

Detecting children with developmental-behavioral problems: The value of collaborating with parents

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Abstract

Half of all children with disabilities are not identified before school entrance. This precludes their participation in early intervention programs that have known value in reducing school drop out, criminality, increasing employment, and delaying child-rearing all of which accrue enormous costs to citizens. Although screening tests can greatly improve detection rates, these have not been popular in primary care due to test length, time constraints, and difficulty managing children's behavior when hands-on measures are used. An alternative is to rely on parents' concerns because these are not only accurate and efficient indicators of problems, but also because focusing on parents' concerns makes visits relevant, engenders a much needed collaborative relationship in early detection, and increases the likelihood that parents will follow through with the recommendations of professionals. Nevertheless, careful attention must be paid to the wording of questions and use of parents' concerns. Early detection is most effective when evidence-based decision-making guides professionals' decisions. This review focuses on the use of parents' concerns, meaning in their own words, to accurately detect and address developmental-behavioral (including social-emotional/mental health) problems. Suggestions for future research are described throughout.

Key words: developmental screening, developmental surveillance, parents' concerns, child development, disabilities, behavioral screening

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Background

Early intervention confers enormous benefits to children, families and society by ameliorating existing problems and, in many cases, preventing them altogether. Intervening with young children in need increases the likelihood of school success, high school graduation and employment rates, reduces teen pregnancy and criminality, and generates vast cost-savings to tax-payers (Barnett, 2000; Kube & Palmer, 2009; Lynch, 2010).

Early intervention benefits are only conferred if professionals identify (and refer) children, not only those with existing delays and disabilities, but also those who are likely to acquire them due to psychosocial risk factors (e.g., children whose parents have limited education, mental health problems including depression or anxiety, minimal social support, more than 3 children in the home, minimal income, housing or food instability, less than responsive parenting styles, etc.) (Sameroff, Seifer, Barocas, Zax & Greenspan, 1987; Glascoe & Leew, 2010). But early detection is challenging! Many commonly used screening tests (e.g., the Denver-II) take too long for busy clinics. Many clinicians use informal milestones checklists including selecting items from longer measures. Such ad hoc tools lack criteria, have no evidence of accuracy, and not surprisingly, miss the large majority of children with difficulties (American Academy of Pediatrics, 2006; Hix-Small, Marks, Squires & Nickel, 2007).

One of the best solutions for brief and accurate early detection is to use quality screens making use of information from parents. Parents have far greater opportunity to observe their children than professionals do. Parents are enormously interested in their child's development and so welcome the opportunity to answer questions about how their child is learning and behaving. In health care or other clinical services, families often have "down-time" (e.g., in waiting or exam rooms, at home in writing or online) and their efforts to answer screening test questions independently reduce the time demanded of overly burdened professionals. Such an approach to early detection helps parents recognize that professionals are a helpful source of information and increases parents' sense that professional services are relevant, timely, and worthy of the often substantial efforts made to attend appointments (Sices et al, 2008). When parents are actively engaged in early detection, they are also more likely to return for scheduled visits and to follow through with professionals' recommendations for additional services (Smith, 2005; Schonwald et al, 2009).

The goal of this article is to briefly define options for accurate screening (brief measures that sort children who probably have problems from those who probably do not) that capitalize on parents' insights about their children's strengths and weaknesses. The central focus of this review is on the value of eliciting parents' concerns (also called free-text or thought-listings), i.e., what parents think, in their own words. Throughout, directions for future research are noted.

Definitions and brief review of the types of information parents can contribute to accurate early detection

Report: This most common approach to screening presents parents with descriptions of milestone-type tasks that most children of the same age can perform. Parents by virtue of the substantive time they have to observe their children can be quite accurate reporters of current skills. Challenges with this method include: a) literacy demands (if written measures are required); b) length (completion of longer measures such as the Ages and Stages Questionnaire) may exceed the span of time families spend in waiting or exam rooms, thus complicating clinic work-flow (Schonwald et al, 2009); c) accurate computation of chronological age with any needed adjustments for prematurity (so that the correct form for the child's age is selected); d) substantive professional time and expense in photocopying and managing of different forms for different ages; e) the fact that parents often report success with skills that are only emerging but not yet mastered (meaning not fully generalized and demonstrable in unfamiliar settings (Diamond & Squires, 1993); f) that skill-focused multiple-choice questions, although helpful in teaching parents and providers about child development, rarely capture disordered development [e.g., a child may be using age-appropriate three word utterances, but if those utterances are repetitive and non-functional then a language disorder may be undetected (Glascoe, 2002)]; g) skill-focused questions do not give parents an opportunity to describe their specific developmental-behavioral challenges (e.g., bed-time or eating problems); h) when professionals lack information about parents' unique issues, they are less able to respond with appropriate advice and specific referrals; and i) as a consequence true parent-professional collaboration is lacking. Thus encounters may lack relevance to families which, in turn may deter follow-through with recommendations (Glascoe, 2002; Schonwald et al, 2009).

Predictions: Although not commonly used in screening tests, research on prediction involves asking parents how they think their child will perform in the future. Parents whose children have severe to profound disabilities often predict *normal* adult functioning. In contrast, parents of typically developing children tend to offer perhaps optimistic appraisals, (e.g., that their child will most likely govern a country, become a movie star, a lawyer or doctor, etc.) (Glascoe, 2002). Clearly, parental predictions do not yield particularly accurate indicators of current or future functioning (Diamond, 1987; Glascoe, 2002). And many parents of children with disabilities are exposed to the vague diagnosis, "developmental delay", and may interpret that to mean their child will inevitably catch up with time (Glascoe & Dworkin, 1995).

Age Estimations and Ratings: Estimations (meaning parents provide a guess at the age at which their child is functioning) and ratings (usually rankings such as "below average", "average", "above average") can provide accurate indicators of developmental status although much more research is needed. Nevertheless, age-estimates and ratings are a challenge to elicit and interpret. Parents do not often think about development as a range of domains and need considerable prompting to offer numerical answers (or ratings) by domain. Most parents are clearly uncomfortable with such questions (which may be a function of not fully understanding developmental domains, finding unfavorable age-

estimates and rankings painful, or because coming up with ‘guesstimates’ is not a common way for parents to appraise their child’s progress) (Glascoe & Sandler, 1995). Although parents sometimes offer a spontaneous single global estimate when their child is referred for developmental evaluation (e.g., “*he’s more like a two-year-old than a four-year old*”), this phenomena seems rare in public health or preschool programs where children are often undetected, parents are just beginning to notice problems, and so have not machinated thoroughly over the extent or domains of delay or disorder. Interpreting parents’ age-estimates is also a challenge because estimates commensurate with chronological age often reflect substantive delays, and a single global estimate tends to mask strengths and weakness across domains.

Concerns: This approach to early detection (described in detail below) involves eliciting parents’ observations and child-rearing issues in their own words. The most collaborative of approaches to early detection, eliciting parents’ concerns has many strengths: a) professionals come to understand parents’ unique child-rearing issues and are better able to discern disorder from delay (e.g., when a verbal child has the disordered language development typical of autism spectrum disorder); b) parents learn that their observations and parenting questions are truly of interest to professionals; c) as a consequence of improved collaboration with professionals, parents, especially those with limited education who tend to be problematically reticent, are more likely to raise concerns and to attend appointments for well-visit and parent-teacher conferences (Smith, 2005); d) questions about concerns, if carefully written and probing all domains help parents think about development as professionals do – as relatively discrete skill areas; and f) professionals are better able, given parents’ precise worries, to focus child-rearing advice and referral recommendations toward parents’ and children’s unique needs. A more detailed review of research on parents’ concerns including challenges, weaknesses, and strengths is presented below.

Early research on parents’ concerns

Hickson and colleagues (Hickson, Altemeier & O’Conner, 1983) found that parents waiting for preventive health visits rarely had concerns about their child’s physical health. Instead, 70 % had psychosocial concerns including worries about: The effects of careers on children’s well-being (35 %); social difficulties (8 % - 13 %); explaining a recent death in the family (10 %); and discipline (24 %) [See Glascoe, 2002 for a more thorough review of research on the frequency and types of parental concerns.] Particularly striking in the Hickson study was the fact that ~14 % of parents had concerns about children’s learning and cognition; a figure quite in keeping with the expected prevalence of developmental problems in childhood (Newacheck & Halfon, 1998). Testable research questions logically followed (e.g., Do parents’ concerns about their children accurately reflect genuine difficulties? How are parents’ concerns best elicited? Can parents’ concerns serve as an accurate approach to early detection?).

The validity and accuracy of parents' concerns about development

To address such hypotheses, researchers (after much pilot testing to generate workable questions) elicited concerns from parents of 100, 0 to 6 year old children waiting for pediatric care in the general practice outpatient clinics of two teaching hospitals (Glascoe, Altemeier & MacLean, 1989). Children were administered a battery of screening tests measuring all developmental domains. Twenty children appeared to have developmental problems and only 1 had been previously identified. Of the 20, 80 % had parents with concerns about speech-language, fine motor, or global development all of which were associated with measurable difficulties. Of the 80 children without developmental problems, 94 % of their parents had no concerns or concerns in other areas such as behavior, or self-help.

These findings were confirmed in three cross-validation studies involving 661 children using a measure that became *Parents' Evaluation of Developmental Status (PEDS)* (Glascoe, 1997a, revised 2010, Glascoe 2002). Examiners blinded to parents' concerns or their potential significance, administered a lengthy battery of diagnostic tests to children including measures of intelligence, language, adaptive behavior, and, in older children, school skills. Speech-language, global/cognitive, and fine motor skills again proved to be highly significant predictors of developmental problems. These concerns identified, via unique patterns of concerns, i.e., discriminant validity studies, 74 % to 80 % of children who were found to have intellectual disabilities, specific learning disabilities, speech-language impairment, and autism spectrum disorder (quality studies of *PEDS* with children who have motor disorders are still needed). The absence of such concerns correctly identified 70 % to 80 % of children without disabilities (Glascoe, 1991; Glascoe, 1994, Glascoe, 1997; Glascoe, Macias, Wegner & Robertshaw, 2007).

In all the above studies, the presence or absence of parents' concerns found to identify children's disabilities, produced detection rates to both typical and problematic development within acceptable standards for developmental screening tests, i.e., both sensitivity to developmental problems and specificity to the absence of developmental problems above 70 % (also known as criterion-related validity). The findings clearly suggest that professionals can routinely elicit parents' concerns in an effort to detect children with undetected difficulties (Glascoe, 1999; 2002).

The validity and accuracy of parents' concerns about social-emotional, behavioral and mental health status

Parents often have concerns about their children's psychosocial well-being (Starfield & Borkworf, 1969; Hickson, Altemeier, O'Conner, 1983). When parents raised concerns about emotional/behavioral issues, physicians were 13 times more likely not only to notice psychiatric problems but also to make needed referrals (Dulcan et al, 1990). In subsequent research, more than 70 % of children who failed standardized screening

measures of behavioral/emotional problems, could be identified by parents' concerns (on *PEDS*) about behavioral and emotional status. At the same time, more than 73 % of parents without concerns had children without measurable behavioral problems (Glascoe, MacLean & Stone, 1991; Glascoe 2003).

Similarly, Mulhern, Dworkin and Bernstein (1994) using a group of children referred to a developmental/behavioral evaluation clinic, found higher rate of concordance between parental concerns about behavior and children's behavioral problems: 87 % of children with attention-deficit hyperactivity disorder had parents with concerns about impulsivity, inattention, or over-activity (although such unusually high sensitivity may be attributable to a population with a large probability of psychosocial problems). Nevertheless, the findings corroborate research on typical populations (e.g., in day care centers, public health clinics) in showing a close relationship between parental concerns about emotional and behavioral problems and true psychiatric and behavioral disturbance (Glascoe, 2003).

The meaning of parental concerns

Most of the above studies suggested a strong parallel relationship between the type of concern and the subsequent diagnosis. Thus it is easy to assume that parental concerns could be taken at face value, i.e., that the kind of parental complaint indicates the type of problem children are likely to have. Indeed, some research corroborates a close relationship between domains of concern and the final diagnosis (Chen et al, 2004). However, Oberklaid, Dworkin, and Levine (1979) using a population referred for further testing showed that parental concerns about behavior and emotional well-being often reflected deficits in developmental rather than behavioral areas. In another study, 50 % of pre-school children referred to psychiatry clinics (presumably due to parental concerns about behavior) were found to have language impairment, not psychiatric disturbances (Helland & Heimann, 2007). A lack of equivalence between concerns and diagnosis was found in a study of children randomly selected from five day care centers serving very low-income families. The study found that children with cognitive delays (IQ's below 79) often had parents with concerns, not about slow learning, but rather about behavior or expressive language. Indeed, 83 % of globally delayed children were identified by behavior and/or expressive language concerns alone (Glascoe, 1994). Chen et al (2004) also concluded that concerns about cognitive delays were rare and better captured by other patterns of concerns; although when cognitive concerns do arise they appear highly predictive of intellectual deficits.

One explanation for the nonequivalent relationship between the type of parental concern and the final diagnosis is that parents who are, for example, worried about their child's behavior, may not have considered a range of explanations (e.g., that their child might not hear well, have the receptive language skills to comprehend some requests, the cognitive or motor skills to execute commands, etc.). Another hypothesis is that some domains of development such as behavior or expressive language are more salient than others

(e.g., self-help, fine motor). At any rate, it is clear that clinicians eliciting parents concerns need evidence-based guidance on how to interpret them.

Influences on parents willingness to express concerns spontaneously

It is known that parents with socioeconomic (SES) disadvantages (e.g., limited education, income) are sometimes intimidated by professionals, reluctant to raise the concerns they hold especially if focused on social-emotional/mental health issues, or are not always aware that professionals are even interested in their worries [(e.g., that preventive health visits should embrace non-medical issues (Wildman, Kizilbash & Smucker, 1999; Sices et al, 2008)]. Meanwhile, professionals: a) often notice that low SES parents rarely raise developmental-behavioral concerns; b) are often aware of the challenging life circumstances surrounding families with psychosocial adversities; c) may conclude that such parents are too distracted with challenging life events to pay much attention to their children's development and behavior; and d) often over-ride parents' legitimate concerns with 'junk science' (e.g., informal milestones checklists, clinical judgment) (Reijneveld, Meer, Wiefferink & Crone, 2008).

Stickler and colleagues (Stickler, Salter, Brouhton & Alario, 1991) challenged the above assumptions by actively questioning parents about a broad range of health, safety and psychosocial concerns. In contrast with the higher SES parents, parents with low SES [whose children indeed face far greater likelihood of health and developmental/mental health problems (Sameroff et al, 1987; Glascoe & Leew, 2010)] had far more concerns about their children's health and psychosocial challenges (e.g., many more worries about suicide, chemical dependency, homicide, unwanted pregnancy and child abuse).

The value of carefully eliciting parents' concerns rather than waiting for spontaneous complaints, was researched as part of validating *PEDS*. Children and parents ($n = 408$) were recruited from schools and day care centers. Parents' concerns were elicited, and children's development was measured with a battery of diagnostic tests covering all developmental and behavioral domains. Parents with concerns on *PEDS* were asked whether they had shared their worries with health care providers: 40 % had not, and such parents were disproportionately of lower SES backgrounds. In contrast, parents who had discussed concerns tended to have baccalaureate degrees, and they also had children who were 11 times more likely to be enrolled in needed special education services (Glascoe, 1997b; Glascoe, 2006). These findings confirm the need to actively question parents about their concerns.

Eliciting parents' concerns

Questions to parents must be carefully worded. In pilot work on *PEDS* questions about concerns were piloted on 200 parents and then field tested on 100 parents seeking care in either pediatric or developmental clinics (Glascoe, Altemeier & MacLean, 1989). The

preliminary study revealed that questions such as, “*Do you have any worries about your child’s development?*” or “*Do you think your child has any problems?*” were not effective – only 1 to 3 % of parents’ responded – a figure far lower than prevalence estimates (Newacheck & Halfon, 1998). Apparently, parents found these questions too pejorative or threatening and so few if any responded. This observation is corroborated by other research showing that parents found terms such as “worries” or “problems” too ominous (Lichtenstien & Ireton, 1984). More innocuous wordings such as “*Do you have any concerns about your child’s development?*” were also problematic since only half of all parents know the meaning of “development” (Gablehouse & Gitterman, 1990). More effective is the pairing of “learning” with “development”; a combination that seemed to facilitate both comprehension and communication. Even so, when this combination was used, few parents mentioned concerns about behavior. Thus the first item on what eventually became *PEDS*, uses a highly effective combination of terms, “*Please list any concerns about your child’s learning, development, and behavior*” (Glascoe, Altemeier & MacLean, 1998).

Still, many parents do not seem to think, at least initially, about development in the same manner as professionals-- as a range of domains. Because professionals need information about each developmental area to focus advice and referrals, it is important to probe parents’ concerns in more depth. For example, many parents answered the first *PEDS* questions with concerns only about behavior (e.g., “*My child doesn’t obey me*”). It made sense to help parents consider whether their child hears well enough, has sufficient receptive language to understand what is being asked, the attention span or motor skills to execute commands, etc. Nevertheless, devising prompts was challenging because parents rarely understand professional terms (e.g., cognitive skills, adaptive behavior, motor coordination, etc.). Thus subsequent *PEDS* research deployed probes for each developmental domain using colloquial or euphemistic phrases (e.g., for expressive language, “*Do you have concerns about how your child talks and makes speech sounds?*”) (Glascoe, 1991; 1994; 1997c).

How parents’ respond to questions about concerns

In response to questions about concerns, parents typically make a range of statements as shown in Table 1. Although parents’ concerns can reliably be grouped into the various developmental domains, there are several challenges in the categorization of parents’ concerns. These include: a) a need for professionals to be thoroughly familiar with developmental domains so they can categorize parents’ comments correctly; b) how to categorize concerns that reflect limited knowledge of development such as, “*He’s my first (or only) so I’m not really sure but....*”; “*I’m not sure what a 6 month old should be saying.*”; c) Parents who mention concerns from the past such as, “*I was worried about his talking but I think he’s doing better now.*” The latter two types of seemingly equivocal responses were assessed statistically, found to have a high probability of reflecting a disability, and are thus coded as a concern on *PEDS* (Glascoe, 2002). Nevertheless, professionals may ignore the evidence suggesting such answers reflect probable prob-

lems worthy of additional screening, probe informally for descriptions of development, and then disconfirm the concern without valid evidence. While more detailed discussions about development can be valuable, they may rely on informal milestones and varying degrees of professional acumen, and surely lead to the 70 % under-identification of developmental-behavioral problems in primary care (Sices et al., 2004; Silverstein et al., 2005; AAP, 2006; Sices, Stancin, Kirchner & Bauchner, 2009). These observations suggest that an evidence-based algorithm for interpreting concerns is essential for deciding when referrals are needed.

Table 1:
A sample of parents' responses to *PEDS* questions about concerns

Type of Concern	Typical Responses
Global/Cognitive	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
Expressive Language and Articulation	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
Receptive Language	Doesn't understand what you say; doesn't listen well
Fine-Motor	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
Gross Motor	Clumsy; walks funny; can't ride a bike yet; falls a lot; limps, poor balance; hates soccer
Behavior	Stubborn; over-active; short attention span; spoiled; aggravating; throws fits; only does what she wants
Social-emotional	wants to be left alone; mood swings, clingy; whiny; bothered by changes; angry disinterested in usual things; easily led; easily frustrated; acts mean; bossy; shy; class clown; is angry; is mean; hates me; I don't like him very much
Self-help	won't do things for herself; won't tell me when he's is wet; not toilet trained yet; still wants a bottle; can't get dressed by herself
School	Can't write his name (coded 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
Other	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
No concerns	Typical child; development is normal; he's coming along just fine; she's advanced

How parents derive concerns

Parents' regardless of socioeconomic backgrounds, tend to compare their children to others when forming appraisals (e.g., "*I see what other kids can do and then see if he can.*") (Glascoe & MacLean, 1990). Comparisons involve the simple cognitive processes of matching (noting developmental similarities among children) and discriminating (noting developmental differences). These thinking skills are mastered by almost all adults, even those who themselves have intellectual deficits, learning disabilities or other developmental problems (Robinson & Robinson, 1976). Thus, parents of diverse SES backgrounds appear equally able to appraise their children's status because they seek and use information about development at a basic functional level; in a way that seems to cut across educational and other class distinctions. As an aside, this hypothesis may also explain why researchers have not been able to illustrate that parents know much about child development: Most protocols assess parents' knowledge using recognition and identification type questions (e.g., asking parents to name the typical age at which children accomplish various developmental skills or giving multiple choice options) (Vukelich & Kliman, 1985; Cudaback et al, 1985; Rikhy et al., 2010). Focusing research questions to rely more on tasks requiring comparisons (e.g., matching chronological ages to descriptions of child behavior, or discriminating among descriptions of advanced versus delayed performance) might better assess parents' pragmatic developmental knowledge and more importantly help focus parent training programs to provide parents information about development they can apply in real life.

Influences on the accuracy of parents' concerns

Socioeconomic status and other variables

A series of studies tested hypotheses about possible influences on the accuracy of parents' concerns. These found no differences in the accuracy of concerns on the basis of SES (including parents' level of education or income), numbers of children in the family, children's birth order, area of residence (urban, suburban or rural), participation in day care, or parents' exposure to other family members or relatives with disabilities. Further, the accuracy of parents' concerns was not found to vary according to parenting experience (defined as the number of children in the home, hours spent with children per day, and the child's birth order) (summarized in Glascoe, 1999, 2002, 2006). These surprising findings may well be a function of the similarity with which derive concerns, i.e., by comparisons, despite differences in SES.

Influences on parental concerns: Children's age

One variable that does appear to impact parents' concerns is children's age. In light of the fact that the prevalence of developmental problems increases as children grow older (as new skills fail to emerge sufficiently), it is to be expected that parents of younger

children have fewer concerns about development than do parents of older children (Bell, 1986). In a study of 771 families of children from birth to 8 years of age using *PEDS*, the frequency and types of parental concerns generally increased with children's age: Concerns about language, school, and motor skills emerged and increased with time, although behavior concerns arose mostly around 18 months and began to wane at 3 ½ to 4 years. Simultaneously, the same group of children was more likely to be diagnosed with disabilities at older ages (upon concurrent testing). Older children were more likely to have delays, i.e., scoring in the below average but not disabled range (Glascoe, 2002; Glascoe & Leew, 2010). Of note, 86 out of 771 children were under 18 months in the validation study for *PEDS*. Further research on the measurement of parents' concerns to detect delays at various age intervals from 0 to 18 months may be warranted. This research would be helpful, especially since pediatricians (without a screening tool) are less likely to detect developmental delays in younger infants (12-month olds) compared to older toddlers (24-month olds) (Hix-Small, Marks, Squires & Nickel, 2007). So, development develops: Developmental problems and thus parents' concerns do too.

Influences on parental concerns: Children's health status

Children's overall health also has an impact on parents' concerns about development and behavior. Scholle et al. (1995) followed 608 low birth weight 2 year-olds for 12 months. When children were 2 years of age, their parents were administered scales measuring perceptions of global health status. These were then compared to longitudinal data about health-care utilization, examiners' judgments about morbidity, direct measures of children's development, and parent report measures of behavioral status. Fourteen percent of parents perceived their children to be in poor health although this had only a weak association with examiners' perceptions of health status. Far more children were rated as in poor health by their parents than by examiners. Even so, parents who perceived their children to be less healthy despite the opinions of health care providers, had far greater utilization of health care services. Further, their children were more likely to have behavior problems but not necessarily developmental problems (Scholle et al., 1995). In contrast, McCormick, Shapiro and Starfield (1982) found that parents with health concerns were more likely to view their children as developing more slowly regardless of evidence to the contrary (although the quality and accuracy of concurrent developmental measures used in this study were limited). Glascoe (1999, 2002) asked parents to rate their children's health problems as "serious", "somewhat serious", or "not serious" and found that ratings of "somewhat serious" were associated with far more developmental-behavioral concerns. One hypothesis is that "somewhat serious" is associated with a lack of a clear diagnosis for health problems. Anecdotally, health care providers using *PEDS* find its questions about health issues often identify parents' need for a repeated (or better) explanation of prior medical diagnoses (Schonwald, personal communication, 2009, see www.developmentalscreening.org). Thus parents' misunderstanding or receipt of ambiguous information about health problems may exacerbate developmental-behavioral concerns. Nevertheless, it is also well-established that health problems have an adverse impact on development and that parents with both health and developmental-behavioral

concerns are heavily represented among those seeking pediatric care (Boyle, Decoufle & Yeargin-Allsopp, 1994). This means that parents with concerns about behavior and development are particularly accessible for early detection and suggests that parental concerns are a driving force in bringing their children for medical care.

Influences on parental concerns: Parents' mental health

Researchers have questioned whether parental concerns reflect their own anxiety or mental health issues, rather than problems residing in their children. Most, but not all, studies show that a significant proportion of variance in parental concerns is determined by existing parental and family history of mental health problems (including depression, anxiety, panic disorder) and current maternal stresses such as recent divorce (Cambell, Breaux, Ewing & Szumowski, 1986; Forehand, Lautenschlager, Faust & Graziano, 1986; Hodges, Landon, & Colwell, 1990; McClellan, Rubert, Reichler & Sylvester, 1990). While at first glance, these findings suggest that parental distress may be a factor in over-referrals on screening based on parents' concerns, it is well-established that parental mental health problems are strongly related to actual developmental and behavioral problems in children (Sameroff et al, 1987; Glascoe & Leew, 2010). Most of the studies cited above show that depressed, anxious or distressed parents often have children with psychiatric and other problems. Thus one hypothesis is that parents with significant developmental and behavioral concerns who are also obviously distressed, may be *more likely*, not less likely, to offer accurate judgments, perhaps because they lack the "bubble of optimism" present in parents without anhedonia. Not surprisingly, parents with depression were slightly more accurate in appraising their children's delays than were non-depressed parents but were less likely to recognize when their child was gifted and thus far above average (Larosa, Macias & Glascoe, 2009). The findings suggest that professionals should screen and intervene, not only children's development and behavior, but also with parents' mental health, the wise recommendation of the American Academy of Pediatrics Task Force on Mental Health (AAP, 2010).

Accuracy versus inaccuracy in parents' concerns

Although most parents of children with disabilities hold the types of concerns shown to be predictive of actual problems and most parents of children without disabilities have no concerns or non-predictive concerns, some parents are inaccurate. Some seem to worry excessively about their children while others seem insufficiently concerned. The apparent reasons for this phenomenon are discussed below:

When parents' fail to raise concerns

Twenty to twenty-six percent of children with undiagnosed disabilities had parents who failed to raise concerns. These parents differed from other parents in several ways. Their

children tended to score within normal limits on measures of fine and gross motor skills while children of accurately concerned parents performed much lower (both groups scored well below average in intelligence, language, and academic skills). This suggests that parents rely heavily on motor development when forming judgments about children's developmental status (Glascoe, 1997c).

Perhaps more clinically useful is the finding that a subset of inaccurately nonconcerned parents were those with limited command of English. In a study of 408 families, 12 of the 56 families whose children had disabilities did not raise concerns. Of the 12, 4 were non-English speakers. Although all had been asked about their concerns in their native language (Spanish), questions were administered in writing rather than by interview (Glascoe, 1997c). Because illiteracy is common in many ethnic minorities, poor reading skills probably obstructed parents' ability to respond. This supposition was confirmed in a 771 subject meta-analytic study of *PEDS* that showed that parents with identifiable communication barriers (including nonsensical or contradictory answers to questions about concerns), had completed an average of 3 fewer grades than other parents (Glascoe, 1999, 2002).

Conclusions about communication barriers are: a) before giving parents written questionnaires to complete, it is advisable to ask whether they would prefer to be interviewed instead; b) to make sure that parents have offered more than a simple yes-no-a little answer in response to concerns questions; and c) the quality of the translation in other languages is critical. Vetting translations with families and professionals is needed. For example in a study of Chinese-speaking families, 90 % indicated their children were at risk; in marked contrast to the 11 % in all other samples. Chinese families seem to have interpreted the phrase, "*Do you have concerns about your child's....*" as "*Do you think about your child's.....*". So, a stronger synonym, i.e., "worries" was deployed to replace "concerns" which lowered risk reporting to typical incidence levels (King, J. unpublished study, 2000; reported in Glascoe, 2002).

Although parental communication barriers can clearly interfere with discussions of parental concerns, this phenomena only explains a fraction of the inaccurately nonconcerned parents. Other hypotheses for future research sprang from the informal debriefing sessions (required by the Committee for the Protection of Human Subjects) held with all families participating in the various *PEDS* studies. When parents were told how their children performed on developmental tests, many of the inaccurately nonconcerned parents confided that they, in fact held concerns about their child, but had not wanted to bias the examiner. When asked whether they had shared concerns with their child's health care provider, many made such comments as, "*I didn't want to make her start worrying unnecessary*" or "*I figured that if something were wrong my doctor would notice*" (Glascoe, 2002). A hypothesis for further testing is whether, if parents are asked about concerns repeatedly (e.g., across well-visits), that reticent parents may be better encouraged to share their concerns.

Another informal observation about inaccurately nonconcerned parents surrounds those who serve as informants but who may not actually be their child's primary caretaker (e.g., adolescent parents). Often primary caretakers, such as grandmothers or great

grandmothers, use doctor's appointments as a way to increase the biological parents' involvement in child-rearing. Clinically, simple questions about what a child likes to eat, time of last bowel movement, etc. may, if vaguely answered by the child's caretaker, provide a helpful indicator that hands-on screening (e.g., the Brigance Screens or PEDS: Developmental Milestones) would yield better information on developmental status. Another approach, one advocated within the *PEDS* protocols, is to not only use a hands-on measure, but to encourage professionals to add their own concerns before scoring (but not eliminate any the parent has raised) (Glascoe, 1997a, revised 2010).

Finally, some parents who fail to raise concerns are those whose children have been previously diagnosed and enrolled in treatment. Although it seems obvious that such children do not need screening, they are sometimes included in research protocols. And screens are often used by professionals who are new to the child and family (e.g., medical students, pediatric residents) as a way to get to know families. The ensuing challenge for validation studies is that many parents who are pleased with their child's special services, do not raise concerns. A case in point is a study by Pritchard and colleagues (Pritchard, Colditz & Beller, 2005) on children with cerebral palsy that included previously identified and treated children. The accuracy of *PEDS* suffered as a consequence (sensitivity of 68 % which is somewhat below the threshold for screening test accuracy). A recommendation for researchers is to exclude the previously identified when conducting validation studies.

Parents who appear excessively worried

Across *PEDS* studies, 16 % to 23 % of parents held concerns predictive of developmental problems even though their children were developing normally (summarized in Glascoe, 2002). Fortunately, most such parents could be readily identified because they held a single of the predictive concerns whereas parents of truly disabled children tended to have two or more concerns (Glascoe, 1997c, 1999, 2002). Although it is tempting to dismiss as overly anxious parents who worry unnecessarily about their normally developing children, it is also possible that such parents are noticing sub-clinical or subtle manifestations of a problem, which, if left unattended, might burgeon into a diagnosable condition. This notion was explored and partially corroborated in a study of 96 children administered a behavioral screen relying on parental report. Parents with concerns about behavior but whose children passed behavior screening, had children with a significantly larger number of behavior problems (mean = 10) than did parents without concerns (mean = 6) (Glascoe, MacLean & Stone, 1991). In another study in which 23 % (93 of 408) of parents were found to be excessively concerned, their children were found to perform somewhat below average on measures of intelligence, language and academic/preacademic skills and significantly lower than the children of parents without concerns (Glascoe, 1997c). Given that developmental problems can develop and thus excessively worried parents may, in fact, be wisely vigilant, the *PEDS*' scoring algorithm includes a "moderate risk" pathway in which additional screening is recommended and if passed, followed by vigilant, frequent monitoring of developmental-behavioral status and

preferably referrals to preventive services such as quality preschool programs (Glascoe, 1997a; revised 2010).

Related to the issue of seemingly over-concerned parents is that screening tests often over-refer, i.e., children perform poorly on a screen but are not found, on subsequent testing, to actually have a disability that qualified them for special services. Such false-positive results were scrutinized in a study of over-referrals on several different screening tests (Glascoe, 2001). Over-referred children were consistently found to score in the “gray zone” between average and disabled: They were below average on the better predictors of school success, i.e., intelligence, language, and academic/preacademic skills, and they were likely to have numerous psychosocial risk factors. Although not eligible for special education services, they clearly had delays or emerging problems and would surely benefit from additional attention (e.g., tutoring, parent training on developmental-behavioral promotion, participation in preschool stimulation programs such as Head Start in the US, Even Start in the UK, etc.).

Order effects

Glascoe (2002) reports evidence that parents whose concerns were elicited *after* being asked to report on children’s actual skills, were more likely to raise concerns and to be overly worried. One hypothesis is that parents felt their own knowledge of child development was being tested. To prevent any order effects that might needlessly exacerbate parents’ concerns, subsequent studies by Glascoe et al consistently presented concerns questions first in all research protocols. Nevertheless, further research on order effects would be helpful – including the impact of repeatedly questioning parents about their concerns (e.g., does this make them overly vigilant or simply better observers)?

Contradictory evidence

A few studies dispute the validity of parents concerns and found only a limited relationship between concerns and true problems. Sturner (1997) and Rogers et al (1992) employed restricted methods of eliciting concerns (synonyms for “development” were not used and concerns were not probed across developmental domains). Similarly, Merchant, Neger, Sheldrick and Perrin (2010) studied a parents’ concerns question that did not pair “learning, development, and behavior” but rather presented each term separately, i.e., “*Do you have concerns about your child’s behavior?Development?.... Learning? Not* surprisingly, researchers found that parents’ responses were not only infrequent but did not identify the majority of children with measured developmental problems. These results are striking because one of the studies (Rogers et al, 1992) used as subjects 209 high-risk infants, 35 % of whom were found to have developmental difficulties – a sampling condition that typically inflates sensitivity indices. Problems with the wording of research questions (and in some cases problematic choice of comparison tools, e.g., use of the highly inaccurate Denver-II) seems to be the best explanation for why these and

similar studies are outliers in the burgeoning body of research illustrating the accuracy of parental concerns (Glascoe et al, 1992; Glascoe, 2002; Lagerberg, 2005; Reijneveld, Meer, Wiefferink & Crone, 2008).

Predicting future developmental-behavioral status

Do parents' current concerns indicate future problems? Answers to this important question inform professionals about whether parents' concerns reflect fleeting observations and momentary child-rearing hassles, or whether concerns indicate developmental-behavioral difficulties that may well be enduring and suggestive of ongoing problems. Diamond (1987) probed the predictive value of parents' concerns using a random sample of 150 out of 800 6 to 62 month-old children attending a health fair. Four years later, their development was reassessed. Fifty percent of children whose parents had had concerns about language, learning, motor, speech or cognitive/academic skills, encountered substantial school difficulty defined as special class placement, in-grade retention, or participation in remedial reading classes. Another study showed that in 98 % of cases, children subsequently found to have hearing loss could be identified by prior parental concerns (and that parents' concerns lead to substantially earlier detection – by a mean age of 10 1/2 months in contrast with a mean of 2 years for severe losses and a mean of 4 years for mild to moderate losses) (Thompson & Thompson, 1991). Wake and colleagues conducted a predictive validity study on *PEDS* by viewing parents' concerns at age 5 and developmental outcomes at age 7. They found significant associations between certain concerns as well as clusters of concerns, and later deficits in a range of academic and language skills (Wake, Gerner & Gallagher, 2005). It should be noted that standards for screening test accuracy, when it comes to predictive validity, are not established and will surely never attain levels required for concurrent screening (> 70 % sensitivity and specificity). For example, in a two-year time frame between screening and diagnostic testing there will be many attenuating factors (like attending school and actually learning something, tutoring, speech-language therapy, parental engagement with homework, etc.). So it seems remarkable that the slender set of items comprising a screening test, especially given intervening variables, retains a significant relationship with later outcome. For a thorough set of recommendations on how to conduct and interpret predictive validity studies, see Marks et al (2008).

Discussion

Parents' concerns are a valuable resource in early detection of children with developmental disabilities and provide a thoroughly collaborative, family focused approach to early detection. Although parents who are well-educated are more likely to raise concerns without prompting, parents with limited education, if asked and asked well, are as capable as parents with higher SES in accurately appraising their child's development and behavior.

Once elicited, parents' concerns are challenging for professionals to interpret without an evidence-based algorithm. The types of concerns parents raise changes as children grow older and which concerns are predictive of current problems change too. Indeed, the nuances and complexity of parental concerns prompted the development of *PEDS*' paradigm for eliciting, interpreting and appropriately addressing parents' concerns (Glascoe, 1997, revised 2010)

The advantages of early detection via parents' concerns are many: (a) concerns are easy to elicit (if quality questions are used); (b) take only a few minutes of professional time; (c) eliminate the challenges of directly measuring the skills of young children who may be less than cooperative, fearful, asleep, or ill; (d) are a typical aspect of professional encounters with families; (e) reduce disruptive "oh by the way" concerns and help focus appointments on families' specific issues, and thus enhance "the teachable moment, including paving the way for delivering difficult news; (e) unlike most screening tests, facilitate a broad range of decisions such as when to provide patient education about the behavioral issues, when parents need help promoting normal development, when to offer reassurance, when to screen further, etc.; and (f) significantly improve on the detection rates observed in health care settings.

There are several challenges in using a tool such as *PEDS*. These include the need for careful testing of translations and caution about the timing/order of presenting questions about concerns. Further, many providers understandably wish to (and at times need to) confirm parents' concerns with skill-based measures. Encouraging use of a quality screen focused on milestones is needed as is dissuading use of informal checklists.

Finally and ideally, whenever a test is commandeered for use in another country, additional standardization is needed, particularly when populations and cultures vary substantially from original norms. When they do additional validation research is usually needed. For example, in the Middle East where parents seem more tolerant of "kids being kids", behavioral concerns were one-third the rate seen in western nations (Abi Tan, Danielle Lobel, unpublished *PEDS* studies conducted in Lebanon and Israel, 2006; 2007). Self-help concerns were found to detect current delays in India but not in the US (Malhi & Singhi, 2002). Although standardization studies are typically based on a nationally representative sample (in the US, Census Bureau parameters are used to define the expected frequencies of minorities, languages spoken at home, parents' levels of education and income, etc.), it is also important to look at sub-group differences. For example, a recent study of *PEDS* compared frequencies of predictive versus non-predictive concerns to samples of American children whose families had considerably more psychosocial risks (e.g., who qualified due to poverty for free health care, or who were calling a non-emergent crisis "warm line"). As might be expected, samples with higher psychosocial risk factors, including low SES, found significantly more children at high and moderate risk on *PEDS* than did a more typical population (Glascoe et al, 2010). Other suggestions for further research on parents' concerns percolated throughout this article, in the hopes of inspiring new studies on this on the endlessly fascinating topic.

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