 6 and 18 months in 40% of children. The presence of any concern at 6 months held a 48% chance of a concern being present at 18 months. This is remarkable stability given the enormous changes in children's skills (from not sitting to walking, from cooing to real words, etc.). Clearly addressing parents' concerns early in life, and addressing them aggressively, and over time is needed.

Internal Consistency and Item Correlations

Table 3-3 shows the inter-item correlations for all *PEDS* categories using the original sample of 47, 310 children. The highest correlations are apparent within skills that have known associations (e.g., expressive and receptive language versus fine and gross motor).

Table 3-3. Internal Consistency/Inter-item Correlations (N = 47531)

		Expressive Language	Receptive Language	Gross Motor	Fine Motor	Behavior	Social-Emotional	Self-help	School	Other/ Health	Global/ Cognitive
Expressive Language	Pearson Correlation	--	.345	.116	.180	.265	.231	.254	.278	.053	.073
Receptive Language	Pearson Correlation	.345	---	.159	.246	.337	.283	.339	.329	.072	.070
Gross Motor	Pearson Correlation	.116	.159	---	.294	.127	.119	.215	.122	.069	.069
Fine Motor	Pearson Correlation	.180	.246	.294	---	.195	.181	.306	.225	.052	.086
Behavior	Pearson Correlation	.265	.337	.127	.195	---	.490	.278	.290	.093	.046
Social-Emotional	Pearson Correlation	.231	.283	.119	.181	.490	---	.282	.293	.069	.038
Self-help	Pearson Correlation	.254	.339	.215	.306	.278	.282	---	.390	.063	.087
School	Pearson Correlation	.278	.329	.122	.225	.290	.293	.390	---	.052	.061
Other/Health	Pearson Correlation	.053	.072	.069	.052	.093	.069	.063	.052	---	.031
Global	Pearson Correlation	.073	.070	.069	.086	.046	.038	.087	.061	.031	---

*all correclations were signigicant at $p < .0001$

Internal Consistency and Factor Structure

Answers to *PEDS* questions focused on development and behavior generate two distinct factors (as extracted with Principal Components Analysis using Varimax Rotation and Kaiser Normalization). The two factors account for 72.2% of variance in parents' responses: 1) The nonverbal factor includes fine motor, gross motor, and global/cognitive issues (accounting for 1/3rd of variance accounted for); and 2) The Verbal factor (accounting for 2/3rds of variance accounted for) includes expressive and receptive language, behavior, social-emotional, school and self-help skills (although self-help skills were also significantly but less highly correlated with the nonverbal factor). The larger variance in the verbal factor indicates that parents attend more to such skills when identifying concerns. The other/health question was excluded because it loaded equally on both factors (and taps non-developmental issues). The rotated component matrix is shown in Table 3-4. Table 3-5 shows the coefficient matrix showing the two unique factors along with modest correlations between factors.

Table 3-4. *PEDS* Internal Consistency and Factor Structure

	Component	
	1	2
Speech	.560	.131
Receptive	.631	.212
Gross Motor	.077	.729
Fine Motor	.261	.672
Behavior	.742	-.046
Social-Emotional	.723	-.067
Self-help	.539	.408
School	.616	.184
Global	-.023	.432

Table 3-5. *PEDS* Factor Score Coefficients

Component	1	2
1	.902	.432
2	-.432	.902

Internal Consistency and Index of Generalizability

Because performance in developmental domains overlaps considerably in young children (e.g., reaching and grasping is both a gross and a fine motor skill and may also reflect cognitive abilities) and because domains differentiate only with time, internal consistency may change as children age. In Table 3-6 are shown the coefficients broken out by year of age, and thus the extent to which *PEDS*' items measure a homogenous versus heterogeneous set of constructs. Coefficients were modest, not high, meaning that items are not redundant. Note the progression towards higher alphas with age. This illustrates that the older the child, the better parents differentiate domains, and thus score variability diminishes.

Table 3-6. PEDS' Index of Generalizability and Overall Internal Consistency by Age

Age in months	0 - 11	12 - 23	24 - 35	36 - 47	48 - 59	60 - 71	72 - 83	84 - 95	Total
N	13,556	12,849	7,785	4,129	4,902	2,180	994	915	47,310
All items	.623	.638	.672	.743	.722	.746	.751	.729	.692

FIDELITY

Cox et al[1] viewed whether parents' comments addressed the question asked on *PEDS* (or instead focused on a different topic). Two expert coders evaluated 752 *PEDS Response Forms* of which 22% were completed in Spanish. Of the 752 Forms, 206 (27.5%) contained written comments (other than "no concerns"). Spanish-speaking parents were less likely to have made written comments (70%) than English-speaking parents (95%).

When matching the intent of *PEDS* questions to actual responses (working with the 206 families who made comments), 24% (N = 55) did not answer the question asked. English-speaking families had higher rates of mismatches (7%) than did Spanish-speaking families (3%). It may be that Spanish-speaking parents interpreted *PEDS* questions more literally and thus more accurately, while English-speaking parents due to greater fluency "took off" in describing concerns regardless of the question asked. In 6 cases parents answered a question designed to produce non-predictive concerns but answered instead with comments reflecting predictive concerns (meaning 6 of the 55 were reassigned to a higher risk *PEDS* Path). In 21 cases, parents answered questions designed to elicit predictive concerns with comments that were not predictive of likely problems. In the remaining 28 cases mismatched answers would not have resulted in a Path change. The results confirm the value of adhering to the *PEDS Brief Guide*, i.e., reading through all responses before assigning categories of concerns, and re-administering *PEDS* by interview when parents have not made written comments on the *PEDS Response Form*.

Of interest, about 12% of parents' predictive comments (most often regarding expressive language or behavior—the two most common categories of concern) were deemed by the researchers as "developmentally inappropriate"—meaning that parents were unsure or unaware of what children should be doing at specific ages. In general, such comments will generate a Path B or C result for which the *PEDS* algorithm suggests further screening and advising parents about child-rearing. Capturing developmentally inappropriate comments are an important dimension of *PEDS* because these help providers respond thoughtfully to parents who clearly need more information on typical language or behavioral development and how to promote such skills. This means clinicians definitely want to know about and thus address concerns that reflect a need for parenting information.

In 14% of cases, responses on *PEDS* identified medical issues some of which had been addressed at prior visits but parents remained confused about the meaning of recommendations (yet another a valuable feature of capturing parents' verbatim concerns). On the more fun side of *PEDS*, 10% of parents took the opportunity to share positive descriptions about their child's development, behavior and health. Overall, Cox et al[1] supported the value of attending to directions in the *PEDS Brief Guide*, i.e., actually reading through all comments before categorizing, and addressing parents' concerns (while also adhering to the *PEDS*' Interpretation guidelines).

FIDELITY AND *SURVEY PEDS*

SURVEY PEDS consists of 12 closed-ended questions aimed at simulating clinical *PEDS* (with its 10 open-ended questions enabling providers to know exactly the topic of concern to parents and thus intervene in a focused manner e.g., respond to behavior concerns with specific advice, for example about temper tantrums versus biting others).

SURVEY PEDS is used for lengthy telephone surveys (covering a range of topics) wherein researchers felt open-ended questions would add excessive time. Developed for the Promoting Healthy Development Survey (PHDS), First Five California, the National Survey of Early Childhood Health, and elsewhere,

Survey PEDS is used exclusively for community and national needs assessment. Initial results suggested that the incidence of children at high, moderate, or low risk, paralleled that of clinical *PEDS*.

As a result of the many *Survey PEDS* studies, we created a version of *PEDS Online* (in both English and Spanish) using the 12 closed-ended questions alongside the open-ended questions. The goal was to facilitate use of *PEDS Online* in multiple languages without the need to invoke the text-based scoring analyzer that "speaks only English" while at the same time offering both the Clinical and Survey versions of *PEDS* for use by researchers and clinicians. We trialed *survey PEDS* online with 211LA (a non-emergent crisis warm-line interested in administering *PEDS* by interview) in which approximately 55% of callers were Spanish-speaking. The parent support specialists at 211LA asked the 12 *survey PEDS* questions along with the associated 10 open-ended questions. We then matched the question intended to elicit comments within a specific domain to parents' closed-ended responses on the first 125 cases.

In 28% of cases, parents' verbatim concerns did not match their answers to the closed-ended questions. Thus only 72% of children were assigned to correct Paths. Errors were equally divided across Paths with about 1/4th of parents who said "no" to all questions, providing verbatim comments that re-assigned their children to Paths reflecting higher levels of risk. Similarly 1/4th of parents who answered "yes" to various questions predictive of high risk, were re-assigned to lower risk paths when their actual comments were considered.

So, as with the Cox et al[1] study, parents aren't always responding to the question asked. Above all, *Survey PEDS* remains helpful for longitudinal population based needs assessment, it clearly cann not be used for individual care. Survey scientists are encouraged to substitute clinical *PEDS* in order to generate viable results.

Summary of 2013 Reliability Studies

- Test-retest reliability studies were conducted on 193 children over a 0 – 32 day time frame and revealed 94% agreement in *PEDS* Paths and parents' concerns.
- Inter-rater reliability (between an expert coder and the *PEDS Online* text-based scoring analyzer) was established on 355 children for both categorization of concerns (95% agreement) and for correct assignment of PEDS Paths (97% agreement). Teachers and parents had lower levels of agreement (74%), but *PEDS* was not normed for teachers' appraisals (and children often behave quite differently at home than at school).
- Stability of concerns for parents of older children (N = 402) was high over a two-year time frame (for children approximately 5 – 7 years of age). Parents with predictive concerns when their children were five years of age were 5 times more likely to have ongoing predictive concerns when their children were 7 years old.
- Stability of concerns in younger children (N = 352) from 6 months to 18 months) was also high: 48% of parents with concerns at 6 months, had ongoing concerns at 18 months.
- Internal consistency studies (on 45,310 children) showed a predictable factor structure: concerns at verbal versus non-verbal skills clustered significantly and accounted for the majority of test variance. There were modest inter-correlations among concerns, suggesting that answers to each *PEDS* question contribute uniquely to overall results. The coefficient of reliability/index of generalizability was moderately high, again suggesting that *PEDS* items are not redundant.
- Fidelity research shows how well parents are answering the intent of *PEDS* questions (e.g., do parents answer the speech-language question with comments about speech-language?). Although 72% to 76% of parents answer questions according to their intent, the remainder do not, and this wreaks havoc with assignment to *PEDS* paths - if the *Brief Guide* or *PEDS Online* are not used for scoring. As a consequence, *Survey PEDS* with its 12 closed-ended questions should not and may not be used for individual clinical care and decision-making.

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Chapter IV
The Validity of *PEDS*

Original Validation Research

To assess various types of validity, each of the 771 children participating in *PEDS* validation studies was administered a battery of other tests. The battery was purposefully broad, because parents' concerns span all developmental domains. The selection of measures varied across the four separate samples, but in each study of *PEDS*, the battery sampled the following skills: fine motor, gross motor, expressive language and articulation, receptive language, self-help, socialization, behavior, cognitive, and academic/pre-academic. The rationale for selecting a broad battery was to ensure that all aspects of development were measured.

Table 4-1 shows the tests used across *PEDS* studies for children of various ages.

Research Procedures

In most sites (described in Chapter II) two diagnosticians were used, one to interview families and the other to test children. In these cases, diagnosticians were blinded to either the outcome of testing or to parents' concerns. In the remaining sites, the same diagnostician worked with both parents and children. However, in all sites, standardized procedures for interviews and child-testing were used, and diagnosticians were not informed about the potential significance of parents' concerns. This means that examiners' interactions, administration of test items, scoring and interpretations were proscribed and that families were treated in an identical, standardized manner.

Critical Concepts in Screening and Test Construction Validity

There are many types of validity studies required for optimal test construction but first it is critical to define what is meant by child development. Too often professionals think of development as restricted to intellectual skills and that IQ tests, for example, provide a sufficient indicator of developmental status. In fact, child development is the all encompassing term embracing expressive language, receptive language, cognitive, fine motor, gross motor, self-help, academic skills and also behavior, and social-emotional skills/mental health. So, when "development" is used throughout this text, it refers to all domains including behavior, social-emotional/mental health.

Content/Face Validity identifies whether the items within the test under study are perceived to measure what the test is designed to measure. *PEDS* captures parents' concerns across all domains as well as other topics of concern to parents (e.g., health). There are no statistical tests to establish content validity. Rather professional opinion about the content and scope of test questions serves as the standard for content/face validity.

Construct Validity determines whether a test actually measures what we think it is measuring. If we consider developmental domains as theoretical constructs (although the presence of multiple domains seems more fact than theory!), then, we at least want to know if there are predictable relationships among certain domains (e.g., fine motor and self-help; receptive and expressive language, global cognitive delays with deficits in other areas).

CONCURRENT VALIDITY answers questions about the nature of relationship between the test under study and other tests. In this case are *PEDS*' categories of concerns correlated significantly with results of lengthier measures (also referred to as reference standards, criterion battery, or more casually, the gold standard). Related to concurrent validity is CONVERGENT VALIDITY but answers the question, are like domains across measures correlated? For example, on *PEDS* we hope to see that parents' concerns about expressive language are correlated with expressive language scores on lengthier tests.

CRITERION-RELATED VALIDITY also known as **ACCURACY** answers the question, "What percent of children with and without problems are correctly identified by a screening test?" Accuracy is the "acid test" of screening measures and probably the most important indicator of a test's ability to guide us in decisions about whether or not to refer. For this reason, the issue of criterion-related validity is taken up in the next chapter: Accuracy of *PEDS*.

DISCRIMINANT VALIDITY refines validation research even further by answering questions about whether there are distinct patterns of performance on a test that reflect distinct diagnoses. With *PEDS*, we want to know whether there are unique patterns of parents' concerns associated with diagnosed conditions. For example, do parents of children diagnosed with cerebral palsy have different types of concerns than do parents of children diagnosed with autism spectrum disorder? This is not to suggest that diagnoses should be made on the basis of a screening test, but rather to help clinicians make refined and appropriate referral decisions. For screening tests, DISCRIMINANT VALIDITY, is far more important than simply offering correlations between clusters of concerns and outcome measures. Rather we want to know what percentage of children with specific problems are or are not identified by *PEDS*. Such studies are presented in the next chapter, Accuracy of *PEDS*.

PREDICTIVE VALIDITY shows the relationship between the test, or screen in this case, under study and future performance on reference standard measures (usually administered one or more years later). Predictive validity studies inform us that *PEDS* measures enduring and meaningful aspects of child development, and can help confirm the need to take initial results seriously, i.e., that potential problems found earlier in life are likely to remain problems years later. Nevertheless, predicting future performance is fraught with challenges—psychosocial risk may change, intervention may alter outcomes, parents may learn skills that promote development, and development itself proceeds in fits and spurts. So, we cannot apply the same standards for concurrent screening test accuracy when evaluating predictive validity studies. If there is substantial variance accounted for (typically expressed as significant correlations) between a slender set of items on a screening test as compared to criterion measures administered years later, that itself is a confirming, exciting finding. ❀

Concurrent Validity

Children whose primary language was Spanish were tested exclusively in that language using standardized Spanish directions for tests. Their parents completed Spanish versions of *PEDS*, demographic, and other measures. Spanish administrations were used with 25 parent-child dyads, comprising 3% of the study sample.

Concurrent validity shows relationships, usually expressed by correlations, between a test and other measures with similar content. Table 11-2 shows the relationship between specific types of parental concerns and the concurrent battery. Eta correlations are presented (except where noted), because they are the technique appropriate for correlating continuous data (most concurrent tests produced a continuous range of age-equivalent or standard scores) with dichotomous data (the presence or absence of parental concerns in each domain).

Although almost all correlations are high, these are not always in the expected domain. For example, performance on the Eyberg Child Behavior Inventory was more closely related to the presence or absence of concerns about global/cognitive development than to parents' judgments about children's behavior. This suggests that the relationship between parents' concerns and the domains in which children have measurable weaknesses is not a straightforward one. One explanation is that parents may not view development in quite the same way as professionals. For example, the parent who notices poor behavior in his or her child may not have considered that hearing deficits, language problems, intellectual delays, or even motor problems may contribute to child noncompliance. This illustrates keenly the need for skilled probing of parental concerns by professionals and for careful interpretation.

Table 4-1. Concurrent Battery

TEST	CONTENT	AGE RANGE (in years)
Woodcock-Johnson Psychoeducational Battery: Tests of Achievement:		2½–8
Letter-Word Identification	Reading readiness and reading skills	
Applied Problems	Number concepts	
Dictation	Grapho-motor and spelling skills	
Skills Cluster	Composite of the above three subtests	
Stanford-Binet Intelligence Scale (4th Edition) Kaufman Assessment Battery for Children Bayley Scales of Infant Development	These three measures are individually administered, diagnostic measures of intelligence. Their selection varied according to children's ages. The KABC was used when the examiner suspected language problems so as to obtain an unobstructed view of cognitive skills.	2½–8 4–8 0–2½
Slossen Intelligence Test	Provides mental age and intelligence quotients	2–8
Test of Language Development	A diagnostic measure of receptive and expressive language skills.	4–8
Arizona Articulation Proficiency Test	A measure of speech production	3–8
Articulation Screening Test	A measure of speech production	3–8
Vineland Adaptive Behavior Scales	A parent-report measure of socialization, communication, self-help, motor development, and maladaptive behavior.	0–8
Child Development Inventory/Possible Problems Checklist	Parental report measure with 300 items. Provides percentage of delay and age-equivalent scores for language, motor, social, self-help, behavior, health, and pre-academic and academic skills. The Possible Problems Checklist identifies behavioral, health and sensory difficulties.	1–8
Developmental Profile-II	A parent-report measure of socialization, communication, academic self-help, and motor development.	0–8
Eyberg Child Behavior Inventory	A 36-item parent report measure of conduct problems	2½–8
Battelle Developmental Inventory Screening Test	A 30–40-minute screening test that produced age-equivalent and pass-fail scores in each of eight developmental domains. Uses a combination of parent report and directly elicited items.	1–8
Brigance Screens	A 10-minute screening test sampling pre-academic and academic skills, general knowledge, motor, and language skills. Produces pass/fail scores and relies exclusively on direct elicitation.	1½–8

Discriminant Validity

Discriminant validity views the relationship between specific kinds of disabilities and parents' concerns. The objective is to identify whether there are unique patterns of performance on *PEDS* that characterize children with developmental strengths or weaknesses. To assess this, criteria were applied to children's performance on the concurrent battery in order to discern the presence of various types of disabilities. The criteria were drawn from the U.S. federal laws (I.D.E.A.) that ensure public school special education services for children with disabilities. The specific criteria are shown in Table 4-3.

After categorizing children as above, logistic regression was used to identify those concerns most closely associated with various types of disabilities. Of the 130 children with disabilities in the sample of 771, only the 106 for whom specific disabilities were diagnosed are included in this analysis (the excluded 24 were a battery of screening measures, and specific strengths and weaknesses could not be confidently identified). Table 4-4 shows the odds ratios attaining statistical significance. These reveal unique patterns of concerns for almost every type of disability, illustrating that *PEDS* has the power to discriminate different types of problems. While most conditions were associated with unique patterns of parental concerns, two overlapped: specific learning disabilities and physical impairment. To some extent this makes sense, in that children who are eligible for special education due to physical impairments must have deficits in academics, as well as adaptive behavior skills.

Notes on Table 4-2

— *Denotes that correlations could not be computed because concerns were entirely skewed for the particular sample, e.g., no parents whose children were administered a specific test raised this type of concern.*

\+ *Produces pass/fail/suspect scores, so nonparametric correlations were used. These are inherently deflated due to range restrictions. Significance tests were used to show meaningful relationships.*

* *Shows significance for nonparametric correlations.*

Table 4-2. Correlations Between Types of Parents' Concerns and Concurrent Measurement

Criterion Measures	global/ cognitive	expressive language	receptive language	social	self-help	gross motor	fine motor	school	behavior	medical/ other
Woodcock-Johnson Psychoeducational Battery: Tests of Achievement: (N = 352)										
Letter-Word Identification	.54	.43	.60	.44	.54	.45	.50	.48	.43	.42
Applied Problems	.42	.47	.52	.49	.45	.51	.45	.37	.45	.43
Dictation	.65	.47	.50	.45	.50	.52	.51	.51	.47	.62
Skills Cluster	.80	.72	.76	.74	.71	.77	.74	.72	.70	.75
Child Development Inventory (N = 403)										
Socialization	.89	.85	.84	.85	.87	.86	.84	.89	.83	.85
Self-Help	.84	.82	.81	.78	.81	.79	.84	.83	.78	.76
Gross Motor	.76	.75	.77	.77	.78	.76	.78	.74	.75	.74
Fine Motor	.76	.75	.77	.77	.78	.76	.78	.74	.75	.74
Expressive Language	.89	.84	.88	.85	.86	.88	.91	.88	.84	.92
Listening Comprehension	.90	.82	.85	.83	.84	.86	.85	.83	.82	.90
Eyberg Child Behavior Inventory (N = 62)	.82	.68	.56	.59	.35	.64	.56	.60	.67	.52
Kaufman Assessment Battery for Children (N = 39)	—	.85	.81	.79	.75	.56	.85	.69	.79	1.0
Bayley Scales of Infant Development (Mental Development Index)(N = 21)	1.0	.95	1.0	.92	.94	1.0	1.0	—	1.0	1.0
Stanford-Binet Intelligence Scale (4th Edition) (N = 33)	1.0	.76	.68	.79	.82	.76	1.0	—	.71	—
Slossen IQ (N = 408)	.43	.47	.47	.44	.48	.46	.42	.47	.42	.54
Test of Language Development (N = 20)	.71	.88	.82	.89	1.0	—	.85	.87	.89	.64
Arizona Articulation Proficiency Test (N = 16)	.38	.73	.48	.49	—	—	.38	.50	.56	.48
Articulation Screening Test+ (N = 181)	.22	.23	.38*	.12	.32*	.09	.08	.04	.25	.30*
Vineland Adaptive Behavior Scales (N = 91)										
Daily Living	.76	.68	.72	.76	.75	.58	.63	.77	.63	.60
Social	.77	.64	.90	.71	.65	.70	.65	.76	.66	.67
Communication	.77	.74	.82	.63	.74	.62	.66	.60	.69	.81
Gross Motor	.83	.76	.70	.78	.86	.85	.86	.70	.75	.74
COMPOSITE	.92	.72	.84	.77	.73	.70	.82	.50	.67	.77
Developmental-Profile-II (N = 192)	.79	.64	.49	.61	.67	.51	.53	.56	.62	.46
Brigance Screens (N = 408)	.69	.62	.59	.68	.64	.66	.66	.62	.60	.61
Battelle Developmental Inventory Screening Test (N = 156)	.56	.58	.65	.63	.50	.62	.45	.65	.65	.65

Table 4-3. Criteria for Student Classification

CATEGORY	CRITERIA
Special Education	
Speech-Language Impaired	Performance 2.0 or more standard deviations below the mean on receptive and/or expressive language measures/subtests
Mental Retardation/ Developmental Delay	IQ or DQ less than 74, and performance 2.0 standard deviations below the mean on adaptive behavior measures (typically the VABS or Child Development Inventory)
Specific Learning Disabilities	Performance 1 or more standard deviations below IQ in reading, math, or written language
Physical Impairment	1.5 standard deviations below the mean in adaptive behavior and/or academics together with a previously diagnosed physical disability, such as cerebral palsy
Hearing Impairment	1.0 or more standard deviations below the mean in speech-language skills together with a previously diagnosed hearing loss
Emotional/Behavioral	Based either on examiner judgment or a previous diagnosis of such difficulties as attention deficit hyperactivity disorder, autism, adjustment disorder, etc.
Other	Children with other types of previously established eligibility for special education and currently receiving services (e.g., health impairment, traumatic brain injury, autism, etc.)
Within normal limits	None of the above

Table 4-4 Statistically Significant Relationships Between Types of Disabilities and Concerns

Diagnostic Categories	global/ cognitive	expressive language	receptive language	social	self-help	gross motor	fine motor	school	behavior	medical/ other
Speech-Language Impaired (N = 26)	8.05					6.19		5.88		
Mental Retardation (N = 12)	6.26									
Specific Learning Disabilities (N = 29)	4.92					6.44				
Physical Impairment (N = 20)	13.91					5.92				
Hearing Impaired (N = 8)	8.62								8.22	
Emotional/Behavioral (N = 5)								7.68		
Other (N = 6)						7.23				

CRITERION-RELATED VALIDITY

Since one goal of *PEDS*, as for all screening tests, is simply to determine the probable presence or absence of a problem, it is important to know the probability of disability on the basis of parents' concerns. These are presented in Table 4-5. This shows the likelihood of any type of disability given each type of parental complaint. The 95% confidence intervals are presented below each odds ratio. Because complaints and the prevalence of disabilities vary by children's ages, probabilities are broken out by age. The odds ratios show that for each age group, certain concerns carry large probabilities that children have developmental difficulties.

Table 4-5. Odds Ratios (and 95% Confidence Intervals) of Developmental Problems on the Basis of Parents' Concerns According to Children's Ages

Presence or Absence of any Diagnosis by Age	global/ cognitive	expressive language	receptive language	social	self-help	gross motor	fine motor	school	behavior	medical/ other
0 to 1½ years	26.3 1.3–529.9	25.7 2.6–249.5	1.0 0.9–1.0	5.0 0.4–57.2	0.9 0.9–1.0	—*	8.6 0.7–10.8	—*	3.5 0.3–38.0	0.9 0.9–1.0
1½ to 3 years	25.9 2.9–229.6	11.2 4.7–26.4	6.3 2.0–20.1	7.4 3.0–18.1	5.18 1.6–17.2	—*	4.8 0.9–24.7	—*	2.8 1.3–6.0	3.1 0.5–19.2
3 to 4½ years	13.6 2.5–73.2	8.4 3.8–18.8	1.8 0.6–5.4	1.6 0.7–3.6	1.0 0.3–3.3	3.3 0.5–20.3	1.4 0.3–6.9	1.8 0.5–7.32	0.7 0.3–1.5	6.7 2.1–21.2
4½ to 7 years	10.2 3.3–31.2	4.2 2.2–7.6	4.7 2.1–10.2	2.4 1.3–4.5	3.8 1.8–7.9	4.4 1.9–10.1	6.9 2.9–16.8	4.2 2.1–8.5	2.2 1.2–4.0	3.3 0.9–10.7

*— Denotes entirely skewed distributions (e.g., no parents held such concerns at a particular age level) precluding computation of odds ratios.

CRITERION-RELATED VALIDITY: ACCURACY

For measures other than screening tests, criterion-related validity is assessed by viewing the extent to which a measure identifies children with specific types of strengths and weaknesses, usually by examining the amount of variance explained. For screening tests, the issue is more complex, but the need for data more straightforward. With screening, criterion-related validity is defined as the percentage of children with problems who are correctly identified by screening tests (usually by scores below a specified cutoff) and by the percentage of children without problems who are identified (usually by scores above the cutoff). In the case of *PEDS*, the question is, what percentage of children with disabilities are correctly identified on the basis of certain types of parental concerns, and what percentage of children without disabilities are identified by the absence of certain concerns. These percentages are referred to as screening test accuracy. This is the most important aspect of screening test validation, and data on the accuracy of *PEDS* is presented in Chapter V.

2013 Validity Studies on *PEDS*

Content Validity

Content and face validity reflect professional opinion about the scope of test items and whether they identify the range of issues as declared by test authors (and as needed and helpful for test users). Various studies of *PEDS* show that it more than doubles the rates of concerns raised, most especially in the critical and predictive domain of concerns about expressive language (with behavioral and social-emotional issues following close behind) and that *PEDS* greatly increases referral rates.[1-3]

In Cox et al's 2010 paper, "Developmental Screening and Parents' Written Comments: An Added Dimension to the *Parents' Evaluation of Developmental Status* Questionnaire"[2] parents' responses on *PEDS* helped providers see when concerns were developmentally inappropriate (e.g., he's 9 months old and not saying words yet), and thus focus developmental promotion on the topics parents needed to learn. In addition, use of *PEDS* facilitated parental health concerns that providers thought they'd fully addressed but about which parents remained confused and needed repetition and additional information.[2]

Not surprisingly, *PEDS* questions elicited concerns across all 9 developmental domains plus health/other issues. But Cox et al noted that in 24% of cases, parents' concerns did not always match the question posed by *PEDS* (for example, a parent may comment about poor reading skills but place that answer in response to the behavioral question, not the school skills question).[2] This means that it is a good thing that *PEDS* scoring works by categorizing concerns into domains without regard to the question asked—yet another reason for test users to adhere carefully to the *PEDS Brief Guide* to Administration and Scoring or to switch to *PEDS Online*.

Other Measures of Parents' Concerns

Studies of other approaches to eliciting parent's concerns have not fared well. For example, Gablehouse & Gitterman[4] found that 50% of parents did not understand the word "development." So, it is not surprising that the questions suggested in the AAP in the 2006[5] policy statement on early detection, did not fair well because "development" was separated from more commonly understood synonyms, i.e., "Do you have concerns about your child's development?..... Behavior?..... Learning?". Sheldrick et al[6] studied 451 parents and found that only 6% reported concerns in response to the question about development, only 8% mentioned concerns about behavior, and only 4% had concerns about learning, and that 1 in 5 families who reported no concerns indeed had children with problematic scores on other measures, i.e., the ASQ and/or ASQ:SE. The authors wrote, *"There are several possible explanations for why parents' concerns about development [via the questions we posed] did not predict scores on a developmental screening instrument. First, parents may not understand the breadth of what clinicians mean by the word "development." They may not think of development as a set of specific domains as clinicians do and thus may not report concerns about areas of development that are not specifically elicited by this question, e.g., language. Other instruments, such as the Parents' Evaluation of Developmental Status include more specific questions about the child's language, cognition, and motor skills and may be more effective than queries about "development" in general."* [6,(p. 159)]

Similarly, the ASQ's questions about parental concerns, only generate comments about 28% of the time.[7] Although that may sound like a reasonable response rate, given that *PEDS* is designed to triage families in need of counseling, versus referral or further screening, i.e., sort high from moderate from low risk, a 28% response rate is insufficient. More than 50% of families need developmental-behavioral assistance of one kind or another.[1]

In a study of 52 healthcare providers and 483 patients[8] engaged in Bright Futures (an AAP initiative focused in large part on developmental-behavioral promotion), 371 families were greeted with at least one open-ended question. The wording of these questions was not specified in the study but the Bright Futures Guidelines[9] suggests asking an opening question such as *"Do you have any concerns or questions about your child/baby?")*. Assuming such a question was designed to elicit developmental-behavioral concerns (as well as other topics) it failed to deliver: Only 21% of parents raised non medical concerns.

COMMENT ON CONTENT VALIDITY

PEDS clearly does what it is designed to do: elicit parents' concerns across all developmental domains (plus health) and facilitate providers' ability to address these concerns with evidence-based support for optimal responses. The limited effectiveness of other lines of questioning to elicit parents' concerns across the range of developmental issues provides clinical support for the use of PEDS.

PEDS' CONSTRUCT VALIDITY

In the following analysis the factor structure of *PEDS* is evaluated to illustrate relationships among parents' comments (categorized into domains) using data collected via *PEDS ONLINE*. With *PEDS*, in print or online, parents must respond with at least one comment, even if simply "no concerns", and they must answer all 8 multiple choice questions by circling "yes", "no" or "a little". *PEDS ONLINE* ensures correct completion of *PEDS* by refusing to submit to the text-based scoring engine any incomplete forms including those with no comments or missing answers to the multiple choice questions, thus prompting parents and providers to complete *PEDS* per the directions in the *Brief Guide*.

For greater clarity in describing relationships among types of concerns, children receiving Path E scores (meaning "no concerns and all "no" answers to the multiple-choice questions) were excluded. The 12,940 children in the standardization sample with Path B, C, A results were included in the construct validation study. Factor analysis (using principal components analysis extraction with rotation via Verimax with Kaiser normalization) was used for all analyses. Finally, because parents likely view developmental domains differently over time, the relationship among categories of parental concerns was analyzed by children's ages in one or more year increments: birth to 12 months; 1 to 3 years, 3 to 6 years, and 6 to 8 years.

With infants (birth through 11 months, N = 2027), there were two significant clusters of parental concerns types accounting for 64.7% of variance. Factor 1 included: Expressive language (.56), receptive language (.62), behavior (.74), social-emotional (.72), self-help (.61) and preacademic (.62); and Factor 2 included: gross motor (.73), fine motor (.67), self-help (.42) and global (.43). Other/health did not load on either factor. The analysis suggests that parents of very young children differentiate domains of concern into three broad categories (i.e., motor/self-help/overall developmental status; language/mental health/school; versus health).

For children ages 12 – 35 months (N = 5783), parents seemed to have acquired a more nuanced view of developmental domains. Four factors accounted for 55% of variance. Factor 1 included expressive language (.37), receptive language (.64), fine motor (.45), self-help (.67), and school skills (.62). Factor 2 included behavior (.80) and social-emotional (.71) inversely associated with expressive language concerns (-.49); Factor 3 included gross motor (.87) and fine motor (.54) inversely associated with expressive language (-.34), and Factor 4 included other/health (.90) inversely associated with expressive language (-.52).

For children 3 years through 5 years (N = 4453), 55% of variance was accounted for. The factor structure was identical to the pattern of related concerns seen in children aged 1 to 3 years.

For children 6 years through 7 years (N = 677), the pattern varied with 3 factors accounting for 47% of variance. Factor 1 included expressive language (.37), receptive language (.54), gross motor (.68), fine motor (.74), self-help (.57) and school skills (.47). Factor 2 included behavior (.82) and social-emotional (.72) inversely associated with expressive language (-.43). Factor 3 included expressive language (.54) inversely associated with other/health (-.60).

Comment on Construct Validity

The changes in clusters of concerns by children's ages between the 0 - 5 year range show that parents increasingly differentiate developmental domains. By 6 to 8 years, parents also seem to see that domains have to work together for success with the tasks confronting school age children (e.g., that it is hard to do well in physical education classes if understanding of language is limited or hard to do well with self-help skills when fine motor abilities are less than optimal). It also seems likely that parents with any sort of developmental concern scrutinize other developmental-behavioral domains with greater care and thus remark on multiple issues.

PEDS' Concurrent and Convergent Validity

How are parents' perceptions of children's developmental strengths and difficulties, associated with performance on objective measures (concurrent validity)? Is there evidence for convergent validity, i.e., that the type of parental concern is associated with performance in the same domain on other tests? The following analyses examined the relationship, expressed as correlations, among parents' concerns/*PEDS* Paths, and children's performance on other measures.

Two developmental diagnostic measures of development and academic/preacademic skills were used in these studies as was a broad-band skill focused screening test:

a) The Comprehensive Inventory of Basic Skills-II (Readiness Test) (CIBS-II), a measure for children 5 years through 7 years of age, focuses on performance in the broad areas of general knowledge/comprehension, gross motor, and graphomotor, reading, math, and phonemic awareness. The CIBS-II was normed on a large nationally representative sample (N = 1791) in 22 US States. Concurrent validity studies of the CIBS-II were conducted on more than 300 children via a range of measures including the Dynamic Indicators of Basic Early Literacy Skills, the Nevada Criterion-Referenced Test, Michigan Education Assessment Program, The TerraNova, the Wechsler Intelligence Scale for Children-4th edition, and the presence or absence of special education enrollment (including programs for gifted/talented children) and revealed high correlations with concurrent measures of similar content;

b) The Inventory of Early Development-II (IED) is a diagnostic measure for children from birth to 8 years and defines performance in fine motor, gross Motor, expressive language, receptive language, self-help, academic/preacademic and social-emotional skills. The IED requires between one to two hours to administer and produces quotients, percentiles, and age-equivalent scores in each domain. Widely used to determine eligibility for special needs programs, the IED was normed on 1185 children throughout the United States and enjoys high correlations with other measures of like domains;

c) *PEDS:Developmental Milestones* (*PEDS:DM*) is a screening test often given alongside *PEDS* to confirm or disconfirm parents' concerns (and to also discern delays that parents may not have noticed. The *PEDS:DM* produces results in the form of met versus unmet milestones using the 16th percentile as the cutoff. At each age level (from birth through 7 years 11 months) *PEDS:DM* has a single age-appropriate task for each domain: expressive language, receptive language, fine motor, gross motor, self-help, social-emotional. Older children (3 ½ years and up) are also administered a math/premath and a reading/pre-reading item.

PEDS and Academic/PreAcademic Skills

For the norming studies of the CIBS-II, 155 parents of children 5 years to 7 years of age completed *PEDS* while examiners administered the CIBS-II to children in English or Spanish. Parents and examiners were blinded to the results of either test. Settings included public schools and preschool programs. The overall score for the CIBS-II Readiness Test (i.e., a mean quotient of 100 with a standard deviation of 15), was used to view associations with parents' concerns on *PEDS*. For this analysis, Readiness quotients on the CIBS-II were divided into two groups: quotients 85 and below versus 86 and higher and used as the grouping variable in a discriminant function analysis. Predictor variables were parental concerns on *PEDS*. The single discriminant function was significant [$\chi^2 = 26.782$ (df = 9) $p < .002$]. Predictors

from *PEDS* were concerns about expressive language (.61), gross motor (.41) and fine motor (.32). The remaining concerns were non-contributory.

PEDS and Developmental/Social-Emotional/ Mental Health Skills

For this analysis of concurrent validation, *PEDS* was administered to 1168 parents whose children were also administered the IED. Both parents and examiners were blinded to IED results. English and Spanish versions were available for both tests and 6% of administrations were conducted in Spanish. Settings included healthcare, preschools, Head Starts, and public schools. Children ranged in age from birth through 7 years 11 months (median age = 24 months, sd = 21.08).

Of the 1168 parents, 53% (N = 618) had no concerns on *PEDS* while the remaining 47% (N = 550) raised one or more concerns. Of those raising concerns, the mean number was 2.7 (median 2.0 with a range from 1 – 10).

Table 4-6 shows correlations between standardized scores (with a mean of 100 and a standard deviation of 15) for each IED domain, grouped into quotients of < 86 versus 86 and higher. Against each of these domain groupings, parents' concerns were entered into a discriminant function analysis to identify concerns most closely associated with performance on each domain of the IED. Chi-squares and their significance are reported in the bottom two rows. Concerns non-predictive for each IED domain score are shown as NS (not significant).

Consistently, there were significant relationships between IED domains and parents' concerns. Parents' concerns, in turn, embrace a broader set of issues than simply performance on specific skill sets. For example, when academic deficits are present, parents not only worried about school performance but also social-emotional, self-help, expressive lan-

Table 4-6. Relationship between types of parental concerns and performance in various domains of the Inventory of Early Development-II

PEDS	Correlations with Standardized Scores for each IED Domain, grouped into quotients <86 versus 86 or higher					
Type of Concern	Motor Domain	Language Domain	Academic Domain	Self-Help Domain	Social-Emotional Domain	Average of all domain scores
Global	.58	NS	NS	.44	.32	.53
Expressive Language	.30	.65	.54	NS	NS	NA
Receptive Language	NS	.40	NS	.61	.71	NA
Gross Motor	.36	.74	.60	NS	NS	NA
Fine Motor	.30	NS	NS	.51	.76	NA
Behavior	NS	NS	NS	NS	.34	.56
Social-emotional	NS	NS	.56	NS	NS	.47
Self-help	NS	.62	.46	.55	.58	NA
School	NS	NS	.56	.59	.39	.48
Other	.60	NS	NS	NS	NS	NA
χ^2 (df = 10)	60.027	29.354	62.457	100.593	54.665	73.344
p <	.0001	.001	.0001	.0001	.0001	.0001

guage, motor skills, etc. This is surely as it should be because academic deficits have many causes, and often take an enormous toll on well-being, surely most visible when a child is at home.

The above study also provides evidence of construct validity—that parents' concerns in each domain are associated with the same domain on the IED. Nevertheless, other types of concerns were also correlated. To some extent, this may be a function of IED items. For example, the IED's social-emotional domain includes many items focused on attention span, following rules, etc. This may explain why parents' concerns about behavior rather than social-emotional concerns enjoyed significant correlations. Similarly, it may seem odd that gross motor skills would be associated with language performance, but the IED includes both articulation and direction-following items (e.g., "stand up", "sit down", "put the book on the table", etc.) meaning that parents' gross motor concerns may reflect oral-motor difficulties as well as physical limitations interfering with performance on IED items.

PEDS in Relation to the Ages and Stages Questionnaire (ASQ)

It is less than ideal to compare one screen to another because screens, due to their inherent brevity, contain at least some error (usually about 20% to 25% of children with problems will be missed in a single administration—hence why repeated screening is needed). But such error also means that when we compare screens, we don't know if we are compounding error or whether it overlaps. If compounded, the error on two different screens could be 40% or higher. If overlapping perfectly, then detection rates on two separate screens would be closer to 20%.

Nevertheless, use of more than one screen that measure development in different ways can be informative, i.e., rule in or out parents' concerns and otherwise identify problems parents failed to detect. So *PEDS*+*PEDS:DM* or *PEDS*+ASQ Tools offer unique ways of engaging and collaborating with parents, addressing their concerns, while also monitoring children's measured skills; both strengths and weaknesses (and complying with AAP policy on early identification).

Below is a discussion of studies comparing *PEDS* to the ASQ. These describe how the two measures differ and why (and how that's a good thing):

a) *PEDS* is designed to identify performance < the 16th percentile, i.e., 1 or more standardard deviations below average.

b) The ASQ[11] is designed to identify children performing at < the 2nd percentile, i.e., closer to 2 standard deviations below average.

c) *PEDS* is designed to identify children with existing delays and eligibility for Early Intervention (EI), but is also designed to identify children at risk but not yet delayed, i.e., due to parenting problems or psychosocial risk.

d) The ASQ is designed to identify existing delays and eligibility for EI but not those at-risk who are unlikely to be eligible for EI.

e) *PEDS* is designed to identify the unique issues parents hold so that providers can address these specifically (e.g., biting versus toileting problems).

f) The ASQ, although it includes unscored questions about parents' concerns, does not identify the full complement of parents' issues and fewer parents respond to these ASQ questions than to *PEDS* questions.

So the two measures are clearly designed to do some of the same things (e.g., identify children who need to be referred to EI) but *PEDS* also identifies additional issues: what specific information parents need from providers, and which children and families need non-EI interventions (e.g., parent training, Head Start, social work, etc.). So, there is an apples and oranges aspect to comparing the ASQ and *PEDS* that must be considered when selecting measures and when conducting or evaluating research.

A clear illustration of the similarities and the differences between ASQ and *PEDS* results is seen in a study by Sices et al[12] aptly titled, "*PEDS* and ASQ Developmental Screening Tests May Not Identify the Same Children". Of the 60 families participating, children averaged 18 months of age (a convenience sample for whom 77% were Medicaid recipients whose parents had limited education) completed both measures: 37% were at risk on *PEDS* (had either Path A or Path B scores) but only 27% failed the ASQ (2nd edition); 15% did poorly on both mea-

sures and 33% did poorly on one but not the other (13 on *PEDS* and 7 on the ASQ). Because a criterion measure was not used, the accuracy of each tool was not studied, but the larger volume of risk rates identified by *PEDS* suggests that it is performing as it should—identifying both EI eligible children and those who need other kinds of attention.

PEDS PATHS IN RELATION TO *PEDS:DM* PERFORMANCE

Because many providers use the *PEDS:DM* to confirm or disconfirm parents' concerns or *PEDS* Paths it is important to understand the relationship between *PEDS* results and the *PEDS:DM*. This study viewed 9,560 children, from birth to age 8 (mean age = 27 months, sd= 26.34 months), whose parents completed both measures. Data from *PEDS ONLINE* was used to assure correct scoring.

Specifically, parents' concerns were organized into *PEDS* Paths and then results from the *PEDS:DM* were used as predictors in a series of discriminant function analyses. Children were grouped into those scoring on Path A (N = 329), Path B (N = 792), Path C (N = 451) versus Path E (N = 7988). Predictor variables were *PEDS:DM* results (milestones met versus unmet) in each domain. The three discriminant functions separating the four groups were significant and accounted for 100% of variance in *PEDS* Paths [χ^2 = 1389.159 (df = 24), χ^2 = 132.523 (df =14) and χ^2 = 30.130 (df = 6), $p < .0001$].

Discerning Path A from Path B were the following predictors from *PEDS:DM* results: problematic performance in expressive language (.64), gross motor (.64), math (.60), reading (.60), receptive language (.55), self-help (.54), social-emotional (.52), and fine motor (.50). Discerning Path B from Path C were the following *PEDS:DM* results: non-problematic performance in expressive language (-.33), problematic performance in math (.56) and in social-emotional skills (.47). Discerning Path C from Path E were problematic results in gross motor (.56) and social-emotional skills (.34) and non-problematic results in math (-.41).

PEDS' RELATIONSHIP WITH PARENTAL DEPRESSION AND ANXIETY

Leew et al[10] reviewed research on parental depression and anxiety and concluded that parents with limited well-being were more intrusive and insensitive than mentally healthier parents, i.e., children of depressed and anxious parents are at higher risk for developmental (meaning also behavioral and emotional) problems. To further study relationships among parental mental health, and developmental status, the following measures were administered. *PEDS*, the State-Trait Anxiety Inventory-Revised (STAI-Y), and the Edinburgh Post-natal Depression Scale (EPDS). Subjects were 327 mothers and their children receiving well-child care at one of two community health clinics in Calgary, Canada. (Note that in Canada, community health clinics are the usual source of health supervision visits and Calgary itself is a relatively affluent city.) Thus participating families tended to be middle to upper-income with slightly higher levels of education than is typical for Canada, i.e., 43% of parents had college degrees and an additional 13% had advanced degrees. Families were followed over time and seen at 6 months, 12 months, and again at 18 months.

Risk rates on *PEDS*, including Paths A, B, and C were high and fairly uniform over time: 34% at both 6 months and 12 months, and 37% at 18 months. Expressive language concerns were common (9% to 19% over time), followed by behavioral concerns (10% to 12%), gross motor (5% to 10%) and social emotional worries (3% to 7%). Parents reported higher rates of depression and both state and trait anxiety at 6 months and their children had significantly higher rates of risk on *PEDS*, i.e., Path A results. Rates of depression and risk rates on *PEDS* waned substantially by 12 months and continued to be lower at 18 months. Rates of either type of anxiety had a similar pattern.

Only at 6 months of age, was parental anxiety/depression associated with substantially higher than expected risk rates on *PEDS*, i.e., Path A scores. At all other ages, parents with or without mental health problems were equally likely to raise concerns associated with risk paths on *PEDS*. Thus a Path A result in the first year of life should be met with screening for parental mental health problems and treatment if indicated, along with intervention to promote infant development. The findings providing compelling support for the AAP's recommendation to screen for parental post-partum depression early in a child's life.

Comment on Concurrent and Convergent Validity Studies

The types of concerns parents raise on PEDS enjoy significant associations with children's performance in similar domains. Nevertheless, parents also worry, understandably, about other issues (e.g., social-emotional) when children are behind compared to others. So it is not surprising that parents report a range of non-predictive concerns along with concerns associated with the domain(s) of difficulty.

The above studies illustrate that parents are accurate reporters of problems. Prior research also shows that parents with mood and anxiety disorders are not as good at noticing when development is advanced.[13] There is much evidence that parental depression and anxiety have an adverse effect on infant development (e.g., lowered frontal and parietal lobe activity). In any case, psychiatric impairments in parents are associated with real or accumulating deficits in the development of young children. All this suggests that elevated risk on PEDS at young ages is a viable indicator of problems, and not just a reflection of an unhappy parent. Most importantly, the findings indicate that interventions with high risk children need to be multivariate, i.e., encompass parents' well-being, parent-child interactions, as well as promoting children's development.

To comply with the various AAP policies, providers need to elicit and address parents' concerns as well as monitor milestones in all domains and screen for autism spectrum disorders. Evidence is essential and informal questions to parents and milestones questions drawn from other measures lack criteria are clearly not effective. PEDS alone offers a brief, accurate triage approach to early detection and developmental promotion focused on the actual needs of families. But PEDS is enhanced by selective use of a milestones-focused screen such as the PEDS:DM or the ASQ/ASQ:SE.

PEDS' Predictive Validity

Predictive validity research illustrates the relationship between the test under study and future performance on reference standard measures (usually administered one or more years later). Predictive validity studies inform us that a test measures enduring and meaningful aspects of child development, and helps confirm the need to take initial results seriously, i.e., that problems at Time 1 are likely to remain problems years later.

Conducting such studies is an enormous challenge because they are inherently longitudinal and preventing attrition is critical (especially because the families we most want to measure; those with psychosocial risk factors are the most likely to drop out). There are many other considerations for predictive validity studies described in a published paper in *Pediatrics* called "The Thorny Nature of Predictive Validity Studies on Screening Tests for Developmental-Behavioral Problems".[14] Written by the authors of three different screening tests, the chair of the AAP's policy committee on early detection, and an accomplished Canadian screening test researcher, the authors established guidelines for predictive validity studies on screens to which a few suggestions for studying *PEDS* have been added:

1. Intervening variables between data collection points should be accounted for. For example, if a child receives intervention services after screening at age 5, we would hope to see performance improvements when the criterion-battery was administered at age 7. But, intervening variables should also capture changes in psychosocial risk factors (e.g., parents' level of education, marital status, numbers of children in the home, employment, parental well-being, etc.).

2. Real-life events between Time 1 and Time 2 should be included and used, at least in part, as dependent variables (e.g., in-grade retention, high school drop out, injury, witness to violence, etc.) against which to consider changes in outcomes at Time 2.

3. Researchers should ensure that the criterion-

battery is of good quality, i.e., has current and representative standardization, has established reliability and validity and apply meaningful standards to the criterion-battery (e.g., eligibility for special education).

4. Use of a second screening test, even if a different screen, at Time 2 (e.g., age 7) should be avoided because of the error inherent in screening tests (meaning that error can compound rather than simply overlap).

5. The criterion battery should be administered, along with the screen under study, at Time 1 and again at Time 2 in order to establish predictable developmental trajectories and to establish covariance for the screen under study, i.e., answering questions about what is typical variability for a screen.

6. It is wise to view screening test items and performance patterns at Time 1 in relation to Time 2 criterion results. It may be that items not predictive at Time 1, actually are predictive years later—meaning that researchers should search for any significant relationship between screens (both items, score clusters, and results) administered at Time 1 and Time 2.

7. When studying *PEDS*, researchers (and clinicians) should carefully consider the content of concerns (for both concurrent and predictive validity research and quality clinical care). For example, if a predictive study focuses on a subsequent diagnosis of cerebral palsy, even though gross motor concerns on *PEDS* are not always associated with problematic outcomes, researchers/clinicians should use clinical acumen (e.g., to create subcategories of gross motor concerns potentially associated with cerebral palsy such as comments about excessive strength, scissoring, postural rigidity, or floppiness). These subcategories can then be used as predictors of current or future diagnostic outcomes.

8. Given the slender set of items inherent to screening tests and the rapid changes in development status in young children (along with the impact, for better or worse, in psychosocial risk factors), it is not realistic to expect sensitivity/specificity values from concurrent accuracy studies to be as strong as those found in predictive validity studies. Odds ratios or correlations are probably a better way to express relationships over time.

The above is a tall but wise order, but such is the dynamic nature of child development, the influence of intervention and changes in psychosocial risk. Below are described several predictive validity studies on *PEDS* (with commentary on what the findings suggest, and strengths and weakness in research design).

Does *PEDS* Predict a Future Diagnosis of Autism?

Ozonoff and colleagues[15] conducted a particularly exemplary 3 year longitudinal study that adhered thoroughly to the above guidelines for predictive validity research, as well as to *PEDS* scoring directions (including attending to the actual content of concerns and their potential significance, i.e., use of clinical judgment). Entitled "How Early Do Parent Concerns Predict Later Autism Diagnosis?", Ozonoff et al noted that parents often recognize symptoms of autism spectrum disorder (ASD) very early (i.e., one-third of parents raise concerns before a child's first birthday), but that a diagnosis is often not made until the 4th year of life.[15] ASD symptoms surely evolve with time but parents may notice subtle and early manifestations not always measureable with criterion test batteries (e.g., a child may have success with an item confirming use of three word utterances, but parents' verbatim comments may identify a problem: "only says the same three words over and over").

PEDS was administered at 6, 12, and 18 months along with the M-CHAT (at 18 months). A detailed criterion battery was administered at 36 months and included the Autism Diagnostic Observation Schedule (ADOS), the Social Communication Questionnaire (SCQ), and the Mullen Scales of Early Learning (a diagnostic developmental measure providing standard scores for the following domains: Gross Motor, Visual Reception, Fine Motor, Expressive Language, and Receptive Language).

The authors carefully created risk and control groups: Subjects were 174 children who had an older sibling diagnosed with ASD and 100 control children whose older siblings had typical development. There

were no differences in gender, ethnicity, or family income between the two groups. In addition, attrition issues were scrutinized to ensure there were no significant differences in gender, ethnicity or income from those who continued or discontinued participation (N = 31). The authors wisely considered differences in age at enrollment, i.e., 8 ½ months high-risk versus 5 ½ months low-risk) and used these as covariates in their analyses.

Classification of results for the sample of 243, three-year-olds, and the criteria used for determining diagnostic groups, lead to the following:

1. ASD based on ADOS, SCQ results and DSM-IV criteria, [all collated along with expert opinion (N = 26)];

2. Other delays in development or behavior (e.g., global developmental delay, speech-language delayed, marked hyperactivity or anxiety) as determined by performance > 1.5 standard deviations below the mean on one or more Mullen Scales and expert clinical judgment (N = 57);

3. Typical but high–risk, i.e., no diagnosis but older sibling(s) with autism (N = 86);

4. Typical but low-risk, i.e., no diagnosis and older sibling(s) who were typically developing (N = 74).

The researchers carefully coded *PEDS* concerns per the Brief Guide, but also categorized separately comments on *PEDS* that, in their expert opinion, were possibly associated with ASD, i.e., repetitive behavior. This is a commendable approach because *PEDS* calls for clinical judgment about the content and persistence of concerns. So having expert clinicians/coders refine the content of concerns is invaluable and recommended.

In comparing 3 year-olds diagnosed with ASD versus those at-risk but not delayed, parents' concerns at 6 months did not discriminate between the two groups and did not predict an ASD or other diagnosis. The authors hypothesize that parents' concerns at 6 months may be driven, in part, by having an older child on the spectrum. Such worries are understandable and may reflect parents' awareness of genetic contributors as well as a younger child's exposure to and imitation of the unusual behaviors of older siblings on the spectrum.

In contrast, at 12 months, parents of children who were later diagnosed with ASD had far more concerns than at 6 months, especially more of the concerns thought to be associated with ASD. Thus *PEDS* was 83% sensitive to a diagnosis of ASD at age 36 months. Specificity was somewhat limited (60%) meaning that parents held ASD concerns even though their children often had other types of developmental-behavioral problems. The authors recommend that providers take seriously the concerns of parents including those reflecting features of ASD, refer for services, as well as monitor carefully developmental status.

Does *PEDS* Predict Subsequent Deficits in Language and Academic Achievement?

In a two year predictive validity study by the parents and teachers of 268 Australian 5 - 6 year-old children entering one of 22 public schools were administered *PEDS*.[16] (*PEDS* is normed in Australia for use by teacher report although frequencies of concerns raised by teachers are substantially lower than parental concerns. This seems understandable because children imitate each other in classrooms and so behavioral issues, for example, are often less evident to teachers than to parents.) Case children (N = 139) were those whose parents held one or more concerns and control children (N = 129) were those whose parents did not have concerns. The two groups did not differ in terms of language spoken at home, parents' level of education, and children's gender. Both groups were assessed 2 years later (mean age = 8.2 years) with the Comprehensive Inventory of Basic Skills (CIBS-R), the Renfrew Action Picture Test (a measure of general knowledge/vocabulary and grammar). Parents as well as teachers were also readministered *PEDS* (although teachers were only asked to answer 5 of the 10 *PEDS* questions).

Attrition rates were carefully documented. From the original target sample of 302 families, 15% did not participate at Time 2 but demographic characteristics including gender were similar between those who continued to participate and those who did not.

At follow-up, 65% parents in the case group continued to have concerns, often far more concerns. Of the control group parents (those with no concerns at school entry), 25% had concerns two years later.

Parents' and teachers' concerns at baseline were compared to performance on the criterion battery using > 1sd below the mean as a cutoff. Table 4-7 presents the significant relationships between types/numbers of concerns and subsequent performance.

Although the authors did not track interventions provided between school entrance and follow-up two years later, they accounted for in-grade retention. Of the 9 children who repeated a grade between 5 years of age and 7 years of age, 78% (N =7) had parents with at least one predictive concern at baseline.

Does *PEDS* Predict Subsequent Emotional-Behavioral Problems?

Wake et al,[16] using the same sample as above, viewed the predictive validity of *PEDS* at school entrance in light of results of the Child Health Questionnaire (CHQ) administered 2 years later. The CHQ provides scores in Physical Functioning, Role-Emotional/Behavioral, Self Esteem, Parent Impact-Emotional and Parent Impact-Time, plus an overall psychosocial summary score. As seen in Table 4-8, various concerns on *PEDS* were associated with problematic performance on various CHQ factors. Parents holding social-emotional concerns about their children had an extremely high likelihood of overall problematic scores on the CHQ. Other types of concerns and their relationship to the CHQ were not reported but were presumably, non-significant. Teachers' concerns at school entry did not predict any CHQ scores two years later.

Comment on Predictive Validity

It is remarkable that such a slender set of items as PEDS offers enormous predictive value years later. What is particularly noteworthy in the previous studies is the need for careful attention to the type of concern (e.g., social-emotional, self-help and gross motor concerns all lack concurrent validity—meaning they are not always associated with current problems—but have predictive validity for future difficulties). This means that careful follow-up and monitoring are needed whenever concerns are present. Attention to the content of parents' comments is also essential (e.g., discerning descriptions of atypical behavior seen in young children eventually diagnosed with autism spectrum disorder). To facilitate attention to the content of concerns, the following Chapter on PEDS' accuracy, lists the verbatim comments of parents associated with various diagnoses.

Table 4-7. Parents and Teachers Concerns at School Entry Compared to Performance on Diagnostic Measures of Language & Academic Skills Administered Two Years Later (with cutoffs > 1 sd below average and expressed as odds ratios*)

	Renfew Information	Renfew Grammar	CIBS-R Spelling	CIBS-R Reading Composite	CIBS-R Math Composite
Parents' Concerns					
Any predictive concern	--	--	4.6	--	--
1 predictive concern	--	--	--	--	--
> 2 predictive concern--	--	--	5.2	--	--
Global	--	--	--	--	--
Expressive Language	--	--	--	--	--
Receptive Language	--	--	--	--	--
Fine Motor	--	--	5.9	5.8	--
Gross Motor	5.8	--	4.2	--	--
Behavior	--	--	--	--	--
Social-Emotional	--	--	--	--	--
Self-Help	2.8	2.8	--	3.0	--
School	--	--	6.6	3.0	2.9
Teachers' Concerns					
Expressive Language	--	--	--	--	2.8
Receptive Language	--	--	--	--	4.8
Behavior	--	--	--	--	--
Social-Emotional	--	--	--	--	--
School	--	--	3.7	4.7	4.0

* only odds ratios significant at p< .01 or greater are shown

Table 4-8. Parents' & Teachers' Concerns at School Entry, Compated to a Measure of Social-emotional/ Mental Health Skills (the Child Health Questionnaire) Administered Two Years Later (with cutoffs < 16th percentile/> 1sd below average and expressed as odds ratios*)

	CHQ Factors					
	Physical Function-ing	Role-Emotional Behavioral	Self-Esteem	Parent Impact-Emotional	Parent Impact-Time	Psychosocial Summary
Parents' Concerns						
Any predictive concern	2.2	2.2	2.0	2.3	2.5	3.3
Social-Emotional	--	--	--	--	--	10.4
Teachers' Concerns						
Any	--	--	--	--	--	--
Social-Emotional	--	--	--	--	--	--
School	--	--	--	--	--	--

* only odds ratios significant at p< .01 or greater are shown

Discriminant Validity

Discriminant validity studies of *PEDS* refine concurrent validity by determining whether there are unique patterns of parents' concerns associated with diagnosed conditions. For example, do parents of children eventually diagnosed with cerebral palsy have different types of concerns than do parents of children diagnosed with autism spectrum disorder? This is not to suggest that diagnoses should be made on the basis of a screening test, but rather to make visible the strengths and weaknesses of *PEDS* and to help clinicians make refined and appropriate referral decisions.

Discriminant validity studies often use discriminant function analysis or logistic regression to identify which items predict the presence or absence of a specific condition. While helpful for raising clinical awareness, such statistical methods are only a starting point and do not offer definitive information for making clinical decisions. A better approach is to conduct discriminant sensitivity studies in which are reported the unique clusters of concerns that identify specific diagnoses and thus referral needs. So in the next chapter, on criterion-related validity, i.e., accuracy, are presented not only broad studies on *PEDS*' identification rates, but also new and prior studies on *PEDS*' strengths and weakness in detecting specific conditions.

Summary of Original Validity Research

- *PEDS* is highly correlated with diagnostic measures of development, including academics, intelligence, language, and motor skills. Specific concerns do not always have a clear corresponding relationship with children's performance in the same domain, illustrating that parents' definitions of developmental domains may differ somewhat from that of professionals.
- *PEDS* has a high degree of discriminant validity. There are unique patterns of concerns that served as significant predictors of some types of disabilities.
- Certain parental concerns carry very high probabilities that children have developmental problems.

Summary of 2013 Validity Research

- *PEDS*' content validity is evident in the commendations of other researchers who find that *PEDS* facilitates a discussion of concerns across domains of development (also meaning behavioral, social-emotional/mental health, as well as physical health) in a way that other parents' concerns questions do not.
- *PEDS*' construct validity is shown in the finding that each type of parent concern clusters in predictable ways via associations among related domains (e.g., fine motor and gross motor; expressive and receptive language).
- The concurrent and convergent validity of *PEDS* was studied on 11,270 children in relationship to diagnostic measures of development, including academics, intelligence, language, and motor skills, along with two different broad-band screening tests. Although each type of parental concern enjoys significant associations with measures or subtests focused on the same domain, parents often have concerns in seemingly unrelated domains. For example, academic deficits are associated with social-emotional concerns—meaning parents may be commenting on self-esteem problems related to under-achievement or difficulties performing well in a group, i.e., parents' concerns may reflect not just the apparent problem but also its impact on other aspects of development.
- *PEDS*' predictive validity is established in three studies of 442 children showing that concerns raised early in a child's life have a strong association with diagnoses such as ASD, school failure measured 18 months to 2 years later.

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Chapter V

Accuracy in the Detection of Children with Difficulties

Critical Concepts in Screening and Test Construction
Accuracy

Accuracy (also known as *criterion-related validity*) is the most critical type of research on screening tests. Accuracy studies provide information on detection rates, over- and under-referral rates, which types of disabilities are or are not detected well, etc. It is from these studies that test authors provide clinically useful information on when and when not to refer and if referring what types of evaluations are needed. Accuracy research also helps answer such pressing questions as: *"When a child does poorly on a screen, what is the chance he or she truly has a problem?"* Finally, accuracy studies often view how well a screen detects specific diagnoses.

The various indicators of accuracy, their definitions, and how they are computed are described in detail in the beginning of this chapter. Research on the accuracy of *PEDS* follows. Because establishing the accuracy of a screening test involves comparing screening test results to performance on criterion measures, this discussion begins with various ways to define the reference standard.

Ways of Establishing Criterion Performance

The process of conducting accuracy studies, and the various indices they produce, begins by establishing criteria against which cutoff scores on screens are established via comparison to "the gold standard" (a vernacular term but often used). Inherently, criteria for both the gold standard as well as the results of screening measures must be binary (e.g., pass versus fail, below-average versus average and above). But, there are many ways to establish criteria against which to judge screening test performance. Options include:

(a) Determining eligibility for services, i.e., a child receives or does not receive a diagnosis of any kind that enables matriculation into special education programs).

(b) Deploying a battery of diagnostic measures. The criterion battery should provide unique scores for each domain measured by the screening test under study. In the case of *PEDS*, criterion measures should measure and produce scores for at least the 9 types of parental concern about development, i.e., expressive language, receptive language, gross motor, fine motor, behavior/social-emotional, self-help, academic skills, and global/cognitive.

To the criterion battery should be applied performance standards germane to each test studied.

For example, *PEDS* is tied to performance > 1 standard deviation below average versus average/above average. The ASQ is tied to performance > 2 standard deviations below average versus average/above. The Brigance Screens are designed to detect the talented and gifted, meaning that two different sets of criteria are needed (below average versus average/above average and separately below average/average versus above average. This means that researchers should consider various criteria, preferably multiple criteria when studying screens [e.g., 1, 1 ½ and 2 standard deviations below the mean, and if appropriate, 1 ½ - 2 standards deviations (sd) above the mean].

c) The criteria applied to the gold standard should focus on the types of evaluations needed. Even when referral to public special education services is the "one-stop-shop", providers will still want to suggest the types of testing needed (e.g., whether most pressing is a speech-language evaluation or a psychoeducational evaluation, usually meaning measures of intelligence and adaptive behavior and/or measures of intelligence and academic achievement).

d) Another alternative in accuracy studies, is to sort criterion battery results (usually along with expert opinion) into specific types of diagnoses (or lack thereof). Such is the basis for discriminant sensitivity studies that tell us how well screens work in detecting specific conditions. Again, because results have to be binary, such studies can sort, for example, children with cerebral palsy from those without or children with cerebral palsy versus those with other conditions (the latter may be more helpful in clinical decision-making, e.g., sorting, in the case of *PEDS*, unique patterns or content of concerns associated with CP from concerns associated with other problems). Although any diagnosis needs to be born from the results of diagnostic measures and expert judgment, the clinical value of such studies is to raise providers' awareness of probable problems and thus aid in deciding, for example, whether a referral to neurology, physical or occupational therapy is needed or not.

e) Finally, the results of screens must be sorted (and also resorted) into binary categories. Some measures (e.g., the Battelle Developmental Inventory Screening Test) produce cutoffs at 1, 1 ½, and 2 standard deviations below the mean. This means that careful studies of the BDIST's accuracy require its results to be lumped and re-lumped. (e.g., by defining typical development as < 1sd versus < 1 ½ sds, or atypical development as > 1 ½ versus > 2 sds below the mean. Each cutoff on the screen should be tested against criterion results.

With *PEDS* such sorting of results is even more of a challenge because it produces four scores: high, moderate, and low risk but concerned, versus low risk scores. And, the low risk but concerned scores gain predictive value for mental health problems after 4 ½ years of age. This means there can be five distinct results depending on the ages in the sample and the type of diagnoses studied. But the same lumping/re-lumping as described above is still applicable (e.g., Path A + Path B versus Path C+ Path E; Path A versus Path B+C+E, Path A +Path C for children > 4 years, etc.). A bit bewildering but do-able and thoroughly informative. You can email us through *www.pedstest.com* if you need research support or help with translation studies, implementation advice, etc.

Determining an Optimal Cutoff on Screens

Having established method(s) for sorting the results of diagnostic measures as well as those of screening tests, the analysis can now begin! Many test authors and researchers start with Receiver Operating Characteristic (ROC), which is a graph of screening test scores compared to criterion results. ROC, developed from radar technology as it emerged during World War II, helps determine a cutoff score on screens as associated with diagnostic test results, i.e., the optimal balance between detecting as many problems as possible while also correctly identifying as many non-problems as possible.

ROC analysis [available in the Statistical Package for Social Sciences (SPSS) and other software], produces an enormous range of statistics. Much journal space is given to information such as "the area under the curve," but the main point of ROC is to find the

best cutoff score for identifying problems and also non-problems. So the essentials of ROC can also be completed via simple arithmetic by viewing relationships between screening performance and that of diagnostic measures.

It is important to remember that there are about six times as many typically developing children than there are children with delays. So, even though our goal in screening is to detect children with problems, we must also do our best to avoid classifying as problematic children who actually don't have problems. The basic standards for a screening test are at least 70% correct detection of children without and without problems, but preferably > 70% when it comes to detecting those without problems.

For example, given cutoff options of 79% sensitivity and 72% specificity versus 72% sensitivity and 79% specificity, it would be best to choose the latter. This solution dramatically decreases over-referrals while still maintaining an acceptible rate of problem detection.

Indicators of Screening Test Accuracy

Once optimal cutoff scores are established for a screen (and for criterion performance), the results of the screen and the criterion standard are intersected. Figure 5-1 shows an example and the terms used for each. Definitions are provided in the legend.*

Figure 5-1. Terms for Computations for Accuracy Indices in Screening Tests

Sreening Test	Diagnosis: NO	Diagnosis: YES	
Pass	70 (co-negatives/ true negatives)	4 (false-negatives)	74
Fail	10 (false positives)	16 (co-positives/ true positives)	26
	80	20	/100

*Legend

Definitions:

True/co-positives: The numbers of children with problematic screening scores and problematic results on diagnostic testing.

True/co-negatives: The numbers of children with non-problematic screening scores and non-problematic results on diagnostic testing.

False-positives: The numbers of children with problematic screening scores but non-problematic results on diagnostic testing.

False-negatives: The numbers of children with non-problematic screening scores but problematic results on diagnostic testing.

Computations (and their Definitions) in Screening Test Accuracy

Having intersected (as shown in Figure 5-1) the results of the screen and the criterion battery, the following computations and terms are used:

Sensitivity

This analysis answers the question: What percentage of children found to have problems on the diagnostic battery were detected by a screen? The computation involves dividing the numbers of true/co-positives by the sum of true positives/co-positives +false negatives. In this case, 16 of 20 children diagnosed also performed poorly on screens but 4 of the 20 diagnosable children passed the screen. So sensitivity is 16/20 = 75%.

Ideally, all children with disabilities would score below cutoffs on a screen and thus identified as needing referrals for further evaluation/special services. In reality, detection of disabilities is imperfect due to behavioral noncompliance, psychosocial malleability, age-related skill changes in development, imperfections in reference tests (hence the reason for the term co-positivity), and ultimately the necessary brevity of screens. So basic standards for sensitivity are 70% to 80%. While this figure may seem low, many tests fail to attain this level of accuracy. Higher sensitivity may be found if using stringent performance criteria on the reference battery (e.g., 2nd percentile or lower) but such criteria are not appropriate if a screen is designed to identify not only children who probably need IDEA services but also those with milder delays in need of services such as Head Start or quality day care (e.g., < 16th percentile). Nevertheless, because screening tests should be re-administered over time wherein information gleaned from surveillance activities can also be brought to bear, especially on negative (meaning passed) screens, detection rates may improve given repeated measurement.

Specificity

This analysis answers the question: What percentage of children found to have typical development on diagnostic measures also passed the screen? The computation involves dividing the number of true/co-negatives divided by the sum of true/co-negatives+false positives . In this example, 80 children had typical development on diagnostic testing, 70 passed the screen but 10 did not. So specificity is 70/80 = 88%.

As with sensitivity, we would all prefer that 100% of typically developing children pass a screening test, but the exigencies of development and its measurement do not accord such accuracy. So, 70% - 80% specificity is a basic standard, but within that range, closer to 80% or higher is desirable because there are many more typically developing children than not: For each decrement in specificity, there is essentially a geometric increase in over-referrals. So, the balance of sensitivity and specificity needs to be tipped toward specificity if at all possible while still keeping sensitivity in the 70% - 80% ballpark for screening test standards. Again, typical development needs to be carefully defined, often in multiple ways (e.g., is "normal" defined as children not eligible for special services, or does it also include the non-eligible but delayed such as those scoring below the 16th percentile?).

Negative Predictive Value

This term answers the question: If a child passes a screen, what is the chance that he or she does not have an actual problem? The computation involves dividing the number of true/co- negatives by the sum of true/co- negatives+false negatives. In this case, 70 out of 74 children with a passed screen were not found to have problems on diagnostic testing. So the negative predictive value is 70/74 = 95%.

Under-referral rate

This term answers the question: What percentage of children did a screening test fail to detect correctly? The computation divides the number of children without problems on screens by the total number without problems on diagnostic testing. In this case, 4 children who passed screening were found to have a problem on diagnostic evaluations, so 4/74 = 5%. This computation is the same as subtracting negative predictive value from 100%. So in this example, 100% minus the 95% (negative predictive value) equals 5% under-referral rate.

Positive Predictive Value

This term answers the question: If a child fails a screen, what is the chance that he or she truly has a problem, i.e., what percentage of problematic screening results are actually associated with problems on diagnostic measures? The computation involves dividing the number of true/co-positives by the sum of true/co-positives+false positives. In this example, 16 of 26 children who failed the screen also had problems on diagnostic testing, but 10 of the 26 children who

failed the screen did not have a problem on diagnostic testing. So positive predictive value is 16/26 = 62%.

Over-referral rate

This term answers the question: What percentage of children were over-referred for seemingly unnecessary evaluations? The computation involves dividing the false positives (those who did poorly on screens but did not have a problem on diagnostic tests) by the total number of positive screening results. In this case, 26 children had positive results but 10 children were false positives—meaning over-identified as having problems when they actually did not. So the over-referral rate is 10/26 = 38%. This computation is the same as subtracting positive predictive value from 100%. In this example 100% minus the positive predictive value of 62% equals a 38% over-referral rate.

Comment on Over-referral rates

It is important to note that the 38% over-referral rate in the above example, doesn't reflect 38% of all patients, but rather only 10% (10 out of 100 patients). Even so, clinicians are often alarmed at over-referral rates and may be reluctant to refer as a consequence. Should they be? No!!! Described below (in the section called "New Accuracy Studies") is a study on PEDS (plus three other screens) showing that over-referred children still had mild, and possibly increasing delays due to high numbers of psychosocial risk factors. Even if over-referred children do not qualify for IDEA programs, they remain at risk, need vigilant monitoring/rescreening, and most immediately, they need referrals to other types of interventions (e.g., Head Start, Chapter I public school services, parent training, quality day care, social services, mental health programs, etc.). All this means that it is better to refer all children to IDEA who do poorly on screens, and then figure out what else is (surely) needed.[1]

An Accuracy Indicator to Avoid: Hit-Rates

Hit-rates are simply the total number of children for whom a screening test gave accurate information when compared to diagnostic measures. So, co-positives and co-negatives are added together and then divided by the entire sample (co-positives + co-negatives+ false-positives + false negatives). But hit rates are an extremely misleading statistic because the preponderance of results are co-negatives—meaning that specificity carries excessive weight. For example, a high hit rate (e.g., 91%) could mean that 99% of typically developing children were correctly detected (e.g., 89 out of 90) but only 20% of children with problems were correctly detected (e.g., 2 out of 10). Hit-rates can mask serious flaws in accuracy (and most especially serious flaws in sensitivity).

Discriminant Sensitivity

How well do screens detect specific conditions? A final evaluation of screening test accuracy is discriminant sensitivity—a recently coined term for research on how well a screen identifies specific conditions and/or the types of evaluations needed. The analysis involves grouping results from the criterion battery into diagnostic categories (e.g., language impairment, ASD, motor disorders, etc.). Because we always have to deal with binary results for any type of accuracy studies, generally a target diagnosis (e.g., cerebral palsy) can be compared to all other diagnoses with the latter being lumped together, i.e., CP versus not CP. Next children with failing scores on a screen (often in combination with those who were false-negative, i.e., passed the screen but on the criterion measures were found to have a disability), are compared to specific diagnoses or unique referral needs (e.g., children diagnosed with learning disabilities or intellectual impairment require a psycho-educational evaluation, while children with language impairment or ASD both need speech-language evaluations—although with ASD, measures of speech-language are only one among many types of measures required).

Researchers conducting discriminant sensitivity studies tend to adhere to the usual standards for screening tests: At least 70% to 80% of children diagnosed with specific conditions are correctly sorted from other diagnoses. Such research often involves searching for unique patterns of performance on screening tests associated with one diagnosis but not associated with any others. A very nice example of this is seen in the Ozonoff et al[2] study (described in the predictive validity section of the previous chapter) wherein extracting repetitive behaviors as a subcategory on *PEDS* discriminated ASD from other conditions (and also, in the case of this study, helped predict a future diagnosis of ASD).

2002 Original Accuracy Studies

The most important technical aspect of a screening test is accuracy. Information about accuracy lets test users know the percentage of children with and without problems correctly identified, allowing professionals to select tests with the best possible performance. Each separate *PEDS* study included an assessment of accuracy in order to identify which parental concerns best identified children with and without problems. Repeated evaluation of *PEDS'* accuracy across studies revealed the need for slight revisions to the scoring criteria. For example, one study that included children over the age of six years, showed for the first time that concerns about gross motor skills were significant predictors of developmental problems. For this reason, the entire data set of 771 children (excluding the first 200 subjects used to standardize but not validate *PEDS)* was re-analyzed in order to determine the optimal set of concerns to discern children with and without problems. This re-analysis is described next.

Procedures

The results of concurrent measures were used to categorize children into those who met various criteria for disabilities and those who did not. To assess accuracy, the diagnostic test results were further grouped into two categories: presence or absence of a disability. The various parental concerns were then used to predict whether or not children had disabilities (via discriminant function analyses run on each age group shown below). At each age level, the results attained statistical significance. Certain concerns were found to be significant predictors of the presence or absence of developmental disabilities at different ages. Further, the types of concerns found to be predictive increased with age. Table 5-1 shows the predictive concerns for each age group.

Table 5-1. Concerns Found to be Predictive at Various Ages

0 to 1½ years	Global/Cognitive, Expressive Language, Medical/Other, Social-Emotional
1½ to 3 years	Global/Cognitive, Expressive Language, Medical/Other, Receptive Language
3 to 4½ years	Global/Cognitive, Expressive Language, Medical/Other, Receptive Language, Gross Motor
4½ to 7 years	Global/Cognitive, Expressive Language, Medical/Other, Receptive Language, Gross Motor, Fine Motor, School

After predictive concerns were identified, their presence or absence was intersected with the presence or absence of disabilities. This showed *PEDS*' accuracy at different age levels, as shown in Table 5-2 (a-d). The tables reveal that for each age group, *PEDS* meets accuracy standards for screening tests with levels similar to quality screening measures that take far longer to give.

Table 5-2a. Accuracy of Concerns for Children 0 to 1½ years of age (N=86)

Predictive Concerns	Disability: No	Disability: Yes	
No	66	1	67
Yes	16	3	19
	82	4	

sensitivity (3/4) = 75%
specificity (66/82) = 80%
positive predictive value (3/19) = 16%

Table 5-2b. Accuracy of Concerns for Children 1½ to 3 years of age (N=183)

Predictive Concerns	Disability: No	Disability: Yes	
No	117	7	124
Yes	32	27	59
	149	34	

sensitivity (27/34) = 79%
specificity (117/149) = 80%
PPV (27/59) = 46%

Table 5-2c. Accuracy of Concerns for Children 3 to 4½ years of age (N=200)

Predictive Concerns	Disability: No	Disability: Yes	
No	118	9	127
Yes	47	26	73
	165	35	

sensitivity (26/35) = 74%
specificity (118/165) = 72%
PPV (26/73) = 36%

Table 5-2d. Accuracy of Concerns for Children 4½ to 7 years of age (N=302)

Predictive Concerns	Disability: No	Disability: Yes	
No	172	15	187
Yes	73	42	115
	245	57	

sensitivity (42/57) = 74%
specificity (172/245) = 70%
PPV (42/115) = 37%

Table 5-3. Accuracy of *PEDS* for the Total Sample(N=771)

Predictive Concerns	Disability: No	Disability: Yes	
No	473	32	505
Yes	168	98	266
	641	130	

sensitivity (98/130) = 75%
specificity (473/641) = 74%
PPV (98/266) = 37%

Why are Parents' Concerns Accurate?

As described in Chapter VII, one *PEDS* study explored how parents derived their concerns in an effort to understand why concerns are accurate indicators of developmental problems. In this research involving 100 parents from pediatric offices, parents were asked why they thought their children might be "having difficulties" or were "developing all right." Sixty-seven percent of parents were found to derive concerns by comparing their children to others (e.g., "I watch other kids and see what they can do").[3] Comparison is a relatively simple cognitive skill parents can employ regardless of intellectual ability or educational status. Even parents of only children reported making comparisons (although often somewhat tentatively), often identifying places such as pediatric waiting rooms, supermarkets and church nurseries where they observed other children. This finding may explain why most parents can raise accurate concerns despite differences in parenting experience, levels of education, etc.

Exploring Parental Accuracy and Error

In order to better understand the nature of parents' concerns and their accuracy, concerns were intersected with diagnostic measures to produce four groups of parents: Those who are accurately concerned (parents of children with disabilities who had one or more predictive concerns), inaccurately concerned (parents of children without disabilities who nevertheless had predictive concerns), accurately nonconcerned (parents of normally developing children without predictive concerns), and inaccurately nonconcerned (parents of children without disabilities who had no predictive concerns). The four groups were compared and contrasted using chi-squares and analyses of variance (with Tukey's post-hoc tests). Data from one *PEDS* study on 408 children from around the U.S.[4] was used for the analysis, because children were administered a particularly extensive battery of diagnostic tests. The prevailing questions, similarities and differences among groups are highlighted below.

Parents With Normally Developing Children: Are Some Excessively Concerned?

Of the 352 parents of normal children, 259 (74%) had no concerns or nonpredictive concerns (accurately nonconcerned) while 93 (26%) had predictive concerns (inaccurately concerned). These two groups of parents and their children differed in several ways, as shown in the second two columns of Tables 5-4 and 5-5.

Although the children of inaccurately concerned parents scored within the broad range of normal, they nevertheless had significantly lower scores on almost all measures including intelligence, reading, fine and gross motor skills, and expressive language. Inaccurately concerned parents were also more likely than nonconcerned parents to worry about their children's skills in the areas of self-help, socialization, and behavior [(χ^2) = 40.50; 24.09, ($p < .0001$) and 7.30, ($p < .01$)]. More than 25% of inaccurately concerned parents felt their children had serious or somewhat serious medical problems ($\chi^2 = 21.07$, $p < .0001$) and they endorsed more items on the Child Development Inventory's (CDI) health and behavior checklist including: "eating problem—eats poorly or too much," ($\chi^2 = 16.53$, $p < .0001$) and "sleep problems" ($\chi^2 = 14.79$, $p < .0005$).

Parents also tended to endorse one or more CDI items tapping perceived difficulties with articulation, vocal fluency or other language skills ($\chi^2 = 53.29$; 50.20; 22.80; 19.89, $p < .0001$).

These findings suggest that many parents who initially appear to be overly concerned are actually astute observers of their children's development. Such parents seem to be noticing subtle delays that may contribute to less-than-optimal performance on language, motor or school tasks. While their children do not qualify for public special education services, they may benefit from private therapies, and above all from developmental promotion (e.g., suggestions on how to stimulate language development at home) and advice from their providers (e.g., to ensure adequate understanding of any health problems including caloric intake and sleeping skills). Nevertheless, an important next step is to discriminate parents whose concerns are predictive of disabilities and whose children clearly need referrals for diagnostic evaluations, from families whose children do not need testing.

Table 5-4. Comparison of Parents' Judgments by Children's Characteristics

	Relationship Between Parents' Judgments and Developmental Status				
Characteristics of Children	Accurately Nonconcerned (N = 259)	Inaccurately Concerned (highly observant) (N = 93)	Accurately Concerned (N = 44)	Inaccurately Nonconcerned (N = 12)	F
Intelligence Quotient	110[c]	103	96	101	12.06[a]
Reading/Pre-reading Quotient	100[c]	96	89	96	9.08[b]
Math/Pre-math Quotient	102[e]	99	94	99	4.66[b]
Written Language Quotient	94	90	86	93	2.90
Social Skills Quotient	87[d]	80[e]	58	65	19.00[a]
Self-help Quotient	97[e]	93[e]	76	89	13.28[a]
Fine Motor Quotient	89[c]	84[e]	73	83	12.10[a]
Gross Motor Quotient	89[c]	84[e]	73	83	11.95[a]
Expressive Language Quotient	100[c,f]	92[d]	58	66	52.43[a]
Receptive Language Quotient	91[d]	86[d]	57	63	48.98[a]
Age (in months)	54	57	59	61	1.60
	Percentage	Percentage	Percentage	Percentage	χ^{2} [h]
First born	43%	32%	41%	58%	4.79
No prior or current enrollment in day care or school	33%	34%	41%	58%	4.11
	R I S K F A C T O R S				
Four or more children in the home	2%[e]	6%	16%	0%	19.04[a]
Race (minority)	20%	15%	40%	42%	6.07
Eligible for Chapter I[g]	17%[d]	26%	50%	42%	25.93[a]
Four or More Risk Factors (including those in Table 12-5)	12%	10%	16%	25%	2.95

[a] *p < .0001*

[b] *p < .005*

[c] *Significantly different from inaccurately concerned and accurately concerned groups.*

[d] *Significantly different from accurately concerned and inaccurately nonconcerned groups.*

[e] *Significantly different from accurately concerned group.*

[f] *Significantly different from inaccurately nonconcerned group.*

[g] *Chapter I is a federally funded program placed only in low-income neighborhoods. It provides large-group remedial assistance in math and reading in elementary schools. Eligible students are those who score at or below the 16th percentile (equivalent to a standard score of 85) on measures of reading, math, or written language.*

[h] *Between-group comparisons were also computed and are noted in superscript next to each figure.*

Table 5-5. Comparison of Children's Developmental Status by Parents' Characteristics and Judgments

Characteristics and Judgements of Parents	Relationship Between Parents' Judgments and Developmental Status				
	Accurately Nonconcerned	Inaccurately Concerned (Highly Observant)	Accurately Concerned	Inaccurately Nonconcerned	F
Average number of concerns	0.2[c]	1.4[f]	2.2[f]	0.1	130.26[a]
Average number of predictive concerns	0.0[c]	1.6[f]	2.3[f]	0.0	209.72[a]
Average number of problems items endorsed on the CDI	1.2[c,f]	2.2[e]	3.1	2.3	34.78[a]
R I S K F A C T O R S					
Parent's age (in years) at child's birth	27.4	28.0	29.0	26.0	1.40
Parent's level of education (grades completed)	13.1	13.3	12.9	12.4	0.53
	Percentage	Percentage	Percentage	Percentage	χ^{2h}
Non-English speaking	5%[f]	5%[f]	7%[f]	25%	7.79
Not married	32%	31%	50%	33%	5.63
Low income (child qualified for federal free lunch)	29%	37%	36%	25%	2.84
O T H E R C H A R A C T E R I S T I C S					
Had concerns about child's:					
Self-help skills	4%[c]	27%[e]	52%[f]	0%	89.25[a]
Social skills	8%[c]	29%[e]	54%[f]	8%	63.71[a]
Behavior	28%[c]	43%	64%[f]	17%	26.22[a]
Felt children's medical problems were somewhat serious or serious	7%[c]	24%	23%	0%[c]	26.47[a]
Affirmed the following items on the CDI Problem Checklist: [g]					
Growth, height or weight problems	4%[c]	10%	23%	17%	21.48[a]
Eating problem—poorly or too much	8%[c,f]	24%	23%	33%	22.53[a]
Sleep problems	5%[c]	17%	10%	0%	16.08[b]
Does not pay attention; poor listener	3%[d]	13%	25%	25%	30.08[a]
Clumsy; walks or runs poorly, stumbles or falls	2%[d]	3%[e]	18%	0%	27.08[a]
Disobedient; does not mind well, resists	10%[d]	10%[d]	29%	25%	16.25[b]

[a] *p < .0001*
[b] *p < .005*
[c] *Significantly different from inaccurately concerned and accurately concerned groups.*
[d] *Significantly different from accurately concerned and inaccurately nonconcerned groups.*
[e] *Significantly different from accurately concerned group.*
[f] *Significantly different from inaccurately nonconcerned group.*
[g] *Only those CDI items on which there were group differences are presented here.*
[h] *Between-group comparisons were also computed and are noted in superscript next to each figure.*

Which Children with Concerned Parents Have Measurable Difficulties?

To assess differences between groups, the 93 inaccurately concerned/highly observant parents (those with concerns whose children did not have disabilities) were compared to the 44 accurately concerned parents (whose children met criteria for special education services) as shown in Tables 5-4 and 5-5, third and fourth panels. Apart from the obvious differences in how their children performed on criterion measures, the two groups differed in several ways: Accurately concerned parents were far more likely to raise nonpredictive concerns, i.e., socialization, behavior, or self-help skills. Parents with accurate concerns also endorsed more Possible Problems items on the CDI including: "Clumsy; walks or runs poorly, stumbles or falls," and "Disobedient; does not mind well, resists," [χ^2 = 9.05; 8.75, p < .01].

Perhaps most importantly, parents with accurate concerns were almost three times as likely to raise more than one predictive concern [OR = 2.9, CI = 1.4 = 6.0]. Only one-third of the inaccurately concerned parents had multiple predictive concerns, whereas almost two-thirds of the accurately concerned parents had multiple predictive concerns. Table 5-6 shows the frequency of predictive concerns and positive predictive value (percent found to have developmental problems upon referral). Table 5-7 shows the consistency of these values across all age levels on all 771 subjects.

Table 5-6. Frequency of Single Versus Multiple Concerns by Disability Status on 408 Families

	No Disability	Disability	Positive Predictive Value	
No/Nonpredictive Concerns	259	12		
Single Predictive Concern	62	18	18/80	22%
Multiple Concerns	31	26	26/57	46%
TOTAL	**352**	**56**		

Total Sensitivity = 44/56 = 78%
Total Specificity = 259/352 = 74%
Total positive predictive value = 44/137 = 29%

Table 5-7. Frequency of Predictive Concerns in Relation to Disability Status for the Total Sample of 771 Patients

	No Disability	Disability	Positive Predictive Value	
Age 0 to 1½ years				
No or Nonpredictive Concerns	66	1		
Single Predictive Concern	15	2	2/17	12%
Multiple Concerns	1	1	1/2	50%
SUBTOTAL	**82**	**4**		
Age 1½ to 3 years				
No or Nonpredictive Concerns	117	7		
Single Predictive Concern	26	18	18/44	41%
Multiple Concerns	6	9	9/15	60%
SUBTOTAL	**149**	**34**		
Age 3 to 4½ years				
No or Nonpredictive Concerns	118	9		
Single Predictive Concern	35	15	5/50	30%
Multiple Concerns	12	11	11/23	48%
SUBTOTAL	**165**	**35**		
Age 4½ through 7 years				
No or Nonpredictive Concerns	172	15		
Single Predictive Concern	51	18	18/69	26%
Multiple Concerns	22	24	24/46	52%
SUBTOTAL	**245**	**57**		

	No Disability	Disability	Positive Predictive Value	
All Ages				
No or Nonpredictive Concerns	473	32		
Single Predictive Concern	127	53	53/180	28%
Multiple Concerns	41	45	45/86	52%
TOTAL	**641**	**130**		

When is a second screening test helpful?

The findings in Tables 5-6 and 5-7 suggest one obvious approach to identifying which children of parents with a single predictive concern have probable disabilities and which children do not is to administer a second screening test. This potential impact on the accuracy of *PEDS* is presented below, again using the group of 408 families whose children had especially extensive testing. In this sample, the Brigance Screens[4,5] were also administered along with *PEDS*. The Brigance Screens are frequently used in U.S. and Australian public schools and preschools. Norms for the Brigance Screens enable users to view strength and weakness in language, spatial-motor skills and general knowledge, and reading/receptive language. The Brigance Screens involve direct elicitation of children's skills. There are separate forms at various ages: 1½ - 2, 2½, 3, 4, Kindergarten, and First grade. The measure takes about fifteen minutes to administer and score. Its total sensitivity is 74% and specificity is 78%, and at all age levels, sensitivity and specificity reach standards for screening tests, with both values between 70% and 80%.

Of the 80 children whose parents had only one predictive concern, 18 had undiagnosed disabilities and 62 did not. Brigance Screen results for this group are presented in Table 5-8. Recognizing that these children are generally below average, it is no surprise that half the children not eligible for special education still failed the Brigance Screens.

Table 5-8. Brigance Screen Results on Children for whom there is a Single Predictive Concern

Brigance Screens	Disability: No	Disability: Yes
Pass	31	5
Fail	31	13
	62	18

Table 5-9 shows the effects on the accuracy of *PEDS*, when the results of the Brigance Screens are substituted for the original *PEDS* decisions for the group with a single predictive concern (from Tables 5-6 and 5-7). Specifically, referral accuracy improves. Specificity improved by 8%, positive predictive value by 7% and although sensitivity dropped by 8%, the results are still within acceptable limits for screening test accuracy.

Table 5-9. Accuracy of *PEDS* when Brigance Screens Results are used to make Referral Decisions with Families who have a Single Predictive Concern

	Disability: No	Disability: Yes	
Nonpredictive or single predictive concern and child passed Brigance Screen	290	17	307
Multiple predictive or single predictive concern and child failed Brigance Screens	62	39	101
	352	56	

Sensitivity	(39/56)	= 70%
Specificity	(290/352)	= 82%
Positive Predictive Value	(39/101)	= 39%

Overall, the findings illustrate that use of a second screening test in response to a single predictive concern can improve the specificity of referral decisions. The increase in specificity without a substantial decrease in sensitivity is important, because there are so many more children without problems than with. Therefore, keeping specificity in the higher end of the 70% to 80% range minimizes over-referrals and their high associated costs.

Why Not to Screen Those with Multiple Predictive Concerns?

Should screens be administered to those with multiple predictive concerns as well? The answer is a resounding no. As shown below, when children whose parents had multiple predictive concerns are administered screening tests, the error inherent in screening is compounded and sensitivity drops below acceptable levels. Specifically, of the 57 parents with multiple concerns, 46% (N = 26) had children with disabilities. Of the remaining 31, 13 had significantly below-average academic, intellectual, or linguistic achievement. Thus a total of 39, or 69% of the entire group could benefit from additional evaluations in order to better define their problems and needed resources. If, instead of referring all 57, a screening test is administered and these results used to make referral decisions, eight of the 26 children with disabilities would be missed, as would seven of the children with below-average abilities. Table 5-10 (first box) shows the overall results for *PEDS* if children of parents with multiple predictive concerns are screened instead of referred. The second box in Table 5-10 shows the original decisions. Comparing the two sensitivity indices shows that screening in response to multiple predictive concerns lowers sensitivity below acceptable levels.

Table 5-10. Using a Second-stage Screen with Children whose Parents have Multiple Predictive Concerns (Box 1) as Compared with Simply Referring Children for Diagnostic Testing (Box 2)

	Disability	
	No	Yes
No concern or pass Brigance Screens	274	20
Single predictive concern or fail Brigance Screens	78	36
	352	56
sensitivity	(36/56)	= 64%
specificity	(274/352)	= 78%
PPV	(36/114)	= 32%

	Disability	
	No	Yes
No concerns	259	12
One or more predictive concerns	93	44
	352	56
Total sensitivity	44/56	= 78%
Total specificity	259/352	= 74%
Total PPV	44/137	= 29%

Discriminant Sensitivity: What kinds of referrals should be made?

In order to view *PEDS'* clinical usefulness in helping decide what kinds of referrals are needed, children with disabilities whose parents had two or more concerns were divided into two groups: Those whose disabilities required speech-language assessment to determine program eligibility, i.e., those found to have speech-language impairments versus such disabilities as intellectual disabilities or learning disabilities for which intellectual, adaptive behavior, and educational testing are needed. It's important to remember that these three disabilities are the most common, and account for 90% of all disability diagnoses.

Logistic regression was then conducted using parents' concerns as predictors. This analysis revealed that two or more concerns about receptive language, self-help, school and social skills predicted the presence of speech-language disabilities, while fewer than two concerns in these areas predicted the need for psycho-educational testing, as shown in Table 5-11.

Table 5-11. Referral Accuracy when Parents have Two or More Predictive Concerns

	Speech-Language Impairment Only	Other Impairment
Two or more parental concerns about self-help, social, school or receptive language skills	259	12
Less than two such concerns (and concerns in other areas)	93	44
	352	56
Sensitivity (to the need for speech-language testing only)	(19/24) = 79%	
Sensitivity (to the need for psycho-educational evaluations)	(15/21) = 71%	

The above illustrates that *PEDS* can make some basic discriminations among children with the most common disabilities, and that those needing speech-language evaluations can be identified by the presence of two or more parental concerns about self-help, social, school, or receptive language. At the same time, children needing intellectual and educational testing can be identified if there are fewer than two such concerns.

These findings, while helpful, should be used with caution, especially for children old enough to be enrolled in regular education programs. Children without intellectual disabilities or learning disabilities but with speech-language impairments, often begin to have trouble with reading comprehension or other academic tasks as they mature, and may need both speech-language and psycho-educational evaluations. Similarly, children with intellectual disabilities or learning disabilities often need speech-language evaluations to determine whether this developmental domain is noncontributory or in need of intervention. Finally, this particular analysis cannot provide sufficient guidance regarding the need for occupational or physical therapy, counseling, etc. Thus, until there is further research, providers should use the above for initial decision-making, but should also rely on professional judgment to decide whether additional kinds of testing are needed.

Why do some parents of children with disabilities fail to raise predictive concerns?

Returning to the sample of 408 children (because they were administered particularly extensive diagnostic testing), of the 56 parents whose children met criteria for special education services, 44 raised one or more predictive concerns. The remaining 12 had no or nonpredictive concerns. These groups were compared and found to differ in the following ways, as shown in Tables 5-4 and 5-5: Parents with accurate concerns were more likely to also have nonpredictive concerns including self-help skills, social/emotional, and behavior. Inaccurately nonconcerned parents had children with significantly higher performance in gross and fine motor skills than did accurately concerned parents. Although the 12 children of inaccurately nonconcerned parents qualified for special programs, overall they performed better than the children of parents with accurate concerns. Otherwise, there were no differences between groups on the basis of sociodemographic variables, such as severity of children's problems, perceptions of children's health status, parents' education, income, or prior enrollment in special education.

One hypothesis for why some families do not raise needed and predictive concerns is that their children were simply functioning at a higher level and their difficulties were thus less obvious. However, parents with inaccurate concerns, those renamed highly observant parents, clearly detected children who performed well above those whose parents were inaccurately nonconcerned. This suggests that children's skills and behaviors may not be the sole and deciding reason why parents raise concerns. Some support for this notion is evident in the fact that children with inaccurately nonconcerned parents had far fewer concerns about children's health, while the two groups with the most health concerns, parents with inaccurate and accurate concerns, were more likely to have one or more predictive concerns. This conclusion is supported by prior research showing health and developmental concerns co-occur[6] and this reflects the known relationship between health and developmental problems.

A second hypothesis about why some families do not raise needed and predictive concerns is that they may be less exposed to other children and hence have less opportunity to compare their children to others. This hypothesis was explored by viewing whether family size (defined as number of siblings in the home, birth order) or prior/current enrollment in day care or other programs discriminated between inaccurately nonconcerned and accurately concerned parents. But because these variables attained no significance, either individually or in combination, parents' experiences with other children do not appear to influence whether or not they raise concerns.

Because of the small sample size in the preceding discussion, differences between accurately concerned and inaccurately nonconcerned parents were explored using the complete sample of 771 children. Specifically, a discriminant function analysis was conducted on children with disabilities using as the grouping variable, parents with concerns (N = 98) and those without concerns (N = 32). Predictors included all demographic variables, parents' perceptions of children's health, and all nonpredictive concerns. Nevertheless, no predictors were identified. Perhaps then a more practical question is, "Can we identify children with disabilities whose parents do not raise concerns?" This question is explored below.

In the absence of parental concerns, is it possible to discern children with disabilities from those without?

Using the sample of 408, due to its greater depth in assessing family characteristics, the 259 parents who did not raise concerns and whose children were developing normally were compared to the 12 parents who also did not raise concerns, but whose children had disabilities. Apart from the expected differences in children's functioning, accurately nonconcerned parents endorsed an average of 1.2 items on the CDI's Problem Checklist, while inaccurately nonconcerned parents raised an average of 2.3 items [$F(1,269) = 15.31$, $p < .0001$]. The latter were more likely to mention the following concerns: eating problems; aches and pains; stutters or stammers; dependent, clingy or very upset about separating; and, does not pay attention—poor listener.

Nevertheless, inaccurately nonconcerned parents were not more likely to raise medical concerns on *PEDS* or to perceive their children's medical problems as serious or somewhat serious. There were no differences in the two groups of nonconcerned parents on the basis of numbers of siblings in the home, birth order, race, eligibility for Chapter I services, parents' marital status, income, age at child's birth, level of education or in the multiplicity of psychosocial risk factors. Finally, there were no differences in the numbers of nonpredictive concerns raised, i.e., social, self-help or behavior. Parents who were inaccurately nonconcerned raised an average of .45 nonpredictive concerns while parents who were accurately nonconcerned raised an average of .25 nonpredictive concerns.

The above findings, while interesting, are not particularly helpful in identifying a marker to readily distinguish accurately nonconcerned from inaccurately nonconcerned parents. Nevertheless, there was one variable distinguishing the two groups: Inaccurately nonconcerned parents were more likely to speak a language other than English at home ($\chi^2 = 7.48$, $p < .01$). Visual inspection of the raw data on the 12 cases of inaccurately nonconcerned parents revealed that several had difficulty responding to *PEDS* both in writing or orally. Some had nonsensical answers. For example, one mother wrote at length in Spanish about her child's preference for the color red, in a manner that made one suspect either the mother's psychological well-being, language comprehension or literacy. In any case, the ability to communicate well with families is clearly critical for the success of any measure relying on information from parents. Thus, there are several recommendations for practitioners confronted by obvious parental communication barriers: (a) obtain interpreters; (b) consider using measures that rely on directly eliciting child behaviors; and (c) ask parents whether they would prefer to complete *PEDS* independently or via interview to circumvent illiteracy. When communication barriers include mental health problems, families may also be well served by referrals to social workers, psychologists, etc.

In the face of communication barriers, most of which should be obvious when using *PEDS* either by interview or in writing, it seems wise to administer a different screening test to children. This supposition was assessed in the following analysis, in which children were administered the Brigance Screens along with *PEDS*. Of the 408 parents in the sample, 25 did not speak English at home. Of the 25, 17 had no predictive concerns. Of their children, 3 (18%) had disabilities and the remaining 14 did not. The Brigance Screens identified two of the three with disabilities, but 10 of the 14 without disabilities also failed. To determine the extent to which these 10 need evaluations anyway, children's performance on diagnostic measures was compared to that of other children ($N = 171$) whose parents did not have concerns.

Analyses of variance showed the 10 children over-referred by the Brigance had significantly lower IQ scores (mean = 90.7) as compared to the remaining children of nonconcerned parents (mean = 111.9) [$F(1,176) = 20.975$, $p < .0001$]. As might be expected, the 10 children also had substantially lower expressive language scores (mean of 78 versus a mean of 99)[$F(1,176) = 12.6$, $p < .0001$]. This low performance also makes sense when considering that all 10 children had parents who spoke Spanish at home and had difficulty with literacy, and had numerous other psychosocial risk factors: Their parents had completed an average of 7.6 grades of school (as compared with a mean of 13.3 grades for other parents without concerns) [$F(1,187) = 99.037$, $p < .00001$]; and 82% participated in the federal free lunch program (in contrast with 14% of other children).

Table 5-12 shows the total accuracy of *PEDS* when children whose parents had apparent communication barriers were administered a second, direct screening test, the Brigance Screens. The results are combined with the use of the Brigance Screens on children whose parents had a single predictive concern.

Table 5-12. *PEDS*, plus Brigance Screen Results with Children whose Parents had Difficulty Communicating or who had a Single Predictive Concern

	Disability		
	No	Yes	
No concerns or nonpredictive concerns; single predictive concern and child passed Brigance; or no concern and communication barriers and child passed the Brigance	280	15	295
Multiple predictive concerns; or single predictive concern and child failed Brigance; or no concerns and communication barriers and child failed Brigance	72	41	113
	352	56	

Sensitivity (41/56) = 73%
Specificity (280/352) = 80%
PPV (41/113) = 36%

Evident in Table 5-12 is improved sensitivity without an appreciable loss in specificity. The findings suggest that the best response to obvious communication barriers is to administer to children a screen that directly elicits their skills (e.g., *PEDS:DM*).

One last thought about why some parents fail to raise predictive concerns when their children have undiagnosed disabilities is drawn from clinical experience. In all *PEDS* studies, parents were debriefed after they completed the research protocol. When undiagnosed difficulties were found, the researchers explained results and made recommendations for further evaluations and services. Some parents who had not raised needed concerns became especially distressed and several made such comments as, "I had been worried about him but I didn't want to say anything to color your opinion." Several pediatricians whose offices served as sites for *PEDS* studies offered similar explanations for some parents' reluctance to share their worries. Thus one hypothesis for further research is, if using *PEDS* longitudinally, whether repeatedly asking about concerns, parents may be encouraged to share them.

PARENTS WITH CONCERNS THAT ARE NONPREDICTIVE PREDICTORS OF DEVELOPMENTAL PROBLEMS: DO THESE IDENTIFY BEHAVIORAL/EMOTIONAL DIFFICULTIES?

In one study of *PEDS* involving 408 parent-child dyads,[7] children were administered the Problems Checklist of the Child Development Inventory. The Problems Checklist contains 17 items assessing emotional well-being and behavioral self-control. On the average, most parents endorse only 1.4 items (sd = 2.5). Positive responses to five or more items place children 1½ standard deviations above the mean, suggesting probable mental health problems and the need to make referrals for mental health services. By implication, families of children with extreme scores are not likely to respond to the relatively non-intensive interventions that characterize developmental promotion in most pediatric and some early childhood settings. Identifying and referring those with probable problems leaves in providers' hands a group of parents with concerns but whose children appear to be behaving within the broad limits of normal. Logically, this group is most likely to respond to in-office parent education activities such as informational handouts, etc.

To assess whether the nonpredictive concerns identify children with probable behavioral/emotional problems, the following analysis was conducted. Children whose parents had two or more of the concerns that are significant predictors of disabilities were removed from the analysis (since they would have been referred for comprehensive evaluations). Also removed were children whose parents had a single predictive concern and who also failed a second screening test, since these children would also be referred for evaluations It should be noted here that behavior/emotional problems are often secondary consequences of developmental problems. Indeed, the overlap between behavioral/emotional difficulties and developmental problems is about 50%, which is why it is important to identify and refer for developmental problems first. Removing those with developmental problems for the analysis left 271 children (out of 408) whose parents had nonpredictive concerns or no concerns at all. The presence or absence of nonpredictive concerns was then compared to significant scores on the Problem Checklist.

As shown in Table 5-13 children with substantial behavior problems can be identified by parental concerns about behavioral, self-help or other of the nonpredictive concerns. These results were corroborated in a second study involving 99 parent-child dyads in pediatric offices,[3] in which children were administered the Eyberg Child Behavior Inventory (ECBI).[8] The ECBI lists 36 common behavioral problems in children. An excessive number of these common behaviors (16 or more), is associated with such externalizing problems as conduct disorders, attention-deficit hyperactivity disorder, and oppositional-defiant disorder. Children showing such symptoms should be referred for mental health services.

Table 5-13. Accuracy of Nonpredictive Concerns in Detecting Children with Predictive Behavioral Problems

		Child Development Inventory: Possible Problems Checklist		
		≤ 1½ sd above mean	> 1½ sd above mean	
Parental Nonpredictive Concerns	No	177	8	185
	Yes	63	23	86
		240	31	
		Sensitivity		(23/31) = 74%
		Specificity		(177/240) = 74%
		PPV		(23/86) = 27%

Table 5-14. Accuracy of Nonpredictive Concerns in Detecting Children with Predictive Behavioral Problems

		Eyberg Child Behavior Inventory		
		pass	fail	
Parental Nonpredictive Concerns	No	25	2	27
	Yes	18	7	25
		43	9	
		Sensitivity		(7/9) = 78%
		Specificity		(25/43) = 58%
		PPV		(7/25) = 28%

In the subsequent analysis, children whose parents had two or more predictive concerns were removed from the analysis (since they would have been referred for comprehensive evaluations). Also removed were children whose parents had a single predictive concern and who also failed a second screening test. This left 52 children (out of 99) whose parents had nonpredictive concerns or no concerns. The presence or absence of nonpredictive concerns was then compared to ECBI results as shown in Table 5-14.

The findings, while only a small sample, show that parents' nonpredictive concerns are indicative of substantial behavioral problems. However, in this study, nonpredictive concerns did not reach standards for specificity and would produce a substantial number of over-referrals. While additional research is needed, the findings suggest several possibilities, including: (1) administering behavioral/emotional screens to all children whose parents have nonpredictive concerns; or (2) offering in-office counseling and parent education to all parents with only nonpredictive concerns and following children closely to see which respond.

Screening the latter group would then help identify families needing referrals to mental health services and families needing services of greater intensity than in-office counseling, but less than mental health services, i.e., parent-training classes or behavioral intervention programs.

Of the two possible approaches, in-office developmental-behavioral promotion seems most parsimonious, in that far more parents had concerns about behavior than had children with measurable behavioral difficulties. In both analyses, positive predictive value was little more than 25%, which means that for every four children referred for mental health services on the basis of nonpredictive concerns, three would be over-referrals. Even so, parents who complain about children's behavior even though their children score within the broad range of normal on behavioral measures are experiencing more child-rearing difficulties than parents who have no concerns at all (e.g., they typically endorse an average of 10 specific behavioral issues on the Eyberg as compared to parents without concerns who endorse an average of 6 out of a possible 36 items).

Again, the best approach to nonpredictive concerns is to give parents advice and guidance, monitor children closely, and if there is not an appreciable improvement, administer a behavioral/ emotional screen. If this is failed, children should be referred for mental health services. If passed, parents still clearly need something more intense than in-office advice. Referring this group for parent-training classes or behavioral intervention programs is warranted.

In collating all of the above findings, it is clear

Probabalistic Reasoning and *PEDS*

Table 5-15. Likelihood of Disabilities according to the Five *PEDS* Groups

Groups of Parents	Percent of total sample	Frequency of Disabilities		Percent not Disabled but Below Average		Total Either Disabled or Below Average		Odds of Disabilities	95% Confidence Interval
		N	%	N	%	N	%		
Multiple Predictive Concerns N = 86	11%	45	52%	14	16%	59	69%	20.1 p < .0001	10.5–36.3
Single Predictive Concern N = 180	23%	53	29%	30	17%	83	46%	7.6 p < .0001	4.3–13.7
Nonpredictive Concerns N = 151	20%	10	7%	20	13%	30	20%	1.3 p = NS	0.6–2.7
Parental Communication Problems N = 26	3%	5	19%	9	35%	14	54%	4.4 p < .008	1.5–12.9
No Concerns N = 328	42%	17	5%	37	11%	54	16%	1.0	

that *PEDS* and its supporting research illuminate five distinct groups of parents: (a) parents with multiple predictive concerns; (b) parents with a single predictive concern; (c) parents with nonpredictive concerns; (d) parents who have difficulty communicating; and (e) parents without concerns. In the following analysis, odds ratios for developmental disabilities were produced for the first four *PEDS* groups and compared to the group whose parents had no concerns or communication difficulties (which serves as the baseline). Also shown is the frequency of children in each group who scored below average on measures of intelligence, language or academic achievement, the three most important predictors of school success (below average was defined as greater than 1 standard deviation below the mean, i.e., <16th percentile). Table 5-15 shows the findings (using the entire *PEDS* data set of 771 families).

The 5 *PEDS* groups, the varying rates of disabilities and below-average achievement, establishes an algorithm for probabalistic reasoning. This leads to optimal decision-making based on children's likely needs for different types of developmental and behavioral assistance:

Path A: Those who have a high rate of disabilities and whose parents have multiple predictive concerns. These children appear to need referrals for in-depth developmental evaluations.

Path B: Those with a moderate rate of disabilities and whose parents have a single predictive concern. These children appear to need additional screening, followed by either referrals or parent education/in-office counseling. Closely monitoring this group, which tends to perform well below average, is also important for detecting any emerging disabilities and marshaling such resources as tutoring, summer school, private speech-language therapy, etc.

Path C: Those with a low rate of disabilities and whose parents have nonpredictive concerns, mostly about behavior. These children and their parents appear to need advice and parent education, with close follow-up to see who responds and who does not. Those who do not respond to simple interventions (e.g., written handouts, oral suggestions) should be screened for behavioral/emotional status in order to decide whether mental health services are needed versus programs of more moderate intensity such as parent training or behavioral interventions.

Path D: Those with a moderate rate of disabilities and whose parents have difficulty communicating. These children appear to need additional screening, either with an interpreter or with measures that are not dependent on parental report. Those not referred for diagnostic evaluations may still perform well below average and are likely to need other resources such as tutoring, summer school, private speech-language therapy, etc.

Path E: Those with a low rate of disabilities and whose parents have no concerns of any kind should benefit from routine developmental and behavioral monitoring at each well-visit.

2013 Accuracy Findings

How Well Does *PEDS* Detect Children Eligible for Special Education Services?

The following are omnibus studies in which a wide range of disabilities are viewed at the same time.

Study #1

In this 2013 study, 4177 families of children averaging 35 months of age (range birth to 6 years) were administered *PEDS* via *PEDS Online*. Families included two groups: (a) self-selected parents who used *PEDS Online* outside of primary care; and (b) parents completing *PEDS* while attending well-visits. All 50 US States were represented plus three US protectorates/territories, and 68 (2%) resided in Canada. Parents had comparable but slightly higher levels of education than national prevalence: 43% had completed 4 or more years of college (as compared to 30% prevalence per the U.S. Census Bureau). Prematurity rates across the samples were equal and reflective of national prevalence, i.e., 12%.

Of the 4177 children, 657 (16%) were found eligible for services via diagnostic testing [to which was applied each State's unique criteria (e.g., two 25% delays, 1 ½ sd below the mean, etc.)]. The tests administered varied by state eligibility requirements, and included current editions of the Battelle Developmental Inventory, the Mullen Scales of Early Learning, the Preschool Language Scale, the Vineland Adaptive Behavior Scale, and measures of motor development such as the Peabody Motor Scales. *PEDS* results were grouped into Path A + Path B (N = 1186) versus Path C + Path E (N = 2991). Because *PEDS Online* rejects *PEDS* questions without comments, Path D which is designated by providers using *PEDS* in print when parent-provider communication is problematic is not rendered. Instead providers are required to re-administer *PEDS* by interview and in an appropriate language before submitting to the Online scoring engine. Table 5-16 shows the intersection of *PEDS* results with presence or absence of special education eligibility.

When viewing accuracy by age groups, for children under 30 months (Total N = 3525), sensitivity was 97% (538/552) and specificity was 86% (2561/2973). For children 30 months and older (total N = 652), sensitivity was 99% (N = 104/105) and specificity was 76% (N = 415/547).

Table 5-16. Accuracy of *PEDS* in Identifying Children Eligible for Special Education Services

	Eligible for Special Education		
	NO	YES	
PEDS			
PATH A + B	544	642	1186
PATH C+ E	2976	15	2991
			/4177
	3520	657	

Sensitivity = 98% (642/657)
Specificity = 84% (2976/3520)
Positive Predictive Value = 54% (642/1186)

Comment on Study #1

The results show remarkably high levels of sensitivity and specificity. Nevertheless, the rates may be elevated due to the propelling worries of self-selected parents who sought PEDS Online on their own: (a) even though their children had sometimes been tested and enrolled in services, most had not received an actual diagnosis—a situtation that may escalate parents' concerns; (b) many self-selected parents come to PEDS Online via links from autism support websites and clearly had a range of concerns about children's social/emotional, language, behavior and other skills (e.g., parents may be anticipating further evaluations such as an ASD diagnosis); and (c) few self-selected parents seemed fully satisfied with the quality of developmental-behavioral care offered by their child's health-giver—a phenomenon that might increase and solidify parents' concerns. So, below is a second study focused on potential eligibility for special services, using a primary care population.

Study #2

Limbos and Joyce, in 2011[9] studied how well *PEDS* and the ASQ identified children likely to be eligible for services (this study was conducted in Canada and so did not apply US criteria). Children (N = 331) ranged in age from 12 to 60 months, with a mean age of 33 months. Parents were administered *PEDS* (and the ASQ) by their family healthcare provider, while a psychologist blinded to screening test results administered the either the Bayley Scales –III or the Weschler Preschool and Primary Scale of Intelligence -III, the Vineland Adaptive Behavior Scale-II, and the Preschool Language Scale-4. Children were classified as having a delay of any kind if they scored below the 10th percentile on any criterion measure, i.e., DQ/IQ = 81, < ~ 1.3 standard deviations below average.

Of the 331, 34 (10%) children were found to be disabled: 15 (4%) had cognitive delay, 12 (4%) had speech-language impairment, and 2 (0.6%) had motor delay. Researchers excluded children with a prior diagnosis but it was not clear that families who failed to make comments were readministered *PEDS* by interview. *PEDS* (for Path A plus Path B concerns) was 78% sensitive to detection of developmental delay and 75% specific in children 30 months or younger but had less than optimal sensitivity and specificity in older groups. When viewing children performing at lower levels, < 1.5 standard deviations below the mean, *PEDS'* sensitivity was 78% but specificity was 68%. At < 2 standard deviations below the mean, *PEDS* had 100% sensitivity but specificity was 67%.

So what explains differences in the performance on *PEDS* between its 2002 norming study, the 2013 study (#1), and the research by Limbos and Joyce?[9]

There are several possible reasons:

- Administration methods in the Limbos and Joyce study were not clear, i.e., whether parents who did not write anything on the *PEDS Response Form* were re-administered *PEDS* by interview.
- The sample size is extremely small and included only 34 children with disabilities.
- The thresholds for determining disabilities were more stringent than *PEDS* original norming (which used < 1 standard deviation below the mean for developmental delays, and in the case of language impairment and learning disabilities, a 1 standard deviation discrepancy between IQ and performance on language or academic measures). While many IDEA programs use stringent discrepancy formulas (e.g., 1 ½ sd difference between DQ/IQ and domain scores), even so the critiera in the Limbos and Joyce study were not in keeping with the range of IDEA eligibility, especially performance discrepancies across domains.
- The researchers did not identify the broad range of disabilities *PEDS* is designed to detect (e.g., physical impairment).
- The criterion battery in the Limbos and Joyce study used the Bayley III and the PLS-4 whereas *PEDS* original norming used the Bayley II and the PLS-3. The Bayley III in particular is known to have a "Flynn Effect" with scores averaging 1 standard deviation higher than the Bayley II.[10,11]
- Surely as a consequence of both Flynn effects and the austerity of disability criteria, the incidence of disabilities in the Limbos and Joyce study[9] is much lower than expected, i.e., only 4% to 10% across the two disabilities studied. In contrast, we expect up to 16% of children in the 1 to 5 year age range to have a diagnosable language deficit,[12,13] and 5% - 8% for speech-language impairment alone.[14]
- To date, there are no clear methods for Flynn effect adjustments. Although it is tempting to simply subtract 1 standard deviation from existing results, until large scale samples are evaluated, we don't

know whether the Flynn effect is operational at all levels of performance. For example, the effect may not be as strong at 2 – 3 standard deviations above or below the mean. Drs. Aylward and Aylward[10] provide a technical review of the Flynn effect including a report from the publisher of the Bayley III (*www.pearsonassessments.com*) suggesting that Bayley-II scores might have been depressed compared to the Bayley-I or Bayley-III. The Aylwards' report also describes the Flynn effect in the latest edition of the Weschler scales and the PLS-4. So, while this debate continues, diagnosticians and researchers are urged to use expanded criteria when diagnosing cognitive and language delays, for determining IDEA eligibility, and for validation/accuracy studies on *PEDS*, and other screening tools.

PEDS' overall sensitivity and specificity to the need for special services

It is probably wise, given the limitations of both the 2013 and Limbos and Joyce[9] research, to wield the "Sword of Solomon" and combine the numbers detected and undetected to produce composite sensitivity and specificity figures.

Table 5-17. Recommended Indices when Reporting *PEDS'* Accuracy

Age	Sensitivity	Specificity	Positive Predictive Value
< 30 months	(550/568) = 97%	(2685/3139) = 86%	(550/1004) = 55%*
> 30 months	(112/123) = 91%	(497/678) = 73%	(112/293) = 38%*
Overall	96% (range, 91% - 97%)	83% (range, 73% - 86%)	51% (range, 38% - 55%)*

*note that referrals based on Path A and B were used for accuracy figures and that specificity and positive predictive values rise, with little impact on sensitivity, when a second screen is used with Path B children to determine whether or not to refer versus advise parents and carefully monitor progress. Also note that positive predictive value is relatively meaningless given that over-referrals on screens are almost always children with delays and psychosocial risk factors who need non-IDEA type interventions.

A Comment on differences between PEDS and the ASQ

It is worth noting that the ASQ and PEDS have somewhat different purposes. Yes, both identify children with disabilities and both do that well. But, unlike the ASQ, PEDS:

- *Is designed to enhance parent-professional communication and collaboration;*
- *Defines the teachable moment and the focus of parent education during encounters;*
- *Sorts the "worried well" from those who need further screening and referral;*
- *Refines the types of referrals needed;*
- *Unlike the the ASQ (but like the ASQ:Social-Emotional) PEDS is also designed to identify children with behavioral, social-emotional, and mental health problems;*
- *Focuses on the identification of children at moderate risk (those performing at 1 sd below the mean, i.e., 16th percentile);*
- *As a consequence, PEDS tends to be less specific than the ASQ (particularly in studies lumping both Path A and Path B rather than deploying a second screen in response to Path B or Path D if using print PEDS).*

As with any measure, following the directions carefully is critical. As pointed out by Marks[14] many problematic accuracy studies of PEDS and the ASQ suffer from inappropriate administration and scoring.[15,16] In the case of PEDS this includes, for example, failing to re-administer by interview if parents only circled yes/no/a little answers), and making sure PEDS is provided in the language spoken most proficiently by parents. In the case of the ASQ and

PEDS:DM, correct administration requires having parents ask children to demonstrate skills such as writing letters, counting objects, etc. and not (as in Simard et al[17]) have professionals simply guess at children's competence with tasks.

Dealing with Under-detection and Over-referral

Study #1

In a paper titled, *Are over-referrals on developmental screening tests really a problem?,* Glascoe[17] reviewed screening results from the perspective of providers, i.e., when faced with a recommendation on *PEDS* to refer, will a child be eligible for IDEA? If not, is such a child actually doing well? These are essential questions for real-life practice: How should providers deal with the inevitable frustrations of referring due to problematic screening test results—only to find that some children are ineligible for services?

In a study of 512 parents and children (age range 7 months to 84 months), parents completed *PEDS*, while examiners blinded to *PEDS* results administered a battery of diagnostic measures along with several other hands-on screening tests, i.e., the Denver-II, the Brigance Screens, and the Battelle Developmental Inventory Screening Test. Results of diagnostic measures were grouped into the presence or absence of a diagnosis using eligibility criteria for IDEA programs. Results of *PEDS* were grouped into those with problematic performance on screens versus those who performed well. The target comparisons were: (a) those who did not qualify for IDEA but still failed screens (false-positives); versus (b) those who did not qualify for IDEA and also passed screens (true negatives). The goal was to explore performance differences between the two groups.

Children who failed screens, but were IDEA-ineligible, performed significantly lower on diagnostic measures ($p < .0001$) than did ineligible children who passed screens. This false-positive group had scores 1 to ½ standard deviations lower on diagnostic measures of intelligence, language, academic achievement and adaptive behavior—the better predictors of future school success. Odds ratios of delays for the false-positive group within each domain were 3 – 7 times higher than in the true-negative group (those who passed screens). The false-positive group was also far more likely to have psychosocial risk factors (e.g., where ethnic minorities had parents who did not graduate from high school, etc.). But even after sociodemographic variables were adjusted between groups, performance differences continued to be significant ($p < .001$).

Study #2

Deploying current AAP policy to reduce over- and under-referral rates

Despite knowing that over-referrals to IDEA provide important information about families and children's needs for non-IDEA services, there may be far less expensive and time-consuming ways to reduce over-referrals to IDEA while still identifying families who need other kinds of assistance. The American Academy of Pediatrics policy statement[18] encourages providers to elicit and address parents' concerns (e.g., *PEDS*) and monitor milestones (e.g., *PEDS:DM*). This policy leads to a testable hypothesis: If we measure both parental concerns and milestones at the same time, can we reduce over- and under-referrals to IDEA?

So, in the following 2013 study, *PEDS* Paths were viewed along side performance on the *PEDS:DM* (using the 9,473 families from *PEDS Online* who completed both *PEDS* and the *PEDS:DM*). Given that eligibility for IDEA is increasingly stringent and usually requires demonstrable deficits in multiple domains, failure of 3 or more *PEDS:DM* items was used as a referral threshold. Descriptive statistics were used to define groups on each *PEDS* path by age and percent failing multiple *PEDS:DM* items. Via discriminant function analysis and after selecting for ≥ 3 *PEDS:DM* item failures, *PEDS* Paths A, B, and C were separately compared to Path E using demographic indicators as predictor variables.

Of children on Path A (N = 324), 60% (N = 193) failed 3 or more *PEDS:DM* items. These children were older than those on other *PEDS* Paths (mean = 55 months, sd = 23.12) which is understandable given that risk for disabilities increases with age. Correlates of Path A performance in the face of multiple *PEDS:DM* failures were poverty (.56), non-white ethnicity (.43), parents not speaking English at home (.61), but parents who had not graduated from high school (.86) [χ^2 (4) = 14.459, $p < .006$].

Of children on Path B (N = 788), 31% (N = 247) failed 3 or more *PEDS:DM* items. These children averaged 40 months of age (sd = 23.92). Predictor vari-

ables for Path B performance in the face of multiple *PEDS:DM* failures were non-white ethnicity (.47), poverty (.40), and parents who had not graduated from high school (.66). Not speaking English at home was non-contributory [χ^2 (4) = 49.885, p < .0001].

Of children on Path C (N = 447), 23% (N = 105) failed 3 or more *PEDS:DM* items. Children on Path C averaged 36 months of age (sd = 26.35). Predictor variables for Path C and multiple *PEDS:DM* item failures were having parents who had not graduated from high school (.42). All other demographic variables were non-contributory [χ^2 (4) = 15.816, p < .0003].

Of children on Path E (N = 7914), 10% (N = 791) failed 3 or more *PEDS:DM* items. This group averaged 25 months of age (sd = 25.23). As described above, children on Path E when compared to higher risk groups were less likely to be poor, were less likely to have non-English speaking parents, and more likely to have parents with a high school education.

So, assuming that ≥ 3 failed items on the *PEDS:DM* renders likely IDEA eligibility, and follow recommendations from *PEDS* on whether or not to screen further, if we:

(a) Do not provide additional screening for children on Path A, we refer all 324 children and have over-referrals on 131;

(b) Provide additional screening to the 1236 children on Paths B and Path C, we identify 352 in need of referral, with 0 under-referrals;

(c) Provide additional screening for Path E, we identify 791 of the 7914 as in need of referral. But if we do not screen further, we under-refer all 791.

Overall, providing additional screening for Paths B, C, as well as Path E, improved under-referral rates by 12% (N = 1143/9473). Without additional screening on Path A, over-referral rates were only 1% (N = 131/9473).

The findings provide much support for AAP recommendations to elicit and address parents' concerns but also view milestones (with evidentiary tools). Clearly such an approach is the optimal way to prevent under-referrals as well as over-referrals on moderate- to low-risk children. Although milestones measures can be used with Path A and will reduce over-referral rates by 1%, the pressing nature of parental concerns in this group strongly suggest the need for attention from a developmental specialist.

Comment on Over- and under-referrals Research

Providers find it frustrating when children fail a screen, are referred to IDEA, but are not found eligible for special education services. Instead of greeting such results with irritation, clinicians should view them as highly informative of the need for a different type of referral. False-positive results indicate a child is probably at risk of mild but potentially burgeoning delays. Action is needed! Steps should include: (1) a referral to programs such as Head Start, quality day care, after school tutoring, parent training, and with social or mental health services (if the latter are indicated by other information gleaned from an encounter); and (2) vigilant monitoring of progress (e.g., screening more often such as in between annual well-visits or conferring closely with non-IDEA programs because these often provide progress checking.

Nevertheless, diagnostic resources through IDEA are limited. For example, the Regional Centers in California are responsible for IDEA intake, but often have waiting lists up to 9 months long before children can be tested for eligibility. So, we want to refer with parsimony and with a sense of which children are likely to qualify. The addition of the PEDS:DM to PEDS helps identify children most likely to be eligible for IDEA while also identifying those who need other kinds of help.

Discriminant Sensitivity: How Well Does *PEDS* work in Detecting Specific Disabilities?

Screening test accuracy studies determine whether a special education referral, due to any type of potential disability, is needed or not. Accuracy studies are based on a naturalistic sample of children with and without disabilities in proportion to their overall prevalence. In contrast, discriminant sensitivity studies view how well a screen identifies each type of disability. Due to the need to depend on samples of children with high rates of various conditions, discriminant sensitivity studies are typically conducted on high risk populations such

as children with extremely low birth weight for whom rates of disabilities are not only high but also range in type (e.g., intellectual disabilities, cerebral palsy, etc.).

What we want to know from such research is:

- Do parents have difficulty recognizing some conditions?
- Do parents who have problems themselves (e.g., mental health issues) detect problems in their children?
- Do parents who do not speak English or who have psychosocial risk factors (e.g., mental health problems) do as well at early detection as other parents?
- Given that most children in a very high risk sample will receive a high risk score on *PEDS*, are there unique patterns of parental concerns associated with each type of disability?
- How does the content of concerns' categories vary by the type of condition, i.e., what else should professionals attend to in order to make thoughtful referral decisions (e.g., to decide if a speech-language versus neurological versus an autism-focused assessment is needed)?

Discriminant sensitivity studies are expected to have high sensitivity to each condition under study and also unique performance patterns (in the case of *PEDS*, unique patterns of parental concerns including content of concerns, if not also elevated risk as indicated by *PEDS* Paths). But we can also expect limited specificity (than is found in overall accuracy studies) because comparison groups are almost always children with other types of conditions that *PEDS* is also designed to identify. The following discussion is organized by type of disability and the extent to which *PEDS* is sensitive to each unique condition.

Does *PEDS* Detect Autism Spectrum Disorder?

Study #1

From the Ozonoff study[2] (described in the predictive validity section of the prior chapter), we can see that *PEDS* administered at 12 months predicted, with 83% sensitivity, a diagnosis of ASD at 30 months. Specificity was slightly below 70% but the comparison group was children with other kinds of disabilities, meaning that over-referrals on *PEDS* were still children in need of testing. Nevertheless, *PEDS* provided a helpful sorting of those in need of referral to an autism clinic versus those who needed more generic special education referrals. Ozonoff et al[2] also viewed the content of parents' concerns with an eye toward descriptions of autism features, especially repetitive behavior. So, this study illustrates that both the type and content of parental concerns require attention and that *PEDS* is helpful in decision-making about autism-specific referrals long before the age at which the M-CHAT can be administered.

Study #2

A subsequent study[19] assessed *PEDS* in comparison with the M-CHAT and also to an ASD battery (all measures were administered concurrently). Participants were 52 children seen at 18 or 24 months of whom 58% received a diagnosis of ASD approximately two months later. *PEDS* (Path A and B) were 93% sensitive to an ASD diagnosis but only 47% specific (meaning *PEDS* identified children with other problems). The M-CHAT was 93% sensitive but slightly more specific (60%). So, the authors rightly concluded that *PEDS* should be followed by the M-CHAT before deciding whether an ASD referral is needed. This recommendation is especially important because evaluations by ASD specialty clinics are expensive and often have long waiting lists (e.g., 9 months to 1 year). So referring very carefully to ASD programs is essential, but as always, referrals to IDEA are needed while children wait for ASD evaluations.

Study #3

A 2007 study[20] using *PEDS Online* with self-selected parents (those either lacking or frustrated with their child's healthcare provider), compared parents' concerns on *PEDS* to M-CHAT results with a sample of 458 parents and children (who ranged in age from 18 months to 60 months). *PEDS* (Path A and Path B) was found to be 98% to M-CHAT failures but only 15% specific. Nevertheless, attention to the specific categories of parents' concerns proved important and greatly improved the specificity of *PEDS*.

Across age groups, five types of concerns were significantly associated with possible ASD, i.e., M-CHAT performance: behavior, fine motor, gross motor, receptive language, and social-emotional skills:

- In the 0 – 35-month-old age group (N = 249) the presence of three or more of these predictive concerns identified 131 of the 168 M-CHAT failures (sensitivity = 78%) while fewer than three such concerns, identified 61 of the 81 M-CHAT passes (specificity = 75%).

- In children 36 – 59 months of age (N = 209) predictive concerns included receptive language, school performance, social-emotional, and expressive language. The presence of three or more such concerns identified 81% of M-CHAT failures (98/121) while fewer than three such concerns were 70% specific to M-CHAT passes (62/88).

- Despite the sensitivity and specificity of *PEDS* to M-CHAT passes/failures, the authors recommended following *PEDS* with the M-CHAT because the combination of results improved identification rates of probable ASD (as well as other disabilities).

Study #4

The only study suggesting *PEDS* does not predict M-CHAT results with adequate sensitivity or specificity is riddled with error.[20,21] Upon presentation of preliminary results on more than 50% of the sample (at a platform presentation to the Society for Developmental-Behavioral Pediatrics), the authors concluded that *PEDS* (using Path A and B results) was sensitive (~78%) but not specific (26%) to M-CHAT failures—in keeping with all other studies of *PEDS* and ASD (either diagnosed or probable). However, when the paper was finally published,[21] accuracy figures were completely reversed (27% sensitivity and 75% specificity). This statistical impossibility was pointed out in a letter to the editor[22] but unfortunately, the authors refused to reanalyze or retract their results. Overall, given that *PEDS* has repeatedly reasonable levels of sensitivity as well as predictive validity in detection of ASD, ignoring the Pinto-Martin et al studies[21] is wise. Nevertheless, all researchers across all studies of *PEDS'* discriminant sensitivity, suggest adhering to the American Academy of Pediatrics guidelines for routine screening/surveillance followed by an ASD focused screen at 18 and 24 months or whenever there are concerns about a child's development and behavior.

Study #5

Twyman, Macias and Glascoe[23] viewed the categories of concerns on *PEDS* most associated with M-CHAT failures. Within the M-CHAT, children fail on the basis of two critical item failures, or on the basis of any 3 failed items. Critical items on the M-CHAT are those most associated with an ASD diagnosis while non-critical items tend to identify other disabilities (but note that the M-CHAT only detects relatively severe manifestations of non-ASD conditions and thus misses most children with disabilities other than probable ASD). Twyman et al[23] studied 361 parents whose children failed the M-CHAT. Of the 361, 59% failed due to critical items and 41% failed due to non-critical items. The Critical Fail group was more likely to have a *PEDS* score that would lead to referral for further testing (OR = 4.3, 95%CI 1.34-13.77). The predictive items on *PEDS* for M-CHAT critical failures included expressive language (OR= 2.1, 95%CI 1.01-4.55), receptive language (OR = 2.3, 95%CI 1.33-3.91), and self-help (OR = 2.2, 95%CI 1.30-3.69), while behavior concerns were less predictive (OR = .46, 95%CI .21-.99). Each of these concerns was associated with failed responses for these three M-CHAT items: imitation, sharing, and joint attention. Receptive language concerns were associated with failing to respond to name ($p < 0.05$). Twyman et al[23] concluded that parental concerns within language domains are expected, because these are prominent ASD features. The association between the self-help domain on *PEDS* with M-CHAT critical items reinforces the importance of joint attention in detecting a possible ASD. The results affirm the presence of unique performance patterns on *PEDS* in children likely to have ASD. Illustrated is the importance of looking at categories and content of concerns on *PEDS* rather than simply *PEDS* Paths. Table 5-18 shows the critical M-CHAT items along side the categories of *PEDS* concerns most associated with each critical item failure on the M-CHAT.

Study #6

Because the above studies, with one exception, deployed *PEDS* and the M-CHAT with populations at elevated risk, the following 2013 study is a cross-validation of all prior research using a primary care population. The rationale for studying a more typical sample is that parents of children with known risks (e.g., other prior diagnoses, siblings with ASD) may be more likely to report concerns with their targeted child who, in turn, may be more likely to fail an ASD screen. So testing the relationship between *PEDS* and the M-CHAT when deployed in primary care should offer valuable information on what *PEDS* adds to decision-making that the M-CHAT does not, and visa versa.

Although the M-CHAT authors continue to study

Table 5-18. Categories of Concerns on *PEDS* Predictive of Critical Item Failures on the M-CHAT[23]

Critical 6 M-CHAT items	Predictive *PEDS* concerns	□
2. Does your child take an interest in other children	Social-Emotional	<.001
	Receptive Language	0.025
7. Does your child ever use his/her index finger to point, to indicate interest in something?	Global/Cognitive	0.033
9. Does your child ever bring objects over to you (parent) to show you something?	Gross Motor	<.001
	Receptive Language	0.001
	Fine Motor	0.01
	Global/Cognitive	0.01
	Expressive Language	0.03
	Self Help	0.033
13. Does your child imitate you? (e.g., if you make a face will your child imitate it?)	Self Help	<.001
	Receptive Language	0.001
	Expressive Language	0.022
14. Does your child respond to his/her name when called?	Receptive Language	0.001
	Gross Motor	0.006
15. If you point at a toy across the room, does your child look at it?	Receptive Language	<.001
	Expressive Language	<.001
	Self Help	0.001
	School	0.001

which items on the M-CHAT (e.g., the critical six) best predict an ASD diagnosis, they are also studying alternative constellations of critical items (e.g., "Best-7").[24] Nevertheless, Robins et al are not yet convinced that the Best-7 is optimal or that an MCHAT overall failure is any less predictive than critical versus non-critical item failures (*Diana Robins and Deb Fein, personal communication, August 27, 2012*). Therefore, *PEDS Online* continues to report performance on the M-CHAT as an overall pass/fail but *PEDS Online* also indicates whether the pass/fail was based on the critical items versus non-critical item failures. As research on the M-CHAT proceeds (e.g., if the "Best-7" turns out to be the optimal scoring method) this will be reported on *www.pedstest.com/research*, in scholarly publications, and in subsequent revisions to this book.

Thus the abiding questions researched below are:

- What does *PEDS* versus a failed M-CHAT contribute to decision-making about how best to help families (e.g., refer to ASD-focused services, refer to non-ASD-focused services, advise and monitor carefully, etc.);
- How well does *PEDS* detect probable ASD without the M-CHAT?
- What does the M-CHAT add to *PEDS* for correct identification of probable ASD?
- What does *PEDS* versus the MCHAT contribute to identification of probable disabilities not associated with ASD?
- What types of comments do parents provide on *PEDS* when children fail the MCHAT? (given that these may help us recognize children with possible ASD who are either too old or too young for an

ASD focused screen).

Using data from *PEDS Online* in a pediatric clinic where families were administered *PEDS* and the MCHAT by interview (to ensure that limited literacy did not interfere with performance on either test), 2300 parents were administered both measures and 40% were interviewed in Spanish. An interview approach was used due to the elevated psychosocial risk among families served (e.g., 25% had not graduated from high school). Children failing the MCHAT comprised 16% of the sample (N = 378/2300). Children were also at elevated risk on *PEDS*: 22% received a Path A result, 28% received Path B, 23% received Path C, and 27% scored on Path E. *PEDS* Paths A and B were highly sensitive to MCHAT failures, 90% (N = 342 of 378). Specificity was limited, 57%, (N = 1105/1922), meaning that Path A and B, as designed, detect children's risk for a range of problems and not just those associated with autism spectrum disorder (e.g., language impairment, mental health problems, intellectual disabilities, etc.).

Meanwhile providers should learn to recognize the kinds of descriptions on *PEDS* associated with M-CHAT failures, most especially critical item failures (because these items have, in some studies, been closely associated with a subsequent diagnosis of ASD). The reason for this sub-study is that narrow-band ASD screens are only recommended by the AAP at 18 months and again at 24 months. But parents may well describe symptoms of ASD at earlier ages, i.e., before the age ranges at which the M-CHAT or other ASD focused screens can be deployed.

For the following qualitative analysis, M-CHAT failures (800 out of 8950 = 9%) in a general pediatric sample were sorted by whether two or more critical items were failed. Fifty-six percent (56%, N = 451) of all M-CHAT failures versus any three non-critical items and less than two critical item failures (N = 349, 44%). Table 5-19 shows the predictive categories of parental concerns on *PEDS* most associated with M-CHAT critical item failures versus non-critical item failures.

Study # 7

Table 5-19. Types of *PEDS* Concerns in Relation to M-CHAT Critical Item Failures (*Each Unique Comment is Separated by a Semi-colon and Spelling/grammatical Errors are Shown as Written by Parents)*

Predictive Categories of parental concerns due to critical item failures on the M-CHAT	Comments by Category of Concerns
Expressive Language	*At times people cannot understand him when he talks; In order to be understood he has to repeat what he said; He is only using two word sentences; Does not say any words; She does not point or ask for what she wants; He does not express himself and cries out of frustration; Child repeats the last part of a word. But he does not speak; He babbles often, no clear words only says momma-but not to call mother; He usually just brings objects to communicate things; He will not point or repeat words; He mimics tunes, not the words of songs; He used to say Thank you, but not anymore; He has about 6-7 words; He will not imitate sounds; When people cannot understand him he gets frustrated and will start to cry; He also does not use I, just says me; About half of his speech is clear; He will ask for more; He repeats words; Does not talk much; He does not answer yes or no questions; He does state his name, does not point, leads by the hand; Does not sing along to songs; He seams as if he is talking a diffrent language; He communicates by pointing; He makes a sound when he tries to talk but its not words or approximate words; He does not make different vocal sounds, nor imitate sounds; He copies what I say; He does not say I/me; He makes one/two words statement at times; He does have 3 word phrases; He does not really speak he only repeats what people say; He does not say any clear words; He mummbles; Most of his words are partial words; He tries to put words together, but its hard to make out what he says; He can say about 15 words; He does not say any words, he only makes noises; He makes ma sound; He does alot of babbling; His vocabulary is very limited, he has about 100 words in his vocabulary; He is bilingual in English and Chinese; When I ask him things he does not respond; He does not speak much, he uses grunts or vocal sounds; He does not typically point, he attempts to say words, but only says partial sound; He has about 10 words or less; He repeats the last word of a question; He does not speak on his own he just repeats words; He gestures and pulls instead of talking; He grunts, and points occassionally; He will come and get me when he needs something; He uses one word, stop; He only imitates the dog sounds when he plays with it; He babbles and repeats the same type of sound; He will whine or pats me on the leg, he will not gesture or lead by the hand; He will repeat*

table continues

Table 5-19 cont'd

Predictive Categories of parental concerns due to critical item failures on the M-CHAT	Comments by Category of Concerns
Expressive Language cont'd	*sounds from the TV, not many words, just sounds; He typically leads by the hand when he neds something; He has 5 words. He doesnt pronouce them correctly- he only says part of the word; He has a few words, he is not combining words to say phrases; He will point, imitate sounds; He babbles often; He will answer yes or no questions; He drools; The only word he uses is, no; He used to say more, but he had some regression after his brother was born; He has a limited vocabulary, I can understand 15-20 words; He tries to make phrases, but it sounds like jibbersh; If he is excited, he repeats the same sound, but when calm it sounds more like babbling; He will randomly repeat words; I dont see him picking up new words; He is not putting words together; He is not making any phrases or imitate sounds; I dont see him learning new words, he babbles and makes noise, not like typical babbling; He does not communicate things with any sort of gesture; He babbles when playing; He is not pointing or repeating sounds; He is not speaking or saying any words yet; I try to ask what he wants but he will not tell me; He is making a sound that is the same sound he uses for everything; He does not have any words in his vocabulary; He yells when he is excited; He is not talking, or using two-word combinations yet; He will try to repeat what parent says, but does not try to speak on his own; He makes sounds for certain things; He puckers his lips when he's hungry; He will mix his words up when trying to say something; He makes one word statements; He makes vocal sounds that are not words; When he talks he just repeats back what he heard, he does not use words to communicate; When he was younger he would say words but does not anymore; He only says, momma and dada, he just says it- he is not calling me; He repeats words but does to use functional words; He humms througout the day the same sound; He tries to talk, but I can not make out anything of what he is saying; He used to talk more last year, seems like he doesnt want to talk; He doesnt repeat words; He does not use verbs or action words; He does not use plurals; His words are partial. He will not say the whole word, it can be hard to make out what he is saying; He only says one sylable; He only uses single words; I ask her to repeat things and she just laughs; I can only make out the first and last word of his statement; He does not respond to questions appropiately, he says yes to most questions; He babbles, lalala often; He tries to speaks but is not forming words it just sounds like babbling; She only speaks to her mom and her twin; About 6 months she has lost the ability to repeat words. She now says partial, she used to say full words; She keeps insisting on what she wants and says it over and over; She is starting to use profanity; Says just her first name; She is not conversational, she only repeats last word; She repeats words over and over when I ask her something. She says lots of jibberish; She screems a lot when she is trying to speak; She struggles to speak she stutters and closes her eyes; He makes screetch or screaming sounds; Sometimes it seems that he wants to say something and he just opens his mouth-no sound comes out, he gets fustrated with himself; He also sucks his tongue and it prevents him from talking clearly*
Receptive Language	*At times doesn't seem to listen or ignores what is said; Child does not understand a lot; Does not follow directions when asked to do something. Even if I get in his face and touch his shoulders/hand etc.; Does not pay attention to what is being said; Does not respond appropriately; Doesn't make eye contact, likes to "stone-wall"; Doesn't want listen, favorite is "no", laughs at us when we try to discipline her, thinks it's funny. Stubborn, strong-willed; Doesn't engage with parents; English and Spanish-getting confused; Sometimes he does not look at me when speaking; He doesnt fallow litle demands and he ignores us alot and when we try to play with him and show him how to play with the toy he just throes it; He seems to do the opposite of what I ask; He seems to or chooses not to understand; He seems to understand simple speech, such as come here, he knows his name/nick name, objects such as "rubber duckie", that is all he has demonstrated as understanding; I believe his receptive hearing is average, but since he doesn't respond, I can't know; I call him, he almost never respond to my call; Ignores commands-- gives defiant look; only knows when he's in trouble; Just screams anytime you say something to her, ask her questions and just screams; Looks at you like she dosent understand; I have to yell at him to get his attention; Not sure if he can't hear me or just doesn't want to listen. Sometimes I have to repeat my self 2 or 3 times; Only understands a few words and commands. You can point to something and ask him to get it and he will not understand; doesn't listen to what I say; she only repeats after me; some times it seems like he can not hear me tal(k)ing to him; Sometimes have to say his name several times or loudly to get his attention; Sometimes he acts like he understands what I am asking but then when I follow through he gets upset. An example: he understands nap but not tired, sleepy, and bed time. He will say yes that he wants a food and when I give it to him he doesn't want it; Sometimes he follows simple commands, but sometimes he does not; sometimes he looks like he does not understand;Sometimes she ignores/doesn't respond (?) when spoken too; Understands very little; We feel like she understands sometimes, just don't have a response or acknowledgement; We have to repeat what we say more then ones; When I ask him to do something he looks at me like he don't understand; Wonder if he's not hearing or if its understanding*

table continues

Table 5-19. Cont'd

Predictive Categories of parental concerns due to critical item failures on the M-CHAT	Comments by Category of Concerns
Fine Motor	*Doens't pick-up blocks; Acts like does not have any hands; Eats like a dog; He does not point to things; He is very agile and is able to open doors; He only uses 2 fingers to grasp things. Cannot hold a spoon; her fingers are always in her mouth. she would let her self fall and hit the ground before she pulled her fingers out of her mouth. she really doesn't grasp things...and if she does it only lasts for a little bit; Keeps hands fisted; Left side hand, thumb not quite doing pincher grasp yet; Not using sippy cup well; Plays with hands a lot; Puts fingers in mouth; Left hand not work as well as her right; She throws most anything she picks up. Is this normal?; Still has trouble feeding himself with utensils; Still raking*
Gross Motor	*A little arm flapping when excited, but that is not too often. More concerned regarding walking as he tends to want to walk on his toes; A lot of tantrums; Bow-legged; He doesn't bend his knees when he runs; He's not walking; Still falls over a lot; His walk is still unstable, he seams on the verge of falling when he picks up any speed; Left foot tendency to be up on toes, twists arms backwards; Not walking; Only rolls; Problems with running and falls all the time, maybe feet go inward; She does a weird routine where she has to stretch her legs, only at night. It's almost like she uses it to calm herself down. She must sleep with 6 or 7 blankets every single night; She doesn't want to crawl or stand on her legs; Sometimes drags left toes when walking and stumbles on leg; Sometimes he walks akward; Walks funny; Very pidgeon toed; Walks on heels; Walks toeing inward, trips over his feet when turning; When I hold his hand to walk he walks with his left leg pointing to the side and not straight; Under-developed in the way he fumbles to run, to stand or walk up stairs*
School Skills	*Difficulty staying focused; Does not follow directions; Does not participate; Refuses to follow directions. Never on task; Does not want to make eye contact, gets very upset and emotional when asked to do something (pick up toys, etc.); Doesn't really seem interested in learning body parts; Finally learned "nose" but took much repetition; Doesn't speak or know colors; I am worried about his socialization; I don't think he is at the preschool level; He can't count but he knows 2 comes after 1; When i try to do litle projects with him that are apropiate to his age he is careless just throws things; He's not too interested (in school type tasks); She takes a long time to grasp things; Struggles with her ABCs; Everything is the color blue*
Self Help	*Concerned with how he accepts the teaching his family gives him; Doesn't seem interested; Doesnt feed self, doesnt take his shoes off; Not going to sleep on his own; He can take his clothes off not put them on. He gets very frustrated and cries when he can't do something. He doesn't listen when he gets upset and he doesn't try to solve the problem. Ex(ample): something blocking his ride on-- he doesn't move the item; He does not try to put on his shirt; He is starting to feed himself, but not used a spoon yet; Wont give up bottle and doesnt like to eat; He is verry smart and figures how to do so many things on his own he just doesnt take direction well; He loves getting dressed! He seems really smart. His daddy thinks he is a genius; He won't brush his teeth; He's resistant to many new things, and sometimes will play with toys or food inappropriately; Hes envelope for learning is slow; In trouble a lot; Is definitely not interested in doing things himself. Refuses to hold bottle. Does hold cup appropriately; It is very difficult to learn when he does not understand what we are asking of him; Learn things very slow; Not doing anything for himself; Our child learns quickly and wants to do things herself. She's very independent; Not potty trained yet, cannot dress herself; Refuses to feed himself. Will get up constantly during meals. Distracted beyond reason. Has a difficult time paying attention for more than 3 min. on ANY task. For his age, he does not participate in school activities, such as the art projects; She doesn't know how to handle a bottle yet. She doesn't know how to drink from the bottle unless somebody does it for her; She gets angry very quick; She is overly eager to do things for herself and doesn't let me help or teach her; She trys more advance things she does need assistant; Slow to attempt new things. difficulty in completing task; Some problems with self-feeding; Very delayed in all areas; Wants to be carried up the staircase otherwise has a "meltdown", Screaming and crying until we give in*

Because research on the M-CHAT is ongoing and because failure based on specific critical items may or may not be relevant to early detection, Table 5-20 shows the comments of parents in the remaining *PEDS* categories when the M-CHAT is failed. Almost all categories of concerns on *PEDS* were significant predictors of overall MCHAT failure via discriminant function analysis [χ^2 (10) = 840.898, p < .0001]: receptive (.807), self-help (.59), expressive language (.54),behavior (.51), social-emotional (.49), school skills (.40), fine motor (.39), gross motor (.31) with other/health and global/cognitive being non-contributory.

Table 5-20. Additional Categories and Content of Concerns on *PEDS* when the M-CHAT is Failed

Remaining Categories of parental concerns given failure on the M-CHAT	Comments by Category of Concerns
Behavior	*A lot of concerns- he is hyperactive. He bangs his head against the wall. He bangs books on his head; A lot of temper tantrums; Aggressive;aggressive when upset, bites, claws, scratches, throws objects directly aimed at people; All he does is fight, hits with any object he gets ahold of; Always says no; At night she wakes up screeming 2 to 3 times a night; Bad tempered, doesn't listen, very hyper; Does not behave very well; Bites; Child will hit anyone at anytime. lack of control over child; Cries more often than other children. Very clingy to me; Cries on a regular and daily basis. Sometimes just out of the blue. He is extremely attached to me; Only cries when she wants something. very insistent; Cries and throws fits; Doesn't sleep and has unusual behaviors; is not enjoyable; Everything has to go his way; Extremely aggressive, does not give or accept affection, does not play well with others, physically aggressive with others, does better alone than with others; Extremely active wont stay still to play and eat; Gets up at night and gets into food even when takes a nap, and hard to get to go to sleep; Fights a lot; Gets upset easily; Has violent temper tantrums; He bites and has little or no remorse; He has many fits and would bang his head against the floor and rolls his eyes to the back of his head; He is verry disobedient he doesnt fallow instructions doesnt stay in time out no mater how many times you put him in it he throes tantrums and throes everything; Does not understand rules of any sort. Doesn't know how to react to things properly; He is very tough and rough; he seems to sit and stare at the walls; He sometimes hits his head against the wall or tries to hit himself; He throws himself on the ground and hits his head on the floor, rolls around and screams. angers easily; he will bit himself out of anger; Very very shy; Kicking and hitting when Mom goes away or when someone tries to go in his room; Looks to the side and laughs; Banging his head--leaving leaving bruises in the middle of his forehead; Very rigid in his schedule. Changes set him off; Runs up to people and sometimes bites them; Screams, hits, yells; Seems to be in his own world; She has a difficult time sitting quietly in new and quiet environments (doctor's office); she seems very needy, always wants to be held, -doesnt want to go play on her own, unless your there; She's too strong willed, doesn't like to listen. When she has a task it must be completed, won't move on until it is completed. Otherwise a temper tantrum. Screaming starts, as well as hitting. Hits furniture, parents, screams "NO"; She can't sit still for very long. Constantly moving; Only cries when she's asked to do things, but other than that she is a happy child; fussy and meaner as he gets older; She's kinda wild; Very wild child he climbs on everything and is always hurting himself*
Social-Emotional	*Still at the phase where she is not doing interactive play with other children; Always has to have his own way; Always pushing and hitting with playing with other children; Always says mine; Biting all the time whether happy or sad or angry; Shy and doesn't like to play with other kids; Does not get along with other people; Does not like to play with others; Doesn't approach other children; Doesn't socialize at daycare; Doesn't talk to anyone but her close family; Enjoys other's company but does not fully react to situations properly; Hard to play with; He acts mean; Doesn't like playing with other kids; Just wants to be by himself; He likes to play with other kids but he hits them alot or throws things at them he doesnt follow simple game instuctions and its hard to get his atention; He plays alone most of the time; He seems less interested in other children than other 2 year olds; Hits at random; Mean; Not interacting with others; Doesn't like people; Both shy and violent; Too shy*

Comment on M-CHAT critical item failures and the associated content of parents' concerns

Receptive language Concerns clearly reflect trouble understanding commands and the common parental complaint that a child "acts deaf". Clearly an audiological evaluation along with referral to Early Intervention for a broad developmental evaluation are needed so that providers can be sure hearing loss is not interfering with understanding of language, compliance, or interest, per AAP recommendations for early detection.[17,25]

Self-help Concerns often reflect too much independence (e.g., a child may be avoiding communication due to limited understanding) or too little independence (ASD is highly associated with global/cognitive delays).

Fine Motor concerns often reflect repetitive motor behavior, difficulty imitating others, uneven motor development bilaterally, etc.

Gross Motor Concerns, as with fine motor development, can reflect limited attention to the way others move and thus difficulties in imitation, global delays, or differences in bilateral brain development.

School Concerns reveal parents' concerns about peer relationships and problematic socialization, slow learning, and as is typical of children with probable ASD, lack of interest in learning, unwillingness to engage others, etc.

Expressive Language Concerns are common to all developmental disabilities, but in the case of probable ASD parents comment often on children's difficulty imitating, pointing, and using language to communicate needs and shared interests.

Behavioral problems are common with young children but children with probable ASD children have lots more of them, often unusual behaviors, and all take a much longer time to resolve. Parents' descriptions emphasize isolation, self-injury, resistance to changes, avoidance of the unfamiliar, and repetitive behavior.

Social-Emotional issues are also common and include avoiding peers, difficulty interacting appropriately, anger and frustration, excessive shyness, lack of willingness to engage peers, failing to play with toys in the intended manner, etc.

Overall comment on Probable ASD and the Content of Parents' Verbatim Concerns

Taken individually, many of the concerns raised by parents of predominantly two-year-old children who failed the M-CHAT, may well look like the usual "terrible twos". But it is important to remember that such parents have an average of four different types of concerns about their children, while parents of children who passed the M-CHAT have less than two concerns [t (8948) = 16.881, p< .0001]. In addition, parents whose children failed due to two or more critical items on the M-CHAT had an average of five different types of concerns. These findings suggest: (a) administering the MCHAT if the child is in the target age range; (b) referring to IDEA whenever parents have Path A concerns (and screening carefully followed by attentive monitoring of those children on Path B); and (c) referring to IDEA as well as an ASD specialty clinic (if IDEA programs cannot provide thorough testing for ASD) when parents raise abundant predictive concerns.

Comment on PEDS and ASD detection

Although PEDS identifies the majority of children with possible ASD, it is clear that a narrow-band ASD-focused screen is an essential adjunct for sorting children with and without probable ASD. M-CHAT failures (whether critical or non-critical) detect ASD quite well and MCHAT failures otherwise identify children likely to have other types of disabilities—but only those with substantive problems and thus not all disabilities. PEDS in contrast, identifies a broader range of deficits (and also the many issues for which parents need professional advice) but PEDS does not always perform as well as the MCHAT in identifying those without probable ASD. So PEDS and the MCHAT work well together and PEDS should be viewed as a screen focused on the broad range of potential disabilities, with the M-CHAT viewed as it should be—an ASD-focused screen. When children are below or above the age-range of the M-CHAT, providers should be alert to possible ASD based on PEDS alone, via attention to: (a) The unique patterns

of concerns; b) the frequency of concerns; and, c) the content of parental concerns reflecting symptoms of ASD.

Meanwhile, attempting to make a diagnosis of ASD in primary care is neither wise nor desirable—given the limited information that even multiple screens plus brief clinical observation can provide. Instead, providers should make referrals to IDEA programs for more complete evaluations, an M-CHAT follow-up interview, and for collaborative decision-making regarding the need for an autism specialty clinic evaluation.

Does *PEDS* Identify Behavioral, Social-Emotional and Mental Health Problems?

Study #1

Research on *PEDS'* original standardization sample showed that parents' concerns about children's behavior and social-emotional problems were accurate indicators of clinically significant behavioral and mental health scores on measures of behavioral/social-emotional/mental health status.[26] Behavioral concerns alone were both sensitive and specific to a measure of conduct disorders across the age ranges studied (21 months to 95 months of age). When studying mental health problems, behavior and/or social-emotional concerns were highly accurate (87% sensitive and 79% specific by the time children were 4 ½ years of age or older). Nevertheless, in younger children, behavior and/or social-emotional concerns were 68% sensitive and 66% specific, suggesting that parenting advice with very careful monitoring of effectiveness is a better approach with young children. False-positives (parents with behavioral and social-emotional concerns whose children did not fail a separate measure of mental health or conduct disorders), had significantly higher rates of failed items than did true negatives. Such children continue to be at-risk and deserve careful attention (e.g., parent education, in-office counseling, vigilant monitoring, etc.).

Study #2

Using 2013 data from *PEDS Online*, 1293 families were administered both *PEDS* and *PEDS: Developmental Milestones*. This sample, from a single clinic, was used because both screens were administered by interview, i.e., parents' ability to answer *PEDS* and *PEDS:DM* questions was not deterred by literacy barriers. This particular clinic opted for an interview approach because families had elevated psychosocial risk (e.g., 25% of parents had not completed high school, 65% were Hispanic, and 40% spoke only Spanish). Parents' concerns on *PEDS* (both behavioral and social-emotional) were compared to the *PEDS:DM* items focused on social-emotional skills. Of the 1293 children, 153 had unmet milestones on the *PEDS:DM* social-emotional items. Of the 153, 125 parents raised concerns on *PEDS* about behavior and/or social-emotional status [sensitivity (125/153) = 82%]. Nevertheless, 580 of the 1140 parents whose children met social-emotional milestones on the *PEDS:DM*, also had concerns about social-emotional and/or behavioral status [specificity (584/1140) = 51%].

Comment on PEDS and children's mental health problems

The findings illustrate PEDS performs as designed and identifies children with social-emotional and behavioral problems in need of referral. But PEDS also identifies families in need of professional advice and careful monitoring. Despite PEDS' high sensitivity to social-emotional/mental health problems in children, it is clear that an adjunct social-emotional/mental health screen (e.g., PEDS:DM, ASQ:SE) is needed for making decisions about whether to refer versus offer in-office counseling/monitoring.

Does *PEDS* Detect Children with Cognitive and Motor Impairment?

Study #1

In prior *PEDS* research, there was much hope for a one-to-one correspondence between the types of concern parents raise on *PEDS* and the type(s) of diagnoses rendered after further testing (e.g., if children are diagnosed with cognitive deficits, are parents mostly raising concerns in the *PEDS* category that embraces global/cognitive delays)? Toward that end, Glascoe[27] scrutinized a sample of 95 children attending either federally subsidized (N = 63) or nonsubsidized day care centers (N = 33). Subsidized day care programs are designed to serve families with limited income and thus a group with high levels of psychosocial risk. In this sample, 73% of families met federal poverty guidelines versus 0% among non-subsidized day care participants). Parents of children in subsidized day care tended to have lower levels of education (19% held college diplomas versus 84% of those using non-subsidized day care); had larger families (33% of children had two or more siblings versus 6% non-subsidized); were more likely to be single parents (52% versus 9%), and were younger parents (16% in the subsidized group were < 22 years of age, versus 0% in the non-subsidized group). Children in subsidized day care were more often ethnic minorities (97% African American versus 9% in the non-subsidized sample), but between the two groups, ages were not significantly different: [mean age of 39 months (range = 3 to 81 months)].

Parents were administered *PEDS* by interview. Within one week, psychological examiners blinded to parents' comments on *PEDS*, administered one of three age-appropriate measures of intelligence: the Bayley Developmental Scales (first edition), the Kaufman Assessment Battery for Children, or the Stanford-Binet Intelligence Scale (4th edition). Examiners also interviewed all parents using the Vineland Adaptive Behavior Scale (VABS). The presence or absence of cognitive delays was determined by having examiners apply federal/state definitions for special education eligibility. At the time (and in Tennessee where this study was conducted), IDEA criteria included an IQ/DQ and a VABS quotients of < 79 (< 9th percentile). Of the 95 children, 18 children (19%) were diagnosed with intellectual disabilities and concomitant problems with adaptive behavior.

All 18 children with global disabilities had parents who reported concerns resulting in a Path A or Path B score on *PEDS* (sensitivity = 100%, 18/18). Of the 77 children without such disabilities, specificity was 73% (56 of 77 did not have a Path A or B result). Parents whose children had intellectual disabilities raised far more concerns (mean = 2.5) than did parents of children without such problems (mean = 1.2).

So what were the types of concerns parents raised and in what proportions when children had (or lacked) cognitive and adaptive behavior deficits?

Cognitive/global concerns (e.g., "she's behind other kids"; "can't do what others can", "isn't learning well', "slow", etc.) were infrequent—only 22% of parents made such statements (although only by 1% of families whose children were cognitively average.

Self-help concerns were mentioned by 33% (but also by 21% of children who were intellectually average).

Expressive language/speech concerns were mentioned by 55% (but only mentioned by 21% of typically developing children).

Gross motor and fine motor concerns were mentioned by 22% (but by only by 8% of parents whose children lacked cognitive deficits).

Behavior concerns were raised by 78% (but were also mentioned by 44% of children without cognitive delays).

Receptive language concerns were mentioned by 28% (but raised by only 5% of parents whose children had typical development).

Parents whose children with intellectual and adaptive behavior deficits notice difficulties in a range of domains, not just in cognitive skills. *PEDS* Paths A and B (which reflects, to a large extent, both the predictive concerns and the numbers of concerns parents raise) were highly sensitive to intellectual disabilities. Nevertheless it is important to note that parents of children, whether disabled or not, raised many non-predictive concerns—clearly indicating the need for: (a) referrals for those at high risk on *PEDS*; and (b) counseling/monitoring those families with concerns but whose children did not have problems.

Study #2

Pritchard et al[11] administered *PEDS* to 216 children (110 were 2 years of age and 106 were 4 years old) born with very low birth weight, i.e., ≤1250 grams. Of the 216, 37 had cerebral palsy (CP), bilateral blindness, or required hearing aids, while 107 had developmental quotients 1 or more standard deviations below the mean (on either the Griffith Mental Development Scale, the Bayley Scales of Infant Development-II or the McCarthy Scales.

Problems in the administration of *PEDS* were numerous: (a) the authors did not re-administer *PEDS* by interview if nothing was written on the Response Form. This problem occurred with 13% of cases (N = 19/144); and (b) clinicians/researchers did not add their own concerns from observations or physical exam, i.e., over-ride *PEDS* scoring if clinical judgment indicated a problem.

So it is not surprising that the reported sensitivity and specificity for *PEDS* was poor. But, the authors were willing to share their protocols and so the findings could be adjusted to exclude the 19 with no comments, and move to Path A the 6 whose parents mentioned CP but were not assigned to Path A. Accordingly, 30 out of 34 children with a diagnosis of CP or intellectual deficits (< 1sd below average), received Path A or B results, i.e., sensitivity = 88%. Parents whose children did not have a diagnosis of motor disorders but had a cognitive delay, also had high levels of worry (often about language, or described features of ASD and so forth). So, specificity was understandably low (59/163 = 36%).

To aid *PEDS* users in recognizing parents' verbatim descriptions when cognitive deficits or motor coordination disorders were present, 5-21 is a list of common comments from the Pritchard et al study.[11]

Content of Predictive Concerns Reflecting Motor or Cognitive Disabilities

Other/health often included concerns about visual acuity and strabismus as well as problems with elimination (e.g., "constipation"; "urogenic bladder"). Weight issues were frequent (e.g., "too thin"; "poor appetite"). Sensory difficulties (e.g., "fussy about textures"; "doesn't like to have dirty fingers") were occasionally present; sleeping and eating problems were sometimes noted including snoring. Parents also commented often about constant ear and other infections.

Expressive language concerns often focused on articulation difficulties, lisps, lack of intelligibility, the frequent need for parents to request that children "slow down" in order to be understood (e.g., "won't talk to people unless she knows them"; "speech not clear"; "stutters"; "has trouble with complex words"; "only picks up key words"; "struggles to talk to other people"; "trouble saying nursery rhymes"; "repetitive"; "limited vocabulary—still babbling"; "small vocabulary –only 30 words"; "only uses 2 -3 word sentences"; "squeals a lot and only pointing"; "not talking"; "poor pronunciation", etc.).

Global/Cognitive and Receptive Language concerns were common (which makes sense because children with CP often have intellectual disabilities, and because the sample also included many children with intellectual disabilities but without CP). In either case, receptive language concerns were frequent and global/cognitive concerns were apparent in parents' frequent comments that their child was "behind"; "delayed"; "needs lots of repetition"; "can't handle more than two instructions"; "has trouble focusing on instructions"; "slower than most kids"; "doesn't seem to understand 'no'"; "not meeting milestones"; "does not understand complete sentences"; "only minimal understanding", etc.

Content of Non-Predictive Concerns reflecting motor or other developmental disorders

Shown in Table 5-21 are descriptions of traditionally non-predictive concerns provided by parents whose children were diagnosed with CP or other disabilities (either prior to or during the study). These are presented to help clinicians recognize and attend carefully to the content of parents' concerns and thus use clinical judgment to help recognize when parents' comments are likely to reflect substantial problems that might not be detected otherwise. Note that some behavioral problems (such as tantrums) and social-emotional concerns (e.g., parallel play) are common among 2-year-olds who are typically developing. But some of the concerns raised at age 2 were more troubling (e.g., purposeless play). Even more troubling is that at age 4, many children were continuing to have tantrums and parallel play—an age where the behavioral and social issues seen in typical 2-year-olds, should have waned dramatically.

Table 5-21. Categories and Content of Concerns Associated with Motor Coordination Disorders and Cognitive Deficits at 2 Years versus 4 Years of Age

Category of Concern	Examples of Parents' Comments
At Two Years of Age	
Gross Motor	*Falls over, clumsy, poor balance; Can't walk; Physical concerns; Throws one leg over the other and tenses body, rolls on her right side when walking; Not walking unassisted; left leg turned out, moves on knees, right heel turned out; walks on toes; foot turned in; core strength is poor, weak; can't jump; not sitting; left side weak; stiff in legs and movement; paraplegic, scoliosis,*
Fine Motor	*Contracture of index finger due to neonatal infection; tension in fingers, crosses fingers when stressed; left hand weak; right-hand hypertone;*
Self-Help	*won't use a spoon only finger feeds; isn't toilet trained, won't get dressed or try to help with dressing; slow toilet training;*
Behavioral	*Hyperactive, doesn't seem to have purpose, takes clothes off when distressed; poor attention; controlling, spoilt; destructive, defiant; too quiet; grabs knives and throws them; naughty; pinches; head-banging; very very active; tantrums, bites; yells and hits a lot; very hard to keep on task –only in small bursts; throws food; difficulty concentrating; takes poop out of his diaper and smears it everywhere; hold breath until he passes out; hits his head a lot; self-harming; too independent; aggressive temperament; just drops toys on the floor and doesn't play with them; dangerous climbing;*
Social-Emotional	*Throws things when frustrated; hits and screams when angry; tense; very strong personality; seems frustrated a lot; overly excited or frustrated when unable to voice issues; shy; doesn't have friends; doesn't like to go to sleep; loud screaming when angry; moody; doesn't do well in large groups; very cautious; clingy; doesn't interact with us as much as my other children did; doesn't like sharing; takes a while to warm up, even to play by herself; afraid of things; sometimes happy and then all of a sudden cranky; only plays by herself; timid;*
School skills	*Has to learn activities over and over but still doesn't grasp it; cannot discriminate shapes/colors; takes a lot of effort to pick up skills;*
At Four Years of Age	
Gross Motor*	*poor coordination; wobbly running, clumsy, hypertensive ankles; right leg stiff; difficulty moving, balance problems; very stiff or tense; falls down—not sure if this is balance or coordination; weak; can't use right arm; walks on tip toes; trips a lot; when running falls over or fast walking looses balance; walks toe to heel, behind; runs on toes; can't peddle a tricycle; can't walk;*

table continues

Table 5-21. Cont'd

Category of Concern	Examples of Parents' Comments
	At Four Years of Age, cont'd
Fine Motor**	*High tone, fine motor problems; webbing on toes and fingers; wonky fingers; restrictions in left hand; struggles to raise fingers; not drawing—not sure if he won't or can't; no strength in hands, poor control with pencils; only uses one hand; lacks fluid hand motions; behind others (with fine motor skills);*
Self-Help	*Slower than most but finally beginning to dress himself and use the toilet; have to repeat requests; trouble putting clothes on; trouble using cutlery; has to be told to dress herself, not toilet trained until 3 years; not independent; toilet training is very trying; trouble putting clothes on;*
School	*Not interested in learning; may need extra tutoring; has trouble understanding numbers, colors; is behind in school skills for age; can't write well; doesn't like school; not interested in learning school skills*
Behavior	*Demanding; acts like a baby sometimes; can't focus; difficulty with minor changes in routine; gets aggressive; slaps, hits; peculiar behaviors, eccentric; throws things; noisy; restless; smart-ass; still throws tantrums; test boundaries frequently, very stubborn; poor attention; obsessed with routines and rituals; too much rough and tumble; strikes out physically when interacting; says bad words for attention; spiteful; goes crazy; naughty;*
Social-Emotional	*No eye-contact; distressed often; angry; doesn't interact; loner; attention-seeking; high-strung; too friendly; very shy especially when parents are around; won't play with other kids; separation anxiety; disengages; overexcited; bad temper; gets upset easily; bossy; lacks the will to persist with learning; moody; unfriendly; withdraws when others try to interact with him; doesn't engage others; better with younger kids;*

**Gross motor concerns are predictive starting at 3 years of age, but examples of concerns associated with motor disorders are included for honing clinical acumen*
***Fine Motor concerns are predictive starting at 4 ½ years of age*

Comment on the concerns of parents whose children have cognitive or motor disabilities

Table 5-21 and the preceding comments, repeatedly illustrate the broad impact of motor disorders and/or cognitive deficits on all aspects of development. There is not a perfect match between parents' concerns and types of disabilities. For example, parents may take more notice of language, social, behavioral or motor difficulties, when, in fact, a child has an intellectual disability. This means that providers (although they should never diagnose on the basis of a screening test) need to look at more than just PEDS scoring but rather make use of everything that parents describe, enjoin the results of professional observation and physical exam, and thus feel free to over-ride a low-risk result on PEDS with clinical judgment in order to fully discern when problems are potentially present.

PEDS and Children with Chronic and Significantly Acute Illness

Peterson et al[28] studied the prevalence of developmental-behavioral problems in children hospitalized for acute care children who were 6 months through 17 years of age. Tests administered included *PEDS*, the Child Development Inventory (the assessment level version of the Ireton screens for children up to 6 years old), the Pediatric Symptom Checklist (administered to children from 4 years to 18 years), and the parent portion of the Vanderbilt ADHD Diagnostic Rating Scale (for children 6 years to 18 years). Records were reviewed for presence of a prior diagnosis, test results, and patients themselves were examined by an experienced neurodevelopmental pediatrician to determine the probability of a diagnosis.

Of the 325 participants, 22% had a prior diagnosis and 11% were considered diagnosable (N = 107). Of those who completed *PEDS*, sensitivity to a prior diagnosis was 86%, sensitivity to a suspected diagnosis was 77%, and specificity to the absence of prior or suspected diagnoses was 82%. The authors found that hospitalized children had substantially higher rates of developmental-behavioral problems than the general population. For example, cerebral palsy was found in 6% of the sample whereas prevalence is 0.15% to 0.25%. Intellectual disabilities were also higher than expected: 8.6% in hospitalized children versus 1.5% - 3% in outpatient samples. Parents were far more likely to be single mothers whose hospitalized children received Medicaid. Hospitalized children with developmental-behavioral problems had stays that were almost twice as long as children without problems (7.8 versus 3.6 days).

Comment on PEDS with children who are hospitalized or significantly ill

Peterson's[28] findings suggest that screening (if not use of assessment or diagnostic measures) is useful with hospitalized and chronically ill children. Since many are not physically able to complete hands-on tasks, use of parent-report measures are invaluable. Hospitalized and chronically ill children are at high risk of developmental-behavioral problems and also incur more expenditures than children without developmental problems. Even in a primary care setting, children with developmental-behavioral problems present for appointments at twice the rate of children without problems.[29] So, a viable hypothesis for future research is whether, if developmental-behavioral problems receive prompt attention, healthcare costs can be lowered, and whether parents and children are better served.

PEDS and Detection of Language Impairment

Study #1

Subsequent *PEDS*' accuracy studies found that children with language impairments were identified with > 75% sensitivity and specificity by *PEDS* for Path A.[30] The *PEDS Interpretation Form* shows unique patterns of concerns yielding a Path A result. (At all ages the patterns most associated with language impairment are two or more of the following concerns: global/cognitive, expressive language, and other/health; at older ages concerns also included receptive language, fine motor, gross motor, and school skills.) In addition, most parents whose children land on Path A have non-predictive concerns including behavior and self-help. As a consequence of the presence of both predictive and non-predictive concerns, parents of children with language impairment tended to have the following unique pattern: two or more concerns about self-help, social-emotional skills, school skills, and receptive language.

Why might parents raise a range of concerns that for the most part are not associated with language development? The reason is that language deficits have an adverse impact on many areas of development. If children don't understand what is asked of them or can't express themselves adequately, they are undoubtedly frustrated (social-emotional), have difficulty completing requests to get dressed or bathe (self-help skills), etc. So it is not surprising that parents of children with language impairment raise concerns in many domains.

Study #2

Research on the types of concerns best predicting language outcomes was replicated using 2013 data from *PEDS Online*, i.e., on 1293 families administered both *PEDS* and *PEDS: Developmental Milestones*. This sample, from a single clinic, was used because both screens were administered by interview, i.e., parents' ability to answer *PEDS* and *PEDS:DM* questions was not deterred by literacy barriers. This

particular clinic opted for an interview approach because families had elevated psychosocial risk (e.g., 25% of parents had not completed high school, 65% were Hispanic, and 40% spoke only Spanish).

Using the *PEDS:DM* language items (receptive and expressive) as the grouping variable in a discriminant function analysis, seven parental concerns on *PEDS* were strong predictors of language performance: expressive language (.81), school skills (.63), receptive language (.50), fine motor (.41), social-emotional (.37), behavior (.31) and self-help (.27) [χ^2 (10) = 246.23, p < .0001]. When viewing the above concerns (all of which rendered at least a Path A or B on *PEDS*), parents identified 418 out of 484 children who had language difficulties on the *PEDS:DM* (sensitivity = 86%). Nevertheless, parents' concerns over-identified children who did not fail *PEDS:DM* language items [Path A produced specificity of 62% (N = 502/809)], while Path A and Path B together produced even lower specificity of 37% (N = 302/809).

Why? Parents often raise a single predictive concern that reflects a need for parenting advice (e.g., "I don't know what a child her age should be saying."). Such concerns do not always reflect deficits…. at least not deficits as yet! Schonwald and colleagues [31,32] discuss "developmentally inappropriate concerns" that simply reflect limited parental knowledge of child-rearing. Nevertheless, parents who are not learning about child development as their children grow and learn, may not be parenting well—responding to their children's communicative attempts, helping children learn new words, etc.

So, again the AAP's policy is wise: We should have a high index of suspicion when parents' raise even one predictive concern, but we should also view actual performance on skill-based measures such as the *PEDS:DM* so as to avoid over-referrals (as the recommended response to Path B results on *PEDS*). Above all, we should counsel such parents in parenting skills that promote development and very carefully monitor progress in families whose predictive concerns indicate that knowledge of child-rearing is limited.

Study #3

In this 2013 study, participants were 4222 families of children averaging 34 months of age (range 16 to 63 months, sd = 11.92). Ninety-eight percent (98%) of families resided in the United States (all 50 states were represented along with three US protectorates/territories, and 2% resided in Canada. Parents had relatively high levels of education: 43% had completed 4 or more years of college. Prematurity rates were reflective of national prevalence, i.e., 12%.

Parents were self-selected and found *PEDS Online* via links from websites focused on autism spectrum disorder—meaning that parents opted for screening outside of primary care often due to unaddressed concerns about autism spectrum disorder. Of the 4222 families, 16% (N = 656) of children were enrolled in special education services because they met eligibility requirements (e.g., two 25% delays, 1 ½ sd below the mean) based on measures such as the Battelle Developmental Inventory, Mullen Scales of Early Learning, the Preschool Language Scale, the Vineland Adaptive Behavior Scale, Peabody Motor Scales, etc.

Of the children already enrolled in special education, specific services were listed for 11% (N = 470). Of the 470, 46% (N= 211) received speech-language therapy, and 55% (N = 259) received physical and/or occupational therapy. To view possible patterns of concerns associated with each type of diagnosis, a discriminant function analysis was conducted to identify performance differences on *PEDS* between the two groups. There were indeed substantial differences in concerns according to diagnosis: predictor variables discerning the two groups' concerns about gross motor (.81), fine motor (.71), school performance (.36), and self-help (.32) [$\chi^2(10) = 30.02$, p< .0001]. Other categories of concerns were non-contributory.

In considering *PEDS* Paths, Paths A and B were 96% sensitive in detecting children with a diagnosis of speech-language impairment (N = 203 out of 211), while 98% of families whose children had a diagnosis of motor impairment also received a Path A or Path B result. This means that while the two elevated risk paths on *PEDS* are highly sensitive to a diagnosis of language as well as motor impairment, *PEDS* Path scores alone do not fully discern which children need which kinds of services. Patterns of concerns are more effective at discerning types of services needed although there is considerable overlap, understandably because speech-language impairments often have a motor component (e.g., in articulation skills) and often co-occur with other fine and gross motor problems.

Comment on PEDS and Detection of Language Impairment

All three studies illustrate PEDS' sensitivity in identifying actual or probable language disabilities. Unique patterns of concerns were found but are not sufficiently discriminatory for providers to make a decision about the types of evaluations needed. Clearly clinical judgment is needed, although it is also important, given the inevitable overlap between language and orthopedic impairments, to make sure children receive comprehensive evaluations viewing all developmental domains. Fortunately, IDEA intake almost always includes a broad assessment and should be the first referral made when parents have numerous concerns.

PEDS and Child Sexual Abuse/Children Newly Placed in Foster Care

Jones et al[33] in studying the developmental-behavioral status of sexually abused children administered measures of intelligence, academic achievement, *PEDS* and the CBCL to parents (and the CBCL teacher report form to teachers) of 21 children (mean age = 7.7 years, range 5 months to 15 years). In 76% of cases, the reporters (mother, step-father or father) were also the abusers.

Of the 21 children, 28% had substantial intellectual or academic deficits and 62% had significantly elevated scores on the CBCL. *PEDS* showed a sensitivity of 64%, specificity of 60% with a positive predictive value of 77%.

Comment on Measuring Developmental-Behavioral/Emotional Status in Abused or Neglected Children

PEDS performed less well than desired. Preferable are sensitivity and specificity figures well above 70%. Still it is worth noting there are clearly quite a few problems with the Jones study, starting with the minor fact that about half the participants were beyond the age range for PEDS! But, trying to elicit concerns from abusive parents who may be defensive, emotionally disturbed themselves or worried about possible incarceration, etc., suggests that PEDS is probably not an optimal screen to use with such parents. Skill-focused measures administered by observation or directly to children is surely a better approach.

Nevertheless, PEDS is useful (and widely used) with new foster parents (especially when children have been recently removed from their prior homes). In such cases, children may not perform well on hands-on measures. New foster parents may have had little opportunity to observe, and thus have challenges on reporting children's skills.But foster parents (who are often experienced care-givers, or knowledgeable about the child because they are extended family members) can often provide gist concerns, i.e., respond thoughtfully to PEDS questions, in the early days of the new placement—when they have not had time to observe actual skills.

More importantly, children who have been neglected or abused, really don't need to be screened. We already know they are at high risk for developmental and behavioral problems. Ideally, all should be referred for intervention services. If measurement is a condition of placement, as it often is, such children deserve more in-depth measurement than a screen can provide. The PEDS:DM Assessment Level, the Developmental Profile-III, or the Battelle Developmental Inventory Screening Test (along with separate measures of emotional well-being) are far more appropriate for children with histories of disturbing interactions with care-givers. PEDS continues to have a role in identifying the unique issues parents have, whether foster or biological, but should be used together with other measures, especially with biological parents who may be perpetrators.

Using *PEDS* with Parents who are at Psychosocial Risk, those with Parenting Stresses or have Mental Health Problems

Study #1: Review of Research on *PEDS* and Psychosocial Risk

Parents with psychosocial risk include those who have limited education, (typically less than high school), who are poor, ethnic minorities, and who don't speak English well. Providers often notice that parents with psychosocial risk factors don't raise concerns as often as educated parents. This leads clinicians to wonder whether such parents, given abundant stressors and many distractions, even notice problems with their children. This is a reasonable hypothesis but one that has been thoroughly debunked.[34-37] Families with psychosocial risk factors do notice problems—and notice problems in proportion to the higher rates of disabilities their children face. But families at risk tend not raise concerns—unless asked. When they do raise concerns, they tend to focus on healthcare issues, not developmental-behavioral ones. Such families do not always know that professionals are interested in non-medical concerns.

Glascoe [34-37] found no differences in the accuracy of parents' concerns in detecting disabilities whether parents had attended college or had less than a high school education (sensitivity and specificity > 70%). But educated parents were 11 times more likely to raise concerns spontaneously. Not surprisingly, their children were 11 times more likely to have a child enrolled in needed special services. Asking about concerns is clearly needed!

Study #2

Parents with depression and anxiety are known to be as accurate as parents without mental health problems in identifying deficits in their children's development and behavior (although, not surprisingly, such parents are not as adept as those without mental health problems in identifying above-average/gifted development in their children—as is consistent with the pessimistic outlook of depression/anxiety, i.e., "the glass is half-empty").[29,38]

Study #3

Voigt et al[29] viewed the relationship between parenting stress [measured by the Parenting Stress Index (PSI)] and parents' concerns on *PEDS*. Parenting stress is a marker for depression and anxiety and Voigt et al found significant relationships between PSI domains (> 85th percentile) capturing isolation, attachment, parenting skills, and total stress and elevated rates of concerns on *PEDS*. Although an objective diagnostic battery was not used to corroborate parents' concerns, it is well-established that problematic parenting skills are associated with substantive developmental-behavioral problems.[39,40] So, it is invaluable that parents under duress hold more concerns about their children than do parents with healthier well-being. Voigt et al also commented that parenting stress is surely exacerbated by having a child with developmental-behavioral problems.[29]

Comment on Psychosocial Risk, Parenting Stress and Mental Helath Problems

Parents with psychosocial risk factors, especially limited education, may not raise concerns spontaneously (or even recognize that their concerns are important to providers). Identifying the non-medical concerns of such parents requires asking—not relying on—parents to raise concerns on their own. Parents at psychosocial risk are better able to state their concerns if they are asked via PEDS' questions. But, literacy barriers can interfere with quality responses on PEDS. To circumvent literacy problems, use of PEDS by interview is essential if we want to do our best for underserved populations and level the "playing field" between the "haves" and the "have nots".

Parents with depression, anxiety, and other stressors, are as able as parents without mental health problems to identify developmental-behavioral problems in their children. Parents under duress tend to have children with more problems than parents without stressors or parenting problems. So, we should take the concerns of all parents seriously –detect, address, measure, monitor, and refer to a wide range of services designed to help not only children but also help their parents do an optimal job of parenting.

International Accuracy Studies

The Standardization Chapter described numerous international initiatives to translate and standardize *PEDS*. A few such studies included an accuracy component and are described below. Although many other studies are ongoing (e.g., Malaysia, Philippines, Jordan, Hungary, Portugal, Australia, Israel), when completed, the research will be reported on *www.pedstest.com* and in subsequent revisions to this manual.

England

In a study conducted in the Milton Keynes Primary Care Trust[41] nurses administered *PEDS* to 76 families of whom 56% were of white British background and the remainder Pakistani and black African immigrants. *PEDS* was administered in the primary language of the family. All children were two years of age and had been found, at one year of age to be typically developing via administration of the Schedule of Growing Skills (SOGS), a comprehensive assessment level measure. Of the 76 parents, 26 raised social-emotional or developmental issues (about half of which focused on speech-language). The 26 children were then retested with the SOGS at age 2 and all were found to have developmental deficits. The authors commented, *"this finding speaks to the value of repeatedly monitoring developmental status."*[41]

Indonesia

Researchers at Udayana University in Bali conducted a study comparing *PEDS* to the Battelle Inventory of Development Screening Test-II (BDIST-II).[42] Subjects were 170 parents of children between three to twelve months of age seeking routine outpatient care at Denpasar Hospital. After translation into into Bahasa, *PEDS* sensitivity was found to be 84% and its specificity was 81%.

Taiwan

Researcher/clinicians in Taipei[43] studied 101 families with children between 6 to 77 months (mean age = 39 months), suspected of having developmental delay. Parents were administered *PEDS* in Mandarin or Taiwanese Hokkien, and all children were administered the Chinese Children Developmental Inventory (CCDI), a broad assessment level measure covering all developmental domains. Additional measures were added based on the clinicians' initial impressions and recommendations (the researchers on this study were subspecialist physicians in rehabilitative medicine, psychiatry, and neurology) and included the Peabody Developmental Motor Scale, Peabody Picture Vocabulary Test, Gross Motor Functional Measure, and the Wechsler Preschool and Primary Scale of Intelligence. Performance < 2sds below the mean was used as cutoffs. Children were classified into six subgroups: speech-language, motor, behavioral, cognitive, global delays, or normally developing (with separate diagnoses of autism spectrum disorder and/or ADHD). Parental concerns on *PEDS* about speech-language, motor, and behavior produced high sensitivity (77% to 89%) and high specificity (85% to 88%) to diagnosed deficits in these same domains. Lower sensitivity (15% to 36%) was found between the global concerns category on *PEDS* but specificity was extremely high (93% to 96%). The authors noted that very few parents raised global concerns.

Comment on the Taiwan study

This study is impressive for the clinical expertise of the authors, their use of clinical impressions to better to define a diagnostic battery, and their willingness to view a wide range of disabilities at once. Such effort is required for a thorough evaluation of any broad-band screening measure because such screens are inherently designed to identify a broad range of potential problems.

A bit problematic are the stringent cutoffs for defining each type of disability and the expectation of a match between the type of concern and the type of problem. For this reason a better approach is to search for patterns of concerns associated with each condition (e.g., via logistic regression or discriminant function analysis). Otherwise, the authors approach to studying PEDS serves as an invaluable example for researching any broad-band screen.

India

Drs. Malhi and Singhi, professors of pediatrics at the Postgraduate Institute of Medical Education and Research in Chandigarh, India, assessed 79 parent-child dyads seeking well-child care. Children ranged from 24 to 60 months and had no history of diagnosed disabilities, chronic illness or perinatal problems.[44] Parents were administered *PEDS* in English or Punjabi and also completed the Developmental Profile II (a broad assessment level measure producing quotients for physical, self-help, social, academic/cognitive, and communication skills) and the Vineland Social Maturity Scale (which measures self-help, social relations, locomotion and self-direction and produces a single social quotient score).

In keeping with US research on *PEDS*, parental concerns were common: Behavioral issues were the most

frequent (40%), followed by social-emotional (22%), other/health (18%), expressive language (18%), and global/cognitive (6%). Children were categorized into two groups, those with DQs < 70 (16%) and those with DQs of 70 and above (84%). Parents of children with developmental delays were more likely to receive a *PEDS* Path score of A or B producing sensitivity of 62%, although the authors noted that the remainder tended to raise non-predictive concerns, and that children whose parents had predictive concerns on *PEDS* often had delays above a DQ > 70, but remained far below average. Specificity was 65%. Drs. Singhi and Malhi[44] also found that parents' concerns about self-help skills were also strongly predictive of problems.

Comment on India study

In a published letter to the editor,[45] discussion ensued about whether the US patterns of concerns leading to risk Paths on PEDS should be reconsidered in other nations—given the potential that parents from other cultures may have quite different perceptions about child development (e.g., which skills are valued and thus which domains are especially salient to parents). The authors agreed not only to look at different cutoffs but also to identify whether, for India, a different constellation of predictive versus non-predictive concerns would provide greater sensitivity and specificity.

Malaysia

Drs. Toh, Lim, and colleagues are conducting a series of standardization and validation studies on *PEDS* as translated into Malay and Mandarin. Dr. Toh worked closely with the *PEDS* Translations team on the Malay translation and reworked the original problematic Mandarin translation (where the word "concerns" also meant "care" and not "worries" as intended (as described in Kiing et al).[46]

The first completed study is described here: 86 parents of children between 1 and 6 years of age completed the translated *PEDS* and answered questions regarding the acceptability and usefulness. *PEDS* was repeated 2 weeks later while the children underwent Griffiths Mental Development Scales. Preliminary data illustrated that 26% of caregivers reported two or more significant concerns and 17% had no concerns. Data analysis showed significant correlation between *PEDS* and global developmental disabilities and/or language disorder as assessed by the gold standard test ($p < 0.001$), with sensitivity of 74% and positive predictive value of 68%. Test-retest agreement revealed a high degree of inter-rater reliability. Almost all caregivers (98%) rated *PEDS* as easy to understand and complete: 91% found it acceptable as a developmental screening tool, and 62% believed *PEDS* is useful for Malaysian health professionals.

Comment on International Accuracy Studies

It is wise for international researchers to anticipate that the constellations of concerns leading to various PEDS Paths and thus to risk levels, may need rethinking when applied in other countries and languages. In other words, US norms may not be applicable due to differences in standards for school performance at various ages, eligibility criteria for special services, cultural demands, etc.

The critical first step is to ensure that translations are of good quality—meaning thoroughly vetted by numerous professionals and parents. The US PEDS Research and Translations Team can provide translation guidelines based on International Test Commission Standards (and our hard-won experience). We can often help researchers locate colleagues who are working on PEDS Tools.

We encourage researchers interested in validation and accuracy studies to adopt a broad concurrent battery and to identify the full range of disabilities against which to compare a broad-band screen such as PEDS. International researchers should consider more than just the accuracy of US norms and explore fully the possibility that different patterns of concerns may be more effective at predicting risk on PEDS. PEDS researchers are willing to freely advise on appropriate concurrent measures, study design, and data analysis.

Finally, we donate use of PEDS Tools in developing nations and for unfunded research throughout the world. PEDS Tools are co-published in Australia, the Philippines, and England, and co-publication is in-progress in Iceland, Jordan, Indonesia, and elsewhere. Links to established co-publishers are provided on www.pedstest.com.

Summary of *PEDS* Accuracy Studies

- Some concerns are significant predictors of developmental status, and these vary in number and content with children's ages.
- Using the presence or absence of significant concerns to identify children with probable disabilities approaches standards for screening tests. Sensitivity ranges from 74% to 79% and specificity from 70% to 80%. Accuracy levels fluctuated only modestly by children's ages, and consistently remained within the desired range for screening tests, 70% or greater.
- Parents with more than one significant concern are most likely to have children with disabilities or high risk for school failure. Administering a screening test to these children is not advised because this appears to compound measurement error and leads to a loss of sensitivity—too many children with problems would not be referred. Thus, referral for evaluations is the best response. The findings also distinguish the need for speech-language versus psycho-educational testing, although professional judgment should be relied on to indicate whether other types of evaluations are needed.
- Some of the inaccuracy in *PEDS* surrounds those parents who raise only one significant concern. Responding to this group (about 20% of all children) with a second developmental screening test increased the accuracy of *PEDS* without producing excessive under-referrals on children who need diagnostic testing.
- Under-referrals on *PEDS* are often related to communication barriers. These barriers may include absence of a common language between examiner and parent, parents with limited literacy inadvertently given a written version of *PEDS*, parents with mental health problems, parents with language delays or disorders of their own, an informant who is not the primary caretaker, and/or parents who are simply reluctant to share concerns. When these barriers are apparent, it is advisable to administer a measure that directly elicits children's skills, obtain an interpreter if needed, and consider whether parents need referrals for special assistance or counseling. Parents' reluctance to share significant concerns (perhaps due to worries about reducing the objectivity of professionals' judgments) may be lessened by repeated use of *PEDS* over the course of the well-visit schedule. Providing a second screen to those with communication barriers improved the sensitivity of *PEDS* without jeopardizing specificity. Otherwise, providers should use professional judgment to decide when to refer children whose parents do not raise concerns, but who appear to have developmental or behavioral problems.
- Most children with significant behavior and emotional problems can be identified by the nonsignificant parental concerns. However, many more parents raise such concerns than have children with serious emotional/behavioral problems, so advice and counseling are advised initially. If ineffective, children should be administered a behavioral and emotional screening test and the results used to determine the kinds of referrals needed.
- The accuracy of *PEDS* is largely unaffected by sociodemographic variables. This appears due to parents' tendency, regardless of educational attainment or child-rearing experience, to compare their children to others. Nevertheless, parental illiteracy and foreign language or other communication barriers can interfere. Parents were equally able to provide strong predictors of developmental status, despite differences in levels of education, race, income, parents' ages, marital status, or parenting experience and exposure to other children, i.e., children's birth order, family size, prior or current participation in day care or school programs.

  One demographic variable associated with *PEDS'* accuracy is children's ages. Older children were more likely to have concerned parents. This seems to reflect the greater likelihood of disability as children grow older, and greater opportunity for parents to compare their child to others at school entrance and beyond, a phenomenon that may lead parents to notice subtle delays (e.g. below average IQ, language, achievement, academics, poor grades, etc.).
- *PEDS* demarcates five distinct groups of children based on the nature of parents' concerns. Differences in the likelihood of disabilities across the five groups suggests differing optimal responses for detecting and addressing developmental and behavioral issues.

- Accuracy indices were computed across two separate studies on 4473 children who were administered a variety of diagnostic measures to determine eligibility for special education services.
- Summary figures are: sensitivity = 86% and specificity = 74%.
- Over-referrals on *PEDS* continue to include children with psychosocial risk factors and delays, but delays insufficient for special education eligibility. For this reason, positive predictive value (37% for special education eligibility) lacks meaning.
- Discriminant sensitivity (meaning research on how well *PEDS* identifies specific conditions) are numerous and show unique patterns of concerns and often *PEDS* Path differences when children have autism spectrum disorder, mental health problems, cerebral palsy/motor disorders, intellectual disabilities, language impairment, etc. In all cases sensitivity was greater than 80% except for abused and neglected children when the informant was the likely perpetrator.
- Two studies viewed the ability of parents without and with depression, anxiety, and other mental health difficulties to raise concerns on *PEDS*. Both groups performed similarly suggesting that *PEDS* can be used effectively with parents who have mental health difficulties (at least mild ones).
- *PEDS,* given careful translations in the US and other nations, continues to show high sensitivity and specificity to problematic development.
- The accuracy of *PEDS* is not affected by sociodemographic variables (except parental illiteracy, lack of available translations or other communication barriers). Parents are equally able to provide strong predictors of developmental status, despite differences in levels of education, race, income, children's ages, parents' ages, marital status, parenting experience or exposure to other children (e.g., children's birth order, family size, prior or current participation in day care or school programs). Nevertheless, an interview approach to *PEDS* administration is especially useful when families have psychosocial risk factors.

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Chapter VI
Directions for Future Research

Percolating throughout prior chapters of this manual are critiques of research on *PEDS*. These highlight the strengths and weaknesses of the many studies. Several consistent themes emerged:

1. Attention to test directions is needed when it comes to administration, scoring and interpretation of *PEDS* (and for any other screen or criterion measure). While such adherence should be axiomatic, many studies suffer from failure to follow directions! For example, *PEDS* cannot be scored if nothing is written on the form or if items are skipped. This is an indicator of literacy problems creating substantial threats to the validity of research. Re-administration by interview is required. In addition, providers must add their comments based on clinical observation and history and/or elevate children to a high risk path on *PEDS* when parents' comments include previously established conditions or indicators of undiagnosed conditions (as described in the chapter on Accuracy).

2. When researching any broad-band screen, the "gold-standard" reference battery should be comprehensive. Because screens tap a wide-range of domains, the concurrent, preferably diagnostic battery must do the same.

3. Performance on screens should be evaluated against reference batteries in relation to the domains measured but, the criteria for determining the presence or absence of disabilities should be meaningful, i.e., does a child qualify for special education services or not? An arbitrary cutoff score for the concurrent battery (and its domain sub-scores) is not sufficient. Many disabilities are defined as discrepancy of one or more standard deviations between intelligence and performance in other domains. Thus, for example, a child with an IQ of 105 may be eligible for services if his or her quotient in language is < 90 (< 25th percentile). Grouping diagnostic results by eligibility criteria is challenging (because US States vary in definitions of eligibility), but sorting children by one or more of the more common criteria is needed

4. Quality translations, fully vetted by bilingual speakers is essential. *PEDS Tools* are translated according to the International Test Commission's Guidelines for adapting tests, i.e., viewed, tweaked and trialled by a cadre of bilingual speakers—both by parents and by professionals from various backgrounds who work with children (*www.intestcom.org*). A poorly written translation wreaks havoc with the validity of research results and renders them uninterpretable. If you need translations or help developing new translations, please contact us via *www.pedstest.com /ContactUs*. We will send you translation guidelines and, if available, put you in touch with other researchers/clinicians

who are working with the same translation/ language.

5. Capturing psychosocial risk factors and demographics (e.g., ethnicities, geographic location, languages spoken at home) are essential for quality standardization. For example, children who are poor and rural typically perform less well than affluent children with access to education. Studies of tools must strive to measure performance differences and to identify the needs of these children via screening test performance.

6. In researching *PEDS* in other nations, it is important to explore alternative patterns of concerns on *PEDS* and whether there are better constellations of concerns by age for generating *PEDS* Paths. Adaptations of North American tools often require not only translations, but also changes to imagery, content, and norms, other considerations include differences in ages at school entrance and differences in performance expectations at school entrance. For example, in a nation where children do not start school until age 6 and are not expected at school entrance to write their name, identify letters, etc., parents may not have as many concerns about school performance or fine motor skills in children < 6 years of age.

7. International researchers should also anticipate cultural differences in parents' expectations. For example, self-help concerns were highly correlated with problematic outcomes in Asian subcontinent studies, and were also found to be predictive of long-term outcomes in Australia. These findings suggest that parents have different valuations of children's skills based on cultural differences and expectations. Again, international researchers should explore which concerns are predictive of problems and reconsider *PEDS'* Paths accordingly.

8. In some countries, services are extremely limited and eligibility restricted to only the most severe disabilities. This makes applying criteria difficult. In such cases, North American criteria may be useful but should also be viewed as a "needs assessment" used in advocacy for improving services.

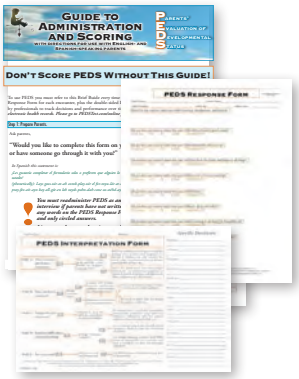
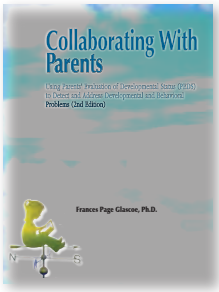
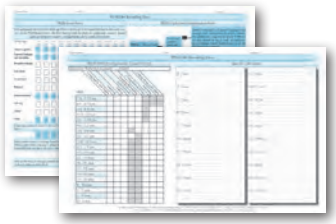
9. Many countries outside of North America lack fully standardized diagnostic batteries—meaning that screens and concurrent measures may need to be validated together. In such cases, it may be most cost-effective to norm *PEDS* alongside a hands-on administration of an assessment level tool focused on children's skills across domains (e.g., *PEDS:DM Assessment Leve*l from which the *PEDS:DM Screening Test* can also be normed). Standardizing two very different measurement approaches are advised because this reduces threats to validity and thus strengthens and confirms research findings.

The *PEDS* research team welcomes studies on *PEDS TOOLS* and naturally wants to make sure they are done well. If you need advice, guidance, or ideas, please check the enormous range of information on *www.pedstest.com* and if more is needed, then go to *www.pedstest.com/ContactUs*. This portion of the site helps you identify the focus of your questions and diverts messages appropriately (e.g, if about translation issues then the message goes to the *PEDS* Translation and Research team).

In case you need information on the various *PEDS TOOLS*, we include ordering information on the next four pages.

PEDStest.com, LLC also donates digital files of *PEDS TOOLS* for unfunded dissertation research and for work in developing nations. Our researchers are happy to consult on needed modifications, research design and analysis. Please contact us if our assistance is needed.

ORDERING INFORMATION FOR PEDS and the PEDS:DM

Item Description		*What do I need to order?*
What is PEDS?		***PARENTS' EVALUATION OF DEVELOPMENTAL STATUS***
PEDS •is a 10 question, validated, accurate screen eliciting parents' concerns, in their own words, about their child's development and behavior. It takes about 5 minutes for parents to complete, and 1- 2 for clinician to score. •reveals whether to refer, give advice, provide watchful waiting, screen further or reassure. •reduces "oh by the way" concerns, increases attendance at well-visits. •can be used with children of any age from birth until 8 years of age. •includes a Brief Guide to Administration, a Response Form, a longitudinal Score /Interpretation Form, and an optional Manual for case examples, how to explain results to families, parent education handouts, etc..	 	•**First Timers:** Order ***#705-PEDS Complete Set*** *(Brief Guide, 1 pad of 50 PEDS Response Forms, 1 pad of 50 Score/Interpretation Forms). This is enough material to screen 50 children).* It is a good idea to also order ***#500*** the ***manual, "Collaborating with Parents."*** *See order form for information on foreign language translations and electronic applications.* •**Reorders-Small Clinics:** Each clinician using PEDS should have a ***#300-Brief Guide*** and each clinic should have a ***copy of #500-"Collaborating with Parents."*** Reorder equal amounts of ***#700-PEDS Response Forms*** (pads of 50) and ***#720-PEDS Score/Interpretation Forms*** (pads of 50). (See order form for Spanish or Vietnemese versions of PEDS forms.) •**Re-orders-Large Clinics:** You'll probably want to request a ***#740-Discounted Bulk Order*** (a 25% discount from individual pads) consisting of 20 Brief Guides, 20 pads of 50 Response Forms and 20 pads of 50 Score/Interpretation Forms. This will screen 1000 children. •**Re-orders-HMOs, Clinic Network:** If you need 50 or more bulk orders (screens for 50,000 children or more during a year or so) and are willing to have them sent to a single address, please email evpress@pedstest.com. We have a discount schedule that can save you 30% to 50%.
What is the PEDS:DM? PEDS:Developmental Milestones		**PEDS:DM for Pediatric and Public Health Encounters**
THE PEDS:DM •is 6-8 items per visit focused on children's skills in each developmental domain: fine motor, gross motor, expressive language, receptive language, self-help, social-emotional, and for older children preschool and school skills. The questions take about 5 minutes to complete and 1 minute to score. •is designed for children at any age from birth until age 8, the measure consists of a laminated book of questions upon which parents mark answers with a dry erase marker. Marks are wiped off in preparation for re-use with the next family. To score, a single template is placed over the completed page to reveal each milestone not met. •replaces informal milestones checklists (known to miss 70% of children with problems) with proven, validated, and accurate items.	  	**<u>800-PEDS:DM for Pediatric and Public Health Encounters</u>** <u>(starter kit)</u> Includes: ***PEDS:DM Family Book*** (in English or Spanish) consisting of reusable laminated forms; 100 longitudinal ***PEDS:DM Recording Forms***; and a ***Binder Case*** housing the scoring template and storage for the Family Book, manual, dry erase marker, and clip to secure the correct page. The starter kit also includes the ***PEDS:DM Professional Manual.*** •**First Timers:** Order ***#800-PEDS:DM for Pediatric and Public Health Encounters starter kit*** (see order form for Spanish or Vietnamese versions of PEDS Forms). •**Small Clinic:** Order ***#800-PEDS:DM for Pediatric and Public Health Encounters starter kit*** plus enough ***#810-Family Books*** *(or #815 Family Book in Spanish)* for each well visit scheduled at the same time. •**Large Clinic:** Order enough of the above ***#800 starter kits*** for each nurses' station, plus enough ***#810-Family Books*** (or #815 Family Book in Spanish) for each well visit scheduled at the same time. •**Re-orders:** Reorder ***#820-PEDS:DM Recording Forms.***

Item Description		What do I need to order?
What is the PEDS:DM (cont'd)?		**THE PEDS:DM FOR EARLY CHILDHOOD AND NICU**
THE PEDS:DM (CONT'D) •includes a developmental promotion component by encouraging parents, once they've completed the questions, to read a short story to their children about age-appropriate parent-child interactions. Online applications are coming soon. See www.pedstest.com for updates. •the PEDS:DM Recording Form is used to record answers and can be re-used with each child to produce a graph of progress over time. •the PEDS:DM manual contains information on parenting, billing and coding, and directions for using the PEDS:DM alone, in combination with PEDS, or with screens of parent-child interactions, psychosocial risk, resilience, ADHD, and autism spectrum disorders, along with parent information handouts, case examples, and training guides. •For NICU follow-up and early childhood settings, the assessment level version of the PEDS:DM presents more items at once and produces age-equivalent scores.		**805-PEDS:DM for Early Childhood and NICU follow-up** *(starter kit)* Adds to the PEDS:DM starter kit the ***PEDS:DM Assessment Level*** *(in Spanish or English)* which offers more items at each encounter and produces age-equivalent scores in 7 domains: fine motor, gross motor, expressive language, receptive language, self-help, social-emotional, and, for older children, pre-academic/academic skills. The Assessment Level includes the laminated ***PEDS:DM Family Book*** (with illustrations needed for the Assessment Level administration); 50 ***PEDS:DM Assessment Level Booklet*** (reusable over time with the same child); and the ***Longitudinal Growth Chart*** (printed on the back of the Assessment Level booklet) for sharing results with families. This version of the PEDS:DM can be mailed out, completed in waiting exam rooms, or administered directly to children by teachers, clinicians, etc. For children less than 3 years of age, the PEDS:DM Assessment Level can also be administered via telephone interview. •**First Timers:** Order ***#805-PEDS:DM for Early Childhood and NICU follow-up starter kit***. •**Small and Large Clinics:** Order ***the #805 starter kit*** plus enough ***#810-Family Books*** and ***#840-Assessment Level Booklets*** (or #815 and #845 for Spanish) for each visit scheduled at the same time. •**Re-orders:** Reorder ***#810-PEDS:DM Assessment Level Booklet*** *(or #815 for Spanish booklet)*.
What is THE BEST APPROACH? TO USE BOTH PEDS AND THE PEDS:DM!		
PEDS:DM PLUS PEDS **THE BEST APPROACH** •adding PEDS to the PEDS:DM (both at the same time, or the PEDS:DM as needed) offers good compliance with American Academy of Pediatrics policy: eliciting and addressing parents' concerns at each encounter, monitoring milestones, and screening with validated tools periodically. •using PEDS and PEDS:DM together improves communication between families and providers, increases the likelihood of attendance at follow-up visits, and offers optimal program evaluation/ research metrics.	 	**850-PEDS:DM plus PEDS: The Best Approach for Pediatric and Public Health Encounters** includes the ***PEDS:DM starter kit*** plus 100 ***PEDS Response Forms*** and the ***PEDS Brief Guide***. The ***PEDS:DM Recording Form*** (100 supplied with each order) includes the PEDS Scoring/Interpretation Form that identifies when the PEDS:DM is needed. •**First Timers:** Order ***#850-PEDS:DM plus PEDS:*** **The Best Approach for Pediatric and Public Health Encounters**. •**Re-orders:** Reorder ***#700-PEDS Response Forms*** (or 710 or 730 for Spanish or Vietnamese) and ***#820-PEDS:DM Recording Forms***. **807-PEDS:DM and PEDS for Early Childhood and NICU follow-up**: ***The Best Approach for NICU follow-up and Early Childhood*** includes with the ***PEDS:DM starter kit***, 50 ***PEDS Response Forms*** and the ***PEDS Brief Guide***. •**First Timers:** Order ***#807-PEDS:DM and PEDS for Early Childhood and NICU follow-up***. •**Re-orders:** Reorder ***#700-PEDS Response Forms*** (#710 or #730 for Spanish or Vietnamese) and ***#720-PEDS Score/Interpretation Forms***, and additional ***#840-Assessment Booklets*** *(or #845 for* Spanish).

ORDER FORM for the PEDS:DM

PEDS:DM Binder Case

…with brief administration instructions and scoring template

PEDS Family Book

…with laminated forms and supplementary measures

English Spanish

PEDS:DM Assessment Level Booklet

12-page record booklet Re-usable for each child

English Spanish

PEDS Brief Administration and Scoring Guide

Directions for eliciting and addressing parents' concerns

PEDS Response Form

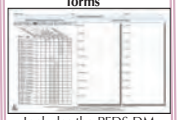
…containing questions about parents' concerns

English Spanish

PEDS Score & Interpretation Form

…for decision support and longitudinal monitoring with PEDS

PEDS:DM Recording forms



Includes the PEDS:DM Growth Chart and PEDS Score/Interpretation Form

PEDS:DM Professional Manual

…with directions, and parent and professional education materials

Item											*Price*	*Quant.*	*Total*
800-PEDS:DM for Pediatric and Public Health encounters (starter kit)	1	1							pk 100	1	$275.00		
803-PEDS:DM for Pediatric and Public Health encounters (starter kit) (Spanish)	1		1						pk 100	1	$275.00		
805-PEDS:DM for Early Childhood and NICU follow-up (starter kit)	1	1		25						1	$318.00		
806-PEDS:DM for Early Childhood and NICU follow-up (Spanish)	1		1		25						$318.00		
850-PEDS:DM plus PEDS: The Best Approach for Pediatric and Public Health Encounters	1	1				2	pad 100		pk 100	1	$315.00		
855-PEDS:DM plus PEDS: The Best Approach for Pediatric and Public Health Encounters (Spanish)	1		1			2		pad 100	pk 100	1	$315.00		
807-PEDS:DM and PEDS for Early Childhood and NICU follow-up: The Best Approach	1	1		50		2	pad 50		pad 50	1	$399.00		
808-PEDS:DM and PEDS for Early Childhood and NICU follow-up: The Best Approach (Spanish)	1		1		50	2		pad 50	pad 50	1	$399.00		
EXTRA COPIES AND REFILLS													
810-PEDS:DM Family Book (English) It is helpful to have a Family Book for each exam room or simultaneous appointment. Includes clip and dry erase marker		1									$110.00 *(10 or more: $80.00)*		
815-PEDS:DM Family Book (Spanish)		1									$110.00 *(10 or more: $80.00)*		
830-PEDS:DM Professional Manual A Manual is recommended for each station where professionals administer the PEDS:DM										1	$40.00 *(10 or more: $30.00)*		
820-PEDS:DM Recording Forms									pk 100		$32.00		
840-PEDS:DM Assessment Level Booklet				25							$75.00		
845-PEDS:DM Assessment Level Booklet (Spanish)					25						$75.00		
PEDS Online	*Please contact: online@pedstest.com*										**Subtotal** *(add to total on next page)*		
Volume discounts/bulk ($25k+) orders	*Please inquire: evpress@pedstest.com*												

ORDER FORM for PEDS FORMS AND GUIDES

Item Description	Cost	Quantity	Total
705-PEDS Complete Set: 1 Brief Administration & Scoring Guide, 1 pad of 50 PEDS Response Forms, 1 pad of 50 PEDS Score & Interpretation Forms	$36.00		
300-Brief Administration & Scoring Guide (for English- and Spanish-speaking families)	$4.00		
(Volume discount (e.g., large clinics, teaching hospitals) orders of 20+)	*($3.50)*		
700-PEDS Response Forms for English-speaking parents (pad of 50)	$18.00		
720-PEDS Score & Interpretation Forms (pad of 50)	$18.00		
710-PEDS Response Forms for Spanish-speaking parents (pad of 50)	$18.00		
730-PEDS Response Forms for Vietnamese-speaking parents (pad of 50)	$18.00		
740-Discounted Bulk Order Package: 1000 Response Forms, 1000 Score & Interpretation Forms, 20 Brief Administration & Scoring Guides (substitutions available on request)	$600.00		
500-Comprehensive PEDS Manual, "Collaborating with Parents" (2nd Edition)	$79.95		
600-Identifying & Addressing Developmental-Behavioral Problems: A Practical Guide for Medical & Non-medical Professionals, Trainees, Researchers & Advocates (Textbook)	$109.95		

Subtotal PEDS Order	
Subtotal of PEDS:DM Order	
Discount Code:	
Sales Tax (TN residents)	
International Shipping & orders over $2000:	**Contact Us**
US Shipping 9% of total, **($8.99 for all orders less than $83.00)**	
TOTAL**	

For information on using PEDS in electronic health records go to www.pedstest.com and follow links to Online Screening.

For ordering enough material to screen 50,000 children during a single year contact: ***evpress@pedstest.com****. 50% prepayment required.*

For versions in other languages, and research issues contact: ***research@pedstest.org.org****. Examples, videos, downloadable training slide shows and research information are also available at* ***www.pedstest.com****.*

***There is a 30 day limit for credit for a returned order. Returned orders, if damaged, will not be credited. Shipping costs plus a 10% re-stocking fee will be deducted from undamaged returned orders. If unsure what to order please read through this ordering guide carefully.*

Billing Information						**Shipping Information** ❑ check if same as billing					
Name						Name					
Organization						Organization					
Address						Address					
City		State		Zip		City		State		Zip	
Phone		Fax				Phone		Fax			
Email						Email					
PO ❑	Visa ❑	Amex ❑	MC ❑			**Who will supervise PEDS use in your setting?* (REQUIRED)**					
Number:		Expiration:				Name:*					
Signature:						Email:*					

By signing above you are agreeing that PEDS/PEDS:DM Forms cannot be reproduced in any manner.

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See www.pedstest.com for trials and information.

FP Glascoe, KP Marks, JK Poon, MM Macias (Eds). ***Identifying and Addressing Developmental-Behavioral Problems: A practical guide for medical and non-medical professionals, trainees, researchers and advocates.*** Nolensville, Tennessee: PEDStest.com, LLC, 2013. *www.pedstest.com*

This indispensible textbook supports life-long learning in medical and nursing school, to residency and fellowships, to precepting and community practice, and from there, into research and advocacy. Explained are the basics of child development and how parent-child communicative play and shared affect promote learning and well-being. Developmental-behavioral as well as mental health disabilities are defined along with prevalence and requisite measurement methods.

Techniques are provided for efficiently detecting and addressing developmental problems in busy clinical settings, i.e., by staggering the tasks of screening and surveillance over time. Because well-visits should also focus on addressing problems (e.g., "the worried well") there is abundant guidance on how to work with families, promote development, deliver difficult news, monitor progress and collaborate with non-medical providers. Much attention is paid to the most onerous issue in primary care: How to actually implement quality developmental-behavioral care. Work sheets and flow charts aid clinicians in planning and deploying an effective process.

The book describes accurate methods for screening school-age children, those in foster care, bilingual/dual-language children, and families who have psychosocial risk factors, including NICU and special needs follow-up. Other chapters cover cultural issues in parents' perspectives and expectations and how these can impact children's development. National and international initiatives in early detection and intervention are presented in detail.

Research methods for measuring child development are delineated, including how to create new items for studies, ensure effective translations, standardize measures, and design quality research protocols. Options for Quality Improvement and Maintenance of Certification initiatives are described. Also specified is a range of techniques for public policy advocacy. Throughout, case examples and professional perspectives are used to illuminate content.

The book comes with access to a website (*www.pedstest.com/TheBook*) offering tools for learning and teaching (e.g., observation forms, a detailed list of milestones, pre/post-tests for assessing learning) as well as tools for community practice (e.g., a list of evidence-based screening and surveillance tools, well-child visit encounter forms embracing health as well as developmental-behavioral care, two-way consent forms, live links to services, etc.). These downloadable tools facilitate instruction and aid practicing clinicians in complying with American Academy of Pediatrics policy -- all within the time constraints of primary care.

The many contributors to this book are content experts but also practical advisors who themselves deal with real-world challenges facing families and work with graduate and under-graduate students, residents, fellows, clinicians, researchers, and advocates. In short, *Identifying and Addressing Developmental-Behavioral Problems* is a practical and essential handbook for all those interested in improving the development and well-being of children and their families.