Parents' Evaluation of Developmental Status-Revised®

PEDS-R® Handbook

Collaborating with Parents to Detect Developmental Delays/Disorders and Mental Health/Social-Emotional/Behavioral Problems

Frances Page Glascoe, PhD.
Shirley Kathryn Woods, M.A.
Terri D. Mills, M.Ed.

Please avail yourself of PEDS-R® training and certification by signing up at Training.

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WELCOME TO *PEDS-R®*

Parents' Evaluation of Developmental Status – Revised® ***(PEDS-R®)*** is a 2023 update to prior editions of *PEDS® (1997; 2003; 2013)*. Changes include:

- Improved identification of **M**ental health, Social-**E**motional, **B**ehavioral (**MEB**) problems, as well as **D**evelopmental **D**elays/disorders (**DD**).
- Two additional questions that probe previously existing *PEDS®* categories: Global/Cognitive and Health, because low income and Spanish-speaking parents tend not to raise such concerns without prompting.
- New *PEDS-R®* Paths that assign **MEB** risk, **DD** risk and their combination, **MEBDD** risk.

Thus *PEDS-R®* divides the original *PEDS®* Paths into:

- **Path A: High MEBDD Risk.**
- **Path A: High DD Risk**
- **Path B: Moderate MEBDD Risk**
- **Path B: Moderate DD Risk**
- **Path C: Mild to Moderate MEB Risk**
- **Path C: Mild DD Risk**
- **Path D/E: Low DD Risk and Low MEB Risk**

Notes:

1. *PEDS-R®*, the test itself, must be purchased by going to *www.pedstest.com*.
2. *PEDS-R® is online along with the Modified Checklist of Autism in Toddlers-Revised (M-CHAT-R) and PEDS: Developmental Milestones® (PEDS:DM®). These three measures are designed for primary care, take 5 - 8 minutes to complete, can be administered via our parent portal (with results sent to clinicians), provides automated scoring, referral reports and recommendations for next steps and comply with AAP recommendations for early detection during well-visits or other brief encounters such as parent-teacher conferences.*
3. *For early intervention, NICU or other subspecialty follow-up clinics, or research studies focused on progress and outcomes, PEDS® Online also offers the 20 - 25 minute PEDS:DM – Assessment Level® (PEDS:DM – AL®). This measure provides a range of scores such as percentage of delay, percentage of skills mastered, and age equivalent scores in each of the following domains: Fine Motor, Receptive Language, Expressive Language, Gross Motor, Self-Help, Social-Emotional, Reading/Pre-Reading, Math/Pre-Math and Cognitive.*

PEDS® Online can be trialed at *www.pedstestonline.com*.

PEDS-R® Questions: Their Intent, Domains Measured and Descriptions

PEDS-R®'s 12 questions probe various domains of development and mental health, along with physical health and psychosocial issues. All questions are open-ended and elicit parents' verbatim concerns. In addition, 10 of the 12 questions also ask for a rating – *"not concerned", "a little concerned"* or *"concerned"*.

Question #	Domain	Intent of Questions/Descriptions/Types of Skills by Domain
#1	*Focuses discussion and elicits first impressions. Parents may comment about any domain.*	
#2	**Expressive Language**	*Vocabulary; Sentence length; Articulation/pronunciation; Coordination of breath, tongue and voice; Vocal quality; Use of words to communicate needs and interests; Syntax (meaning words in grammatical order)*
#3	**Receptive Language**	*Understanding of sounds and words, gestures and facial expressions, and signs and symbols; Following simple and eventually multi-step directions; Interest in listening; Demonstrating comprehension of what's been said or seen by answering questions such as Who?, What?, Where?, When?, and eventually, Why? as well as drawing inferences by answering questions such as, What might happen next?*
#4	**Fine Motor**	*Use of smaller muscles of the hands, fingers, and wrists, i.e., dexterity, as seen in grasping toys, picking up and releasing food or toys, stacking objects, scribbling, turning door knobs, holding a pencil or scissors, writing, cutting, sewing/threading, buttoning, drawing, etc.*
#5	**Gross Motor**	*Use of large muscle groups (arms, legs, trunk, neck) in balance, coordination, strength and endurance as seen in raising head, rolling over, sitting, pulling to stand, standing, walking and stair-climbing (with and eventually without hands held), jumping, climbing, running, skipping, throwing, catching, bike-riding, etc.*
#6	**Behavior**	*Exhibiting self-control; Complying with rules; Noticing and imitating appropriate role models; Paying attention; Absence of aggression (like hitting, biting, throwing objects at others, hurting pets); Cooperating; Recognizing right from wrong; Obeying when asked*
#7	**Social-Emotional**	*Feelings about self and others; Respect and empathy; Willingness to share toys or food; Coping with challenges; Adjusting to change; Motivation; Positive outlook, self-esteem; Engaging with and relating to others; Sharing a common perspective and understanding social conventions; Overcoming fears; Freedom from intrusive, repetitive or destructive thoughts; Affection; Resilience; Persistence*
#8	**Self-Help**	*Learning skills in self-care such as feeding, dressing, tooth brushing, bathing; Helping with chores like cooking, cleaning; Helping younger or less able children with their own self-care; Running errands; Knowing name, parents' names, address, phone number*
#9	**School**	*Discerns differences in shapes, colors, letters, number, pointing to these when named, and eventually naming independently; Identifying common signs and words; Sounding out words; Understanding passages; Writing and spelling; Facility with applied math problems and computations; Knowing specific vocabulary terms in science, social studies; Completing homework independently; Enjoys book-sharing and learning new things*
#10	**Global/Cognitive**	*Rate of learning in all domains that is similar to peers; Finding creative solutions to challenges; Remembering – long- and short-term memory; Information processing (combining and integrating new learning); Judgment; Anticipating consequences; Adequate attention span; Organizational and time-management skills; Curiosity; Creativity*

cont'd

Question #	Domain	Intent of Questions/Descriptions/Types of Skills by Domain
#11	**Health**	*Vitality; Sleeping and eating well; Hearing and seeing well; Appropriate height and weight and dental health for age; Absence of conditions such as asthma; Syndromes; Skin/hair issues; ADHD; Sensory integration problems*
#12	*Parents often write a summary of previously stated concerns but sometimes add new ones, including psychosocial challenges such as food or housing instability, domestic violence, death or divorce, etc. See* ***"Off the Path: Other Concerns"*** *for guidance*	

PEDS-R® PATH BY PATH: EXAMPLES OF PARENTS' COMMENTS ALONG WITH PROFESSIONAL DISCUSSION AND GUIDANCE

PATH D/E: LOW DD RISK AND LOW MEB RISK

Typical Comments:

Learning very fast; She's doing great in school; Every day is learning something new; Great behavior and great development; He's a good baby; On track with comprehension and learning new words; Does well with others and at home; He is doing wonder(fully); Loves to explore and learn new things; A joy to raise and be with; Inquisitive and doing great in all areas; Meeting all milestones; A vibrant and imaginative child; Destined for greatness!

Guidance for Professionals:

- The majority of children, 75% have Path D/E results.
- It is always delightful to find happy and proud parents offering descriptions of typical (or even advanced) development.
- Overall on *PEDS-R®*, 93% of parents whose children are eligible for IDEA/special education raise concerns, but 7% do not.
- How can we identify the 7% who don't raise concerns when their children are at risk? Here are several things to consider:
  - Scrutinize comments for indicators of concerns. Some parents imbed worries within positive comments such as, *"Doing great in all areas but not talking like he should."* In this case, mark "concerned" under the 2nd question about talking and making speech sounds.
  - Was *PEDS-R®* administered in the language parents speak best?
  - Could parents actually read the questions? Skip any items? Were they able and willing to write comments (some are embarrassed by their poor spelling or handwriting)?
  - Is the person answering a main caretaker? A teenage mother or father may rely on their own parents or grandparents and not actually know much about their child.
- If parents simply write *"no"* or *"none"* or just checked "no" on response options, prompt for descriptions by saying, *"Please tell me more about how your child is doing."*
- Do not give examples. If prompting is needed you can say, *"I'd just like to know what you think."*
- Recognize that some parents are reluctant to share their concerns – As one parent explained, *"I just thought I was an overly anxious mom. I didn't want to embarrass myself or make my doctor worry unnecessarily. I figured if there were problems, she'd notice and tell me."*
- Re-administering *PEDS-R®* by interview is even better: *PEDS-R®* teaches parents to think about development as a range of domains and parents are often better prepared and more forthcoming when *PEDS-R®* is given a second time, especially by interview.
- Another option, one in keeping with American Academy of Pediatrics' recommendations for early detection, is administering an autism-specific plus a milestones-focused screen, such as the *M-CHAT-R* and *PEDS:Developmental Milestones® (PEDS:DM®)* screener.
- Indeed, 2% of children on Path D/E failed the *M-CHAT-R* and 5% had 2 or more unmet milestones on the *PEDS:DM®*.
- Be sure to add your concerns and any significant medical conditions before scoring. With *PEDS® Online,* if parents have used the portal, you can pull up the record, add any concerns and then click submit.
- Even when a child's skills are on track, be sure to give parents information on promoting child development/positive parenting skills and provide written handouts.
- Encourage book sharing, use of public libraries, and enrollment in *Dolly Parton's Imagination Library.*

PEDS-R® Path By Path (continued)

PATH C: MILD DD RISK (DEVELOPMENTAL DELAY/DISORDER) RISK

Common Types of Concerns and Typical Comments

Using Arms and Legs (Gross Motor): *When will she roll and stand up?; 6 months old and still does not crawl; Does army crawl instead of regular crawl; 3 months old but not sitting up; Trips and falls a lot; Hates tummy time; 10 months old and not walking; Feet turn in when walking; Is she moving normally for her age?; Walks on tiptoes; Clumsy; Floppy and weak; Extremely strong and even at 7 months can stand for hours; Weak on one side; "W" sits and has to be told to move her legs forward*

Using Hands and Fingers (Fine Motor): *Doesn't use his thumbs when trying to pick things up; Doesn't hold crayons right; Doesn't clap yet; Doesn't wave hello or goodbye; Can't turn pages in a book; Won't use utensils to eat; Keeps one hand in a fist; 24 months old and cannot write name; Spills a lot; Only uses one hand; Flaps hands when excited*

Guidance for Professionals:

- Only about 1% of children score on Path C: Mild Risk for DD.
- These children tend to be very young (average age = 13 months).
- Most parents have a single concern that is not (currently) predictive of developmental disabilities.
- Most concerns focus on Gross Motor (68%) or Fine Motor (21%). Many such concerns can be addressed with advice and guidance but be sure to monitor carefully: Follow up in 6 – 8 weeks to ensure advice was effective.
- Although referring all children who score on Path C: Mild Risk for DD is not recommended, about 10% are eligible for IDEA/special education. To best identify these children:
  - Consider the content of concerns: Some reflect significant problems in need of intervention [e.g., *Only uses one hand; One or both hands fisted (at or beyond 4 months of age*); *Floppy; Weak; Excessively strong]*.
  - Consider the number of concerns: If 2 or more are present, children are at higher risk.
- Be sure to add your own concerns and observations before scoring (or rescoring). Under question #11 (Health issues) note any potentially qualifying conditions such as very low birthweight, seizures, syndromes, chronic health problems, etc.
- Per American Academy of Pediatrics' recommendations for early detection, consider administering an autism specific screen and a milestones-focused screen, such as the *M-CHAT-R* and *PEDS: Developmental Milestones® (PEDS:DM®)* screener. These measures helped identify others on Path C: Mild Risk for DD in need of referral:
  - 8% failed the *M-CHAT-R*.
  - 6% had 3 or more unmet milestones on the *PEDS:DM®*.
- All parents deserve and need information about age-appropriate skills and positive parenting. Many parents on this Path are asking for such guidance. Click here for live links to our *Parenting Resources*. You can also download and share our detailed list of milestones. See Appendix C of *"The Book"*.

PEDS-R® Path By Path (continued)

PATH C: MILD TO MODERATE MEB (MENTAL HEALTH/EMOTIONAL/BEHAVIOR) RISK

Common Types of Concerns and Typical Comments

Behavior: *Gets angry and throws tantrums; Bites others; Bullies; Hits for no reason; Out of control; Aggressive; Violent; Acts out at school; Hyper; Impulsive; Aggravated easily; Defiant; Destructive; Hurts herself when mad; Won't listen or concentrate; Screams constantly; Loves getting in trouble for the attention he gets; Hurts animals; Refuses to mind; Strong willed; Determined to get his way; Repeats the same actions when playing over and over; Stubborn*

Getting Along with Others (Social-Emotional and Well-being): *Separation anxiety; Cries about everything; Morbid talk; Very sensitive; Extremely emotional; Happy one minute and sad the next; Bipolar?; Minimal independent play; Unwilling to be alone; Does not like to share or play with others; Needs calming techniques; Clingy; Too shy; Has too little fear of dangers; He is mean; Afraid of every one; Doesn't have friends; Overly friendly with strangers; Doesn't have many opportunities to learn social skills; Bossy; Withdrawn; Talks back; Lacks confidence; Phobias; Perfectionistic and easily frustrated; Fussy and irritable; Selfish*

Doing Things for Himself/Herself (Self-Help): *Refuses toilet training; Resists pooping on the potty; Won't hold bottle; Won't get dressed or bathe without prodding; Won't use utensils; Doesn't clean up after himself; Wants me to do everything for her; Won't tie shoes; Insists on me feeding him – won't even pick up food on his own; Tries to be too independent – resists our help even when needed; Won't wipe or flush*

Professional Discussion and Guidance:

- 5% of children score on Path C: Mild to Moderate MEB Risk.
- Among their parents, 65% worried about behavior, 37% worried about social-emotional issues, and 12% worried about self-help skills.
- Their children are, on average, 2 ½ years old – the exact age when young children are engaged in an epic struggle between dependence and independence. Temper tantrums are understandable. Even so, better ways to cope must be taught.
- To address these complex challenges, professionals require skills in explaining the difference between discipline (which is teaching new ways to behave) and punishment (which tends to drive problematic behavior "underground"), exploring triggers, catching children "being good", helping parents cope with response bursts (wherein children act out even more as a last-ditch effort to get their way), etc.
- Fortunately, 70% of parents on Path C: Mild to Moderate MEB Risk have only one concern.
  - Professionals may be able to address a single concern with parenting information and motivational interviewing. See Chapter 7 in *"The Book"* and our website page on *Parenting Resources*.
  - Follow-up in 6 – 8 weeks is essential to determine if advice was effective or whether other assistance is needed.
- 17% of children on Path C: Mild to Moderate MEB Risk are eligible for IDEA/special education and/or need mental health services including parent training. To identify this group, look for:
  - The 30% of parents with concerns in two or more domains, multiple concerns per domain, and those with persistent concerns despite prior professional advice: Over half were eligible.
  - The 5% of children with 3 or more unmet milestones on the *PEDS:DM®*.
  - The 5% who fail the *M-CHAT-R*.
  - Child age: Of those eligible, 60% were 3 years of age and older.
- Mental health issues are something of a "family contagion" – meaning that children whose parents are depressed or anxious are likely to become so themselves. For this reason, it is wise to ensure that parents are screened for depression/anxiety and treated if indicated. See also Chapter 10 in *"The Book"*.

PATH B: MODERATE DD (DEVELOPMENTAL DELAYS/DISORDERS) RISK

Common Types of Concerns and Typical Comments

Talking and Making Speech Sounds (Expressive Language and Articulation): Because this domain of development has many components, parents' concerns are sorted accordingly:

- Articulation/Vocal Problems: *Most people can't understand what he's saying; Can't pronounce many sounds; Does not imitate sounds well; Leaves sounds off the ends of words; Repeats words; Stutters; Hoarse; Drools a lot; Only whispers; Hard time swallowing; Chokes or gags often*
- Vocabulary and Syntax: *Is she saying enough words for her age?; Isn't talking; Only jabbers; Does not use full sentences or combine words; Dismissed from therapy but not making progress; Didn't qualify but still having trouble; Words out of order; Behind other children his age; Only uses gestures not words; He does not talk even though he's 2 months old*
- Communication: *Does not make conversation or try to communicate; Only repeats what I say; Only makes grunting noises, growling or high-pitched sounds; Doesn't say words anymore*
- Dual Language Learning. *She seems confused about how to say things because we speak two different languages at home; Mixes up languages*
- Potential Causes: *Nonverbal – does he have autism?; Lisps – is that due to missing front teeth?; Is a pacifier causing speech delays?; Tongue tied; Behind but speech-language delays run in our family; Is he deaf?; Are constant ear infections affecting her talking and speech?*

Health: *Overweight; Small for age; Allergies; Trouble sleeping; Constipation; Reflux; Always sick; Rashes; Scratches constantly; Night terrors; Little appetite; Won't eat solid food; Picky eater; Eyes deviate; Does she see OK?; Squints; Hives; Snores; Mouth breather; Reoccurring headaches; Touches ears or rubs eyes a lot; Often short of breath; Hearing?; Sensitive to loud noises; Eyes, legs and belly hurt; Teeth grinding; Sleeps a lot but still wakes up tired; Runny poop; Teething; Very strong body odor; Cleft palate; Sensitive to bright light; Sensory issues; Chews on everything*

Guidance for Professionals:

- 9% of children score on Path B: Moderate DD risk.
- Their parents have one developmental concern that is predictive of significant problems and often have other developmental concerns that are (as yet) non-predictive (e.g., gross motor). None have MEB concerns.
- 18% have health concerns or mention potential medical causes for delays. This group needs to be seen by their primary care provider.
- 73% have concerns about expressive language/articulation.
- 2/3rds of children with Path B: Moderate DD risk are not eligible for IDEA/special education but need referrals to non-IDEA programs like Head Start, after school tutoring, etc.
- About 1/3rd of children on Path B: Moderate DD risk are eligible for IDEA/special education.
- To discern which children to refer:
  - Take note of particularly troubling concerns (e.g., loss of language, worries about autism or hearing). Such families need prompt referrals.
  - If you've administered *PEDS®*/*PEDS-R®* in the past and children still have risk, refer.
  - Administer additional screens to children on Path B: Moderate DD. These reveal that:
    - 7% fail the *M-CHAT-R*.
    - 26% have two or more unmet milestones on the *PEDS:DM®*.
- All parents need information about typical progression by year of age (e.g., emergence of consonants, gestures, sound substitutions, length of utterance, grammar, stuttering – assuming whole words or word parts are repeated, but not just initial sounds). Please see our speech-language handout under *Parenting Resources* and Chapter 10 of *"The Book"*.

PATH B: MODERATE MEBDD RISK

Common Types of Concerns and Typical Comments

Learning Preschool or School Skills: *Delayed in reading and math; Frequently flips numbers and words; Difficulty comprehending information and applying it; Social anxiety interfering with learning and interactions with classmates; Can imitate rote counting but not on her own; Delayed in reading and if too difficult gives up instead of trying; Difficulty focusing, staying on task and completing tasks; Doesn't like to write; Won't sit still long enough to learn; Easily frustrated with school work; Cries often when doing homework; Not interested; Speech problems are interfering with identification of shapes and colors; Trouble holding pencil and tracing; Doesn't seem to comprehend reading and writing; No day care or preschool experience so I don't know what he's supposed to know; Doesn't remember what's been taught; Trouble following rules, respecting limits; controlling impulses and regulating himself; Was bullied at school and on the bus and bothered greatly by this; Hates school and pretends to be sick every morning; Was asked to leave preschool because of his behavior*

Note: Doing well in school involves skills in all areas of development. Visible in parents' comments are worries about behavioral self-control, the impact of expressive and receptive language delays on learning, retention and following directions, fine motor delays that contribute to problems writing and drawing, and the problems of limited exposure to education (e.g., throughout the COVID pandemic). Social-emotional challenges are often mentioned, such as when children are aware of their own deficits and shy away from tasks they find too difficult. No wonder parents with concerns about preschool and school skills usually have worries about other areas of development, including mental health, social-emotional and behavioral domains.

Guidance for Professionals:

- 5% of all children score on Path B: Moderate MEBDD Risk.
- All children on Path A: High DD Risk should be referred to IDEA/special education should be referred to IDEA/special education and for mental health services, behavior therapy, parent training, etc.
- Their parents have one or more MEB concerns plus one predictive developmental concern [although they may have other developmental concerns that are (as yet) non-predictive (e.g., gross motor)].
- Most parents have more than 2 concerns.
- The most common concerns are Behavior, Expressive Language, Social-Emotional and School skills (the latter is shown above).
- 47% of these children are eligible for IDEA/special education and an additional 22% have ongoing or increasing difficulties, i.e., will likely become eligible with time.
- 29% had 2 or more unmet milestones on the *PEDS:DM®*.
- 14% failed the *M-CHAT-R*.
- Those who do not qualify need other types of professional intervention such as Head Start, parent-training, after school tutoring and monitoring by IDEA/special education and referring professionals.
- Even when referring, parents need guidance on how to help at home. The information hand out on promoting school skills is useful as are those on teaching discipline and language development. See *Parenting Resources* and Chapters 7 and 9 of *"The Book"*.

PEDS-R® Path By Path (continued)

PATH A: HIGH DD RISK

Common Types of Concerns and Typical Comments

Listening and Understanding (Receptive Language): *Doesn't respond to his name or instructions; Not sure if he understands what we are saying; Acts like she can't hear – I have to be loud when talking; Needs visual prompts (or sign language) to understand; Forgets what he's been asked to do; Asks us to repeat ourselves; When I call his name only turns around sometimes; Cannot understand simple commands like "go", "come", "stop", "eat"; Spaces out when I talk to her; Just repeats words back; Comprehension is delayed; Confused when asked to answer questions; Can't hear? Or just stubborn? Or can't pay attention?; Does not listen well; Doesn't do what's asked; Understands Spanish well but not English; Gets confused easily; Too hyper and doesn't listen completely; Listens but does not understand; Won't follow instructions; Selective hearing?; Takes a long time to process what he's heard; Understands but won't mind me; It's hard to get her attention; Can only follow one-step instructions; Can't remember what's been taught; Does not listen; Ignores me; Needs lots of explanations; Her answers don't have much to do with the question asked; Gets upset at loud noises*

Guidance for Professionals:

- 1% of children score on Path A: High DD Risk.
- All children on Path A: High DD Risk should be referred to IDEA/special education.
- Their parents have at least two predictive developmental concerns and usually several (as yet) non-predictive concerns. None have MEB concerns.
- 92% are worried about expressive language, 58% about receptive language (shown above), 20% about school skills, 20% about health; 15% about fine and gross motor skills.
- Concerns about hearing are frequent and need prompt referral to primary care providers and/or speech-language pathologists.
- Often imbedded in concerns about receptive language problems are parents' theories about other potential causes (e.g., short attention span or hyperactivity, deliberate non-compliance). But when children don't understand, they are likely to lose interest, ignore what's being said, fidget, etc.
- Adults can relate: When we've had to attend a boring lecture, say on quantum physics for which most of us don't have a basic understanding, we will space out, day dream, or distract ourselves making grocery lists – although we do know how to sit still and appear as if we are paying attention. Children do not.
- It is best to first view symptoms of ADHD as an indicator of limited comprehension and lack of prerequisite skills rather than as a cause. For example, children cannot learn to name letters until they have mastered earlier skills (e.g., able to match letters before progressing to pointing when named, and only after that can they name letters independently).
- Refer, first of all, for language and psychoeducational evaluations. Once effective interventions are in place with instruction that is developmentally appropriate, if attention problems persist, then consider referral/treatment for ADHD issues. Note that ADHD treatments improve "readiness to learn" but children cannot learn when instruction is too difficult and prerequisite skills are lacking.
- Of children on Path A: High DD Risk, 55% were diagnosed and eligible for/receiving IDEA/special education.
- Of the remaining 45%, 22% failed the *M-CHAT-R* and 20% had three or more unmet milestones on the *PEDS:DM®*.
- Parents will still want guidance on how to help at home. See *Parenting Resources* and Chapters 9 and 10 of *"The Book"*.

PATH A: HIGH MEBDD RISK

Common Types of Concerns and Typical Comments

Behind in most areas and can't do what other kids can (Global/Cognitive). *Slow for age; Very very far behind; Delays in every area; I'm concerned about her intellectual ability; Not as advanced as others her age; He seems younger than his age; Doesn't try to do things like kids his age; Is two grade levels behind; Not at the same developmental level as others; Does not learn from mistakes or from discipline; Doesn't do what other kids are doing; Doesn't remember or retain information; Doesn't catch on like other children; Needs extra help to learn anything; It's hard for him to learn; Can't do what his siblings can; Very late at acquiring skills in any area; Not interested in learning; Her scores on school tests are really low; His learning is slow; Lives in his own world; Slower to do things that most kids his age are doing; Held back in kindergarten and seems delayed; I'm worried about his mental development; Very difficult to teach her new things; Not smart; I worry about his learning, development and behavior—his overall abilities; He can't understand things; Is he at age level?; Forgets everything he's learned; Milestones slow in coming; I know every child is different but I worry about how different she is; I feel terrible comparing my son to others but he seems behind in so many ways*

Causes are frequently raised such as; *His anxiety makes it hard for him to learning anything; Health problems interfere with learning; Does he have autism?; Born drug addicted and that's causing his many difficulties; Hearing and language deficits affect everything; Are hyperactivity, distractibility, and impulsivity causing his problems?; Was in foster care. Did prior family history cause his problems?; Food allergies causing problems?; Is bilingual background interfering with learning?; Skills are under-developed due to COVID isolation; Seizures? His brother is autistic. Is she imitating him?; Fetal alcohol syndrome causing cognitive delays; Down Syndrome causing slow learning*

Guidance for Professionals:

- 4% of children score on Path A: High MEBDD Risk.
- All children on Path A: High MEBDD Risk need referrals for mental health evaluations, behavior therapy, counseling, parent training, etc.
- Their parents have on average 5 concerns across almost all domains: 88% expressive language, 72% receptive language, 55% gross or fine motor, 77% social-emotional, 58% self-help, 55% school, 23% health and 12% global/cognitive (shown above), etc.
- The Global/Cognitive question comes toward the end of *PEDS-R®*. 98% of parents commenting have raised concerns in most areas but sometimes respond to this question with their priority concern (e.g., speech-language). Many others write comments such as, *"See all of the above"*.
- Many children who start out with only developmental problems acquire MEB problems as well. Children are quite aware when they can't do what others can, and usually act up, give up, lose confidence, are increasingly frustrated, etc.
- Conversely most children who initially had only MEB problems eventually end up with MEB plus developmental problems. It is difficult to learn when depressed, anxious, angry, or oppositional, and so children start falling behind in development.
- All children on Path A: High MEBDD Risk need to be referred to IDEA/special education:
  - 70% are eligible for services.
- Of those not yet evaluated:
  - 63% have 3 or more unmet milestones on the *PEDS:DM®*.
  - 51% fail the *M-CHAT-R*.
- Parents always want information on how to help at home. See *Parenting Resources* and Chapters 7 and 9 of *"The Book"*.

OFF THE PEDS-R® PATH

OTHER CONCERNS

Some parents raise concerns about psychosocial issues that need professional attention. Note that such comments are sometimes mentioned in the final question on *PEDS-R®* or imbedded with other concerns, most often Global/Cognitive. Common remarks are shown below together with recommendations for next steps.

Types of Comments and Guidance on Next Steps:

Help Explaining Divorce/Death. *We are divorcing and I need advice on what to say or do to help my toddler adjust; How do I explain a death in the family?*

- Parenting handouts are enormously useful and ones covering divorce and death can be found on our webpage: *Parenting Resources*. If adjustment or grief is protracted, parent support groups can be enormously helpful. Family and child counseling can also be recommended.

Difficulty Finding Daycare or Preschool. *Just got kicked out of day care for bad behavior; How do I find a good preschool program?*

- United Way has a resource directory that can be accessed in almost every US State and Territory (and often internationally) by dialing: 2-1-1.

Financial Problems Including Housing/Food Instability and Disaster Relief. *We can't afford good day care or preschool and I worry that this has put him at a disadvantage; I have trouble getting him to therapy – no money for gas or car repairs; I've lost my job and about to be homeless; No money for food or rent; Family members can't keep us for long; Our house flooded in the last storm and we can't live there. Is help available?; We don't have health care.*

- Help with financial, transportation, housing, and food instability issues, disaster recovery assistance, affordable health care, taxes, etc. can also be found by dialing The United Way at their Warmline: 2-1-1.
- Witness to Violence/Potential Child Abuse/Neglect/Suicidal Ideation. Per grandmother, *parents constantly watch violent TV shows and these upset her grandson;* Per babysitter, *she has lots of bruises, increasingly fearful and clingy.* Per aunt, *her parents abuse drugs and alcohol. She seems to be losing weight and I wonder if her parents are feeding her enough?;* Per teacher, *often dirty and hungry when coming to school; Talks about death, killing himself – not sure if that's just for attention or if he really means it?; Vagina and labia itchy, often swollen and red; Lots of urinary tract and yeast infections.*
  - Children with developmental and mental health problems are at elevated risk for abuse. If you suspect a child is physically or sexually abused, neglected or exposed to violence, promptly call or text the *Child Help Hotline: 800-422-4453* or call 9-1-1.
  - Also be sure to refer to primary health care.
  - For information on preventing sexual abuse see The WebMD website.
  - Even young children can be suicidal. Most have untreated mental health problems such as depression/anxiety. For assistance call the *Suicide and Crisis Hotline: 9-8-8*.

Foster Care. *Was in foster care due to domestic violence. Now heading back to biological parents; Has had multiple foster care placements in the last few years.*

- All children who are in or have been in foster care are at high risk of developmental and mental health problems. All should be evaluated by IDEA/special education programs. All need mental health services such as counseling, behavior therapy, etc.

Issues with Gender Identity/Gender Expression/LGBTQ Parents. *Insists he's a girl and wants to wear frilly dresses and play with girl dolls; How do I help my child explain to others that she has two mommies.*

- The Mayo clinic website has helpful information for parents: *Children and gender identity: Supporting your child*.
- *The Family Equality* website has useful advice for same-sex parents.

Screening for Psychosocial Risk. The *PEDS:DM®* in print includes the *Family Psychosocial Screen* that screens for drug and alcohol abuse, domestic violence, poverty, etc.

FREQUENTLY ASKED QUESTIONS

What Does PEDS-R® Measure

What is the intent of the 12 PEDS-R® questions?

PEDS-R®'s 12 questions enable parents to tell us their specific worries. The questions encourage parents to think beyond the most salient issues (which are behavior and expressive language) and thus consider children's performance in all domains, like professionals do.

What are the domains of PEDS-R® and how do they contribute to types of risk?

The below 7 domains contribute to identification of Developmental Delays/Disorders

- *Expressive Language* including Articulation (talking and making speech sounds),
- *Receptive Language* (understanding what you say),
- *Fine Motor* (using hands and fingers),
- *Gross Motor* (using arms and legs),
- *School Skills* (learning preschool and school skills), and
- *Cognitive* (behind others and can't do what they can), referred to as Global/Cognitive.
- *Health* concerns.

The below 3 domains contribute to identification of Mental Health/Emotional/Behavioral Risk

- Self-Help (learning to do things for himself/herself),
- Behavior, and
- Social-Emotional (getting along with others).

In addition, *PEDS-R®* captures:

- *Other* concerns (family challenges). These are not assigned on the *PEDS-R® Score Form* but still require action such as parenting advice or referral to social services.

How often do children have Low Risk, MEB Risk, DD Risk versus MEBDD Risk?

- ~75% are typically developing and have low risk for DD and/or MEB.
- ~11% have DD risk (mild, moderate or high).
- ~5% have MEB risk.
- ~9% have both DD and MEB risk, i.e., MEBDD risk.

Older children are more likely to have MEBDD risk.

Why are self-help concerns included with MEB Risk?

- Children are quite aware when they can't do what others can do (like tie shoes, button clothes) and this leads to social-emotional issues especially poor self-esteem
- Next up, when children are asked to do things that are too difficult, they tend to act up and refuse to follow commands.
- So, self-help is an indicator of compliance with the typical directions/commands parents give, and also serve as an indicator of children's well-being.
- Note that among parents with self-help concerns, 70% had behavior concerns and 56% with had social-emotional concerns.
- Although self-help concerns are sometimes associated with fine and gross motor concerns, professionals and parents have an opportunity to mark these separately.

Why are Health issues included as a DD Risk?

Some serious health problems lead to reduced and limited vitality, frequent school absences, frequent hospitalizations – all of which may be associated with DD. Some health issues, like certain kinds of rashes, are indicators of physical conditions such as syndromes, that can also contribute to DD.

HOW PEDS-R® HELPS

Why rely on parents' concerns instead of measuring milestones?

Parents' concerns capture the quality of development. Unlike milestones-focused screens, parents' concerns identify:

- Specific issues needing professional guidance (e.g., which parenting information topics should be covered, such as *biting versus managing temper tantrums)*.
- Disordered development (e.g., *says words but her words she says are not useful in asking for what she wants)*.
- Behavioral/social-emotional/mental health challenges (e.g., *Doesn't have friends; Is bullied at school)*.
- The effectiveness or ineffectiveness of prior professional advice (e.g., when parents repeat the same concerns over time, professionals can discern that repetition and/or more help is needed).

How else does eliciting parents' concerns with PEDS-R® help professionals?

- Provides decision support: Indicates when to advise and rescreen, when and where to refer.
- Makes it easier to give difficult news by affirming parents' concerns.
- Increases attendance at well-visits and parent-teacher conferences.
- Establishes a collaborative, supportive parent-professional relationship.
- Improves professional preparedness for encounters by reducing unexpected "oh by the way" concerns.
- Saves time during visits and enables professionals to focus on addressing problems.

How does PEDS-R® inform action steps?

Unlike most screening tests, *PEDS-R®* tells us:

- When to offer parents advice and/or monitoring.
- When to refer for IDEA/special Education.
- When to refer for mental health services.
- When to refer for non-IDEA services such as Head Start or parent training.

I worry that adding PEDS-R® will take too much time.

PEDS-R® actually saves time - 3 minutes per visit on average. *PEDS-R®* reduces time-consuming *"oh by the way"* concerns, and when completed prior to an encounter, professionals can prepare in advance to address issues (e.g., gathering specific parenting information, details about referral sources).

Do parents like PEDS-R®?

Yes! Here's an example of one (of many) parent's appreciation: *"I've been able to list all the concerns I have at the moment. Thank you so much for this opportunity."* Parents are more likely to return for visits when *PEDS-R®* is used.

Is there an electronic application?

Yes. *PEDS® Online* includes three screens that collectively comply with AAP policy: *PEDS-R®*, *PEDS:DM®* and the *M-CHAT-R*. Offered in English, Spanish and Chinese, the site scores automatically, renders a report along with referral letters and a parent-take home summary. Via the *PEDS® Online* Portal, parents can com-

plete screens at home prior to a visit.

For researchers, IDEA/special education intake/follow-up, and subspecialty clinics, *PEDS® Online* offers *PEDS-R®*, *M-CHAT-R*, and *PEDS:DM – Assessment Level® (PEDS:DM – AL®)*. The *PEDS:DM – AL®* is a 20 – 25 minute evaluation measure providing age-equivalent scores and percent of delay/percent of skills mastered. This combination of measures offers detailed tracking of progress.

AGE CALCULATION/FINDING THE CORRECT COLUMN ON THE SCORE FORM

What's the best way to calculate age?

The best way to calculate a child's age is to use our online age calculator at this *link*. The age calculator will ask for the child's birthdate, weeks premature (if any) and will generate the child's Chronological Age and their Adjusted Age to choose the appropriate age column on the *PEDS-R® Score Form*. The Adjusted Age may or may not be the same as the Chronological Age.

For *PEDS® Online* users, Chronological Age, Adjusted Age are calculated automatically when you enter the child's information. The automatic Scoring accounts for the calculated age in the auto-generated report.

How do you adjust for prematurity?

Chronological age adjustment for prematurity only occurs for children less than 24 months of age and greater than 3 weeks premature. The best way to adjust for prematurity is to use our age calculator at this *link*.

PEDS® Online will do all the age calculation and adjustment for prematurity for you in Scoring and Reporting test results.

Which age column on the Score Form do I follow if a child is at the top of an age range (e.g., 4 1/2-years-old)?

For ages shown in years, the " - " (dash) means "up to" but not "through". So, for example, a 4 year 6 month old is not scored on the 4 - 4 1/2 year column but instead in the 4 1/2 - 6 year column. Similarly a child who is exactly 6 years 0 months old, is scored on the 6 - 7 year column while a child who is 7 years and 0 months old is scored on the 7 - 8 year column.

Also note that children who are 7 years, 11 months and more than 15 days old, will have a rounded chronological age of 8 years and 0 months. They remain within the age range for PEDS-R and are scored in the 7 - 8 year column.

SCORING QUESTIONS

What do I do when a parent raises questions instead of answering PEDS-R® questions?

- If parents write a question such as, *"I don't know what he should be doing at his age",* mark this as a concern on the *PEDS-R® Response Form. Such parents need developmental and behavioral guidance and monitoring, just for starters.*
- If administering *PEDS-R®* by interview and parents ask *"What do you mean?"*, do not give examples. These distract from the "big picture" summary we want parents to provide. Just say, *"I'd like to know what you think – whatever comes to mind."*
- Only after *PEDS-R®* is scored should professionals render advice on child development.

Where should I note concerns about hyperactivity/ADHD, or medical/genetic conditions?

Write these in the space for Question 11. Then put a checkmark in the circle for health concerns.

What do predictive and non-predictive concerns mean?

- Non-predictive concerns are those not currently associated with a diagnosis/eligibility for special services.
- Predictive concerns are those associated with a diagnosis/eligibility for special services.

These change by children's age as shown on the *PEDS-R® Score Form*. For example, *Gross Motor* concerns are non-predictive in very young children because parents are usually asking about expected milestones, such as at what age should a child sit up, stand, walk. At older ages, *Gross Motor* concerns become predictive of potential difficulties.

What if I notice a significant problem but the domain is non-predictive or a child scores on a lower risk Path?

In the above example of non-predictive *Gross Motor* concerns:

- If professionals identify conditions such as spasticity, hypotonicity, cerebral palsy, etc., these should be added to *Health* concerns before scoring.
- Professionals may decide, at any encounter, to refer whether or not *PEDS-R®* shows high risk.
- Professionals should always refer when *PEDS-R®* so indicates.

What is the difference between *"A little concerned"* and *"Concerned"*?

- There is no difference when scoring *PEDS-R®*: Either response is considered a concern.
- Both options are shown to discourage parents from circling *"Not concerned"* when they aren't sure whether they should be concerned.
- In other words, parents often observe differences between their child and others, but may not know initially whether or not these differences should be considered troubling. So the *"A little concerned"* response option helps parents express what they've noticed, even if they aren't sure whether or not to be *"Concerned."*

What do I do if a parent raises a concern on the first question but then circles "Not concerned" on a later question associated with the domain mentioned?

Cross out *"Not Concerned"* and circle *"Concerned"* on the *PEDS-R® Response Form* for the domain mentioned. For example, if a parent writes on Question #1, *"I'm worried about his talking,"* but circles *"Not concerned"* for the Question #2 (about *Expressive Language*), cross out *"Not concerned"* and circle *"Concerned."*

If parents did not write any words on PEDS-R®, can I still score it?

- **No!** If parents did not write any comments, only wrote *"No,"* or skipped responses, re-administer *PEDS-R®* by interview.
- Why? Language or literacy barriers may be present.
- Professionals should ask before presenting *PEDS-R®* in writing, which language parents prefer.
- Professionals should also ask, *"Would you like to complete this on your own or have us go through it with you?"*
- *PEDS® Online* offers *PEDS-R®* (and other measures) in English, Spanish and Chinese (we have about 65 other translations are freely provided to *PEDS® Online* users). If parents do not write any comments, *PEDS® Online* will not score. Instead the site prompts for an interview administration.

What if I disagree with parents' concerns? Should I change their concerns?

Parent-professional disagreement is not uncommon but is crucial to collaboration in early detection. For example:

- Young, first-time (and thus inexperienced) parents often worry about issues that professionals recognize as just typical development. Nevertheless, parents' concerns are real and important to them and thus require professional attention, even if just advising parents about child development.
- *PEDS-R®* results will illustrate how best to respond.
- Meanwhile many professionals only see children during brief encounters or only when children

are in classrooms. In such settings, children don't always demonstrate, for example, behavior problems such as attention deficits or an at-home tendency toward non-compliance. *PEDS-R®* enables professionals to learn from parents how children perform in a range of environments.

So, if you disagree with parents' concerns, do not eliminate them when scoring.

Professionals are encouraged to add their own concerns to the *PEDS-R® Response Form* before scoring. For example, parents may notice excessively repetitive play but may not know this could be a symptom of autism. If professionals notice this potential condition, they should comment in the question about *Health*.

I addressed the parents' concerns – should I change the PEDS-R® results?

No! Do not change parents' comments or the *PEDS-R®* response options. You will need to rescreen in 6 – 8 weeks to see if your advice was effective, i.e., to view the previous administration of *PEDS-R®* to see if concerns persisted or not.

What happened to Path D? Why are Path D and Path E shown as Path D/E?

The former Path D alerted professionals to administration errors such as wrong language, informant not the main caretaker, or literacy problems (e.g., no written comments). So if *PEDS-R®* is administered correctly, Path D is not needed. But be sure to double check Path E results to make sure parents understood the questions (See Path-by-Path recommendations above).

I'm a teacher. Can I complete PEDS-R® on my own?

PEDS-R® requires parent and professional collaboration. Many questions, for example, about Self-Help or Health may be difficult to answer by teachers alone. So, please administer to parents and then add your own concerns.

My staff administer PEDS-R®, score it, and then only show the Paths/risk levels in my electronic record – not parents' actual comments.

Parents comments should be included in each child's record. The *PEDS-R®* protocol (especially the final two pages) need to be included in each child's chart to show that not only was *PEDS-R®* administered but what actions were taken in response to parents' concerns. Medicaid and private payers require this documentation when auditing. Please let your staff know to include parents' comments before you see families.

Decisions and Action Steps

I understand that PEDS-R® is well researched, but I also want to see children's actual skills.

Good plan! The American Academy of Pediatrics (AAP) recommends eliciting parents' concerns (*PEDS-R®*), plus measuring milestones *[PEDS: Developmental Milestones (PEDS:DM®)]*, plus a periodic screen for autism spectrum disorders (*M-CHAT-R*). Skill-based screening along with *PEDS-R®* informs professional recommendations and selection of action steps. All three measures are available via *PEDS® Online*.

Do specific concerns indicate the type of problem?

Sometimes but not always. For example, Expressive Language concerns (the most common among parents worries) are associated with a diagnosis of speech-language impairment, but are also associated with diagnoses of autism spectrum disorder and intellectual disabilities. If referrals are indicated by *PEDS-R®*, subsequent testing should be broad-band, i.e., measure all domains of development.

What if a child has lots of psychosocial risks for future problems but appears OK for now?

- Provide guidance to the parent on what the next stages of development are, what to look for and ways parents can interact with their child to enhance development.
- Encourage parents to enroll in *Dolly Parton's Imagination Library* (see Path-by-Path guidance for Path E)
- Rescreen in 6 – 8 weeks to make sure child and parents are making progress.

- Refer to Head Start, Early Head Start, parent training, etc.

What do I do when a child is at high risk on PEDS-R® but doesn't qualify for special education services?

- Refer to Head Start, Early Head Start, parent-training, after-school tutoring, quality day care/pre-school, etc.
- Rescreen more vigilantly, i.e., between established well-visits.

The families I refer for services don't always follow through. What can I do?

Many parents prefer to try even harder to intervene at home. Fine but not always effective. Some parents, especially those who do not speak English are reluctant to call — they may be unsure if referral sources speak their language. Some parents have transportation problems or worry about taking time off work. So:

- Follow up in 6 – 8 weeks to see if families are making progress.
- Facilitate referrals via a 3-way call among professionals, parents, and referral sources.
- Ask referral sources to use *Language Line* or other interpretation services when calling families back
- Ask referral sources to conduct evaluations at families' homes.

Several of my students had Path B, C or E results but failed M-CHAT-R. What do I do?

When a child fails the *M-CHAT-R*, or any other ASD screener, refer to IDEA/special education. You can also refer to autism specialty clinics but these usually have long waiting lists. Children at risk for ASD need prompt intervention so it is best to refer first to IDEA/special education.

Why don't families raise lots of concerns when their children have a known, substantial disability?

When children with special needs are enrolled in helpful services and parents are satisfied with ongoing intervention, they tend not to re-raise concerns. Earlier administrations of *PEDS-R®*, prior to referral/intervention show initial concerns. If you are new to a setting where *PEDS-R®* has been administered in the past, it is best to review the complete record on each child.

What if the parent reporting on PEDS-R® is not actually the main caretaker and doesn't know much about his child – meaning I'm not confident in the results?

Sometimes older siblings or a teen parent who doesn't actually take care of their child as much as grandparents do, accompany children to appointments. In such cases, you can:

- Send a copy of *PEDS-R®* home for the main caretaker to complete. Be sure to include a self-addressed stamped envelope!
- Call the main caretaker and administer *PEDS-R®* over the phone.
- Use *PEDS:DM®* – administering items directly to the child, rather than by parent report.
- Invite the main caretaker to use the parent portal within *PEDS® Online*.

I refer a lot but many don't qualify. What do I do?

Children who don't qualify should be referred to Head Start, quality preschool, after school tutoring and parent training. Usually IDEA will monitor and rescreen. But if not, other professionals, especially primary care providers should monitor and rescreen. These children are likely to qualify for IDEA in the future.

It is great that PEDS-R® detects emotional, behavioral, mental health problems, but there's not much out there to help or refer to.

If we think of mental health services only as counseling by a psychiatrist or psychologist, you are correct – there are not enough of these. But mental health services should be viewed more broadly and include:

- *Identifying and treating parents' mental health, which is most often depression and anxiety*

- *Parent training programs, like Triple P and Incredible Years often have tiers of increasingly intensive services for children and parents who don't respond to initial training*
- *IDEA (early intervention/public school special education) serves children with emotional and behavior problems via individualized instruction, behavior management, teacher-training, counseling by school psychologists, and many other services and programs.*

How do I tell whether MEB risk is mild or moderate? What services should I recommend for mild versus moderate MEB risk?

- If there are multiple check marks in any of the triangles, this indicates moderate risk
- If more than one triangle is marked, this indicates moderate risk
- When moderate risk is apparent, advise families, provide written guidance but definitely consider referrals for parent-training. Rescreen and if no progress consider other types of mental health services such as counseling, therapeutic preschool and referrals to IDEA.
- If only mild risk is apparent (only one checkmark in only one triangle), your advice and written handouts may be sufficient but definitely rescreen in 6 – 8 weeks to make sure your guidance is sufficient and that problems are resolving.

Cultural Sensitivity: Working with Unique Populations and Translations

Can I use PEDS-R® when children have chronic illness?

Yes. Just because a child is chronically ill does not mean they do not need to be screened. Screenings, and screenings over time, allows insight to how they are growing developmentally, socially/emotionally, mentally, and behaviorally. It also allows clinicians to see children's areas of strengths and weaknesses.

Can I use PEDS-R® with new foster or adopted parents?

Yes! Foster parents often have much experience with children and can answers questions on *PEDS-R®*. They may not know as much about milestones (e.g., *PEDS:DM®*) so if using *PEDS-R®* + *PEDS:DM®*, administer *PEDS:DM®* hands-on.

Meanwhile, children in foster care are at high risk and deserve evaluations by IDEA/special education and mental health professionals. Also, many Departments of Human Services use the *PEDS:DM – Assessment Level®* to evaluate current status and progress.

What can I expect if administering PEDS-R® during national catastrophes/disasters?

Lots of concerns – understandably. Parents are aware that disease outbreaks, earthquakes, floods, famine, wildfires, homelessness, etc. are likely to have an adverse impact on children. Ongoing screening and professional guidance are crucial.

What can I expect if administering PEDS-R® to families seeking asylum?

Parents may be less likely to disclose health problems or developmental-behavioral concerns for fear their application will be rejected. It is wise to repeat *PEDS-R®* after resettlement. It is also wise to administer *PEDS:DM®* (hands-on).

Are PEDS® Tools culturally sensitive and appropriate to use with different ethnic groups?

Yes! Verbatim comments always reflect the cultural perspective of parents and professionals. For example, some Middle Eastern countries are highly tolerant of *"children acting like children."* Parents may comment about hyperactivity but endorse *"not concerned"* - in contrast with many North American parents.

Our measures and other publications adhere to American Academy of Pediatrics' Guidelines for Inclusive, Anti-biased Language, and to the American Psychological Association's Guidelines on Psychological Assessment and Evaluation. *PEDS® Tools* are normed on diverse populations including English and Spanish speakers.

Any imagery of people used in our measures reflects various ethnicities. We are committed to quality, thoroughly vetted translations and offer our instruments in more than 60 languages. In addition, PEDStest.com, LLC is a woman-owned business staffed by professionals of various ethnic/racial backgrounds.

I work with parents whose primary language is neither English nor Spanish. Help!

- We have 60+ translations of *PEDS® Tools*.
- These are freely available to *PEDS® Online* users and can be purchased by users of *PEDS-R®/PEDS:DM®* in print.
- To request or purchase translations, contact us: *Translations@pedstestonline.com*.

How do you translate PEDS® Tools and ensure that the translations work well?

PEDS® Tools enjoy complete cultural translations. We begin by using a professional translation service, *Translated.net*. After we receive a translation we generally send it out for vetting and invite comments from professional multi-lingual health care providers. For widely spoken languages for which there are many dialects, translation teams are formed. For example, Spanish is the most widely understood language in the world but there are many different types of Spanish. For this reason, Argentineans, Mexicans, Chileans, Spaniards, Guatemalans and American-Spanish speakers were included in the translation team (23 clinicians in total!) —with the goal of creating, whereever possible, a single translation that works well for all. With some seemingly related languages, a unified translation is not possible (e.g., Portuguese versus Cape Verdean, French-Canadian versus French or Haitian-Creole). In these cases, unique translations are vetted for each speaker group.

We also respond to feedback from *PEDS® Tools* users and identify issues with, for example, our original Chinese translation in which the Chinese word for *"concerned"* back-translated into English with a meaning in each item more akin to *"do you care about how your child is..."*. In practice this was causing over-reporting by Chinese-speaking parents. Our vetting process identified the need to use a stronger term in Chinese which translated to *"worried"* in English, too strong for English-speakers, but more closely akin to the meaning of the English word *"concerned"*.

Feedback and vetting also help us adjust our translations for changes which occur in languages over time because of situations of migration, refugees from war-torn parts of the world, and shifting demographics among native speakers, as well as dialect differences.

I want to study PEDS® Tools in my country but you don't have a translation in the language I need. Are you able to help me?

Yes! To request a translation we do not currently have, please visit our website and fill out the *Translations Request Form* located under the *Resources* tab.

Has PEDS-R® been studied for use outside North America and in other languages?

Yes! Our website, *www.pedstest.com,* houses abstracts with references to studies in other nations including many in African countries, Southeast Asian nations, Europe and elsewhere. We keep the site updated as new studies are published.

Billing and Coding

How do I bill for screening?

1. Attach the - 25 modifier to your preventive service code or E/M service code (to denote the office visit is a separate service from the screening. Then list 96110 times the number of screens given, (e.g., X 3 if using *PEDS-R®+PEDS:DM®+M-CHAT-R)*. [Note that some States (e.g., North Carolina) does not allow an unbundled 96110 but has increased reimbursement substantially for the entire well-visit]. If billing a private payer, particularly Cigna, the -59 modifier is usually required instead of -25

2. Multiple units, with the modifier appended to the visit as described above, best describe the separate entity of performing multiple 96110s. For insurers not accepting units, the distinct procedural service of each test is best represented with - 59 modifier appended to each additional unit of 96110:

   Example: A level 3 office visit in which three developmental screening instruments were administered, scored and interpreted:

   - 99213
   - 96110
   - 96110-59
   - 96110-59

Appeal all denied claims--sometimes State Medicaid Directors aren't aware of the federal ruling from 2005, in which the Centers for Medicare and Medicaid Services published a total relative value unit (RVU) of 0.36 for 96110, which amounts to a Medicare payment of about $10.00. For Cigna and many other private payers, reimbursement is about $20.00. This RVU represents only malpractice and office expense --no physician work is included--meaning that administering screening is largely a staff or parent function, except for explaining results to families.

96110 or 96111 procedure codes do not cover milestones built into EHRs including ones drawn from the Denver due to lack of validation.

What are the best diagnostic codes to use when screening results are problematic?

Commonly used ICD-10 codes are those sufficiently vague as to not interfere with a more complete diagnoses made by those to whom you refer. These often include:

- 783.4 Developmental Delay
- 309.23 Academic Inhibition (school problems)
- 315.4 Developmental Coordination Disorder
- 784.5 Other Speech Disturbance
- 309.3 Disturbance of Conduct

Why do quality screens like PEDS-R® cost? Why not use free tools?

- The biggest cost of screening is your time.
- Your time is valuable and expensive. Your time is best spent helping families.
- Your time is wasted if it is spent more on measurement than on helping.
- The cost of test protocols is minor. Even if free, photocopying costs are high.
- Free measures are not always accurate.
- Free measures are usually lengthy.
- Milestones built into EHRs are not accurate and not reimbursable under the 96110 screening code.
- Some free measures, like the *SWYC,* are not on every State-approved list for reimbursement. So you may waste lots of time administering a free measure that doesn't work well, and for which you may not get paid.
- Quality measures cost because they are expensive to validate, translate, support clinicians and researchers. But the costs of quality screens are vastly outweighed by reimbursement, i.e., use of accurate screening tests should be a profit center for practices.

I work in a community, public health or Federally Qualified Health Clinic (FQHC) and do not receive reimbursement under the 96110 screening code. Since PEDS® Tools cost, how do I justify their use?

Enhanced reimbursement for use of quality screens is often available. If not, working efficiently by using shorter and highly accurate screens is essential.

PROGRAM EVALUATION AND RESEARCH

My research involves only very young children. May I use only some of the PEDS-R® questions — the ones that appear most germane.

No! All *PEDS-R®* questions are needed. Even the question about preschool and school skills when asked of parents with infants, offer important information about what parents are doing at home to promote development. Use of flash cards with very young children alerts professionals to the need to guide parents into interactions offering more appropriate learning activities.

I want to study long-term outcomes starting with PEDS® Tools. Which of your tools is best for a longitudinal evaluation of progress?

The combination of *PEDS-R®* and *PEDS: Developmental Milestones – Assessment Level® (PEDS:DM–AL®)* will provide a range of metrics needed for a longitudinal study:

- *PEDS-R®* variables are qualitative and categorical, i.e., parents verbatim concerns, types of concerns and risk levels
- *PEDS:DM–AL®* has a continuous metric (e.g., # of successfully completed items, age-equivalent scores, percent of delay in each of 9 domains)

Please check out the above combination within *PEDS® Online*, where the *Modified Checklist of Autism in Toddlers- Revised* is also an option:

- *PEDS® Online* also has a parent portal so that families can complete measures independently.
- Digital translations are freely provided to *PEDS® Online* users and can be used alongside *PEDS® Online* administrations.
- *PEDS® Online* generates a unique database for each professional account. This database can be exported and concatenated with your study's database.

For a free trial of *PEDS® Online* go to *this Link*.

I'd like to put all the PEDS-R® questions in my research protocol along with the other measures I'm using. Is that OK?

No! We don't allow the *PEDS-R®* questions to be placed in research protocols. Mistakes in scoring will be made without using the directions for scoring and interpreting results (and some training is needed too). You can sign up for *PEDS-R®* training at *www.pedstest.com* and see why we require researchers to use *PEDS® Online*.

You can put a link on your website to *PEDS® Online*. You will receive two unique links, imbedded with your username and password if you sign up for both the Professional application and the Parent Portal (where parents do not receive results) – either or both links will be needed based on how you plan to deploy measures (face-to-face or parent self-administered).

My nation doesn't allow storage of data on servers in the United States or anywhere outside our country. How can we use PEDS® Online?

PEDS® Online does not have to store your data on our servers after you've exported.

You can let us know when you've retrieved results and then ask for expunging.

For large initiatives [with an IT budget and skills in API (Application Programming Interface)] your server can send information to *PEDS® Online* for analysis with results returned to your website -- all without storage on our servers.

In case an API interface sounds unfamiliar, know that all us who shop online engage in an API interface

every time we use a credit card. The credit card processor takes over the transaction, approves your card, does not store your credit card number, and then returns you to the site where you shopped. API is so seamless that most of us never notice we've been transferred to the credit card processor's site and then returned to our original shopping website!

I'm working with a large initiative that includes many sites. How can I aggregate results?

PEDS® Online offers the best option. Each site receives its own unique login but a master account is created for viewing all sites. Data can be extracted a regular intervals and exported into a spread sheet for analysis.

I am interested in conducting research with PEDS® Tools and wonder if you already have data to share.

Yes. We have many years of longitudinal data capturing parents' verbatim concerns via *PEDS-R®, M-CHAT-R* performance, acquisition of skills via *PEDS: Developmental Milestones®*. Family psychosocial risk factors and diagnoses/enrollment in special needs and other services can be extracted (familiarity with NVivo software is recommended). In addition to completing our research information form (in the *"Contact Us"* menu at *www.pedstest.com*), you will need to submit a research protocol to your local Committee for the Protection of Human Subjects. Data we share will be anonymized. Because the data-set involves established measures, completing an "exempt" protocol is appropriate.

I am interested in conducting research with PEDS® Tools and would like to program them for my study's website. May I do this?

No. We do not offer programming/algorithms for use on other platforms but here are two options:

1. Using *PEDS® Online,* exporting the unique *PEDS® Online* database you've created, and then concatenating with your study's own data base.
2. An API exchange such that *PEDS® Online* results are conveyed to your database - all without the appearance of having left your study's website (an IT expert on your end is needed and you will need to pay for their time and ours).

I want to use PEDS® Tools in print and include them in my research protocol along with other study questions. May I do this?

No. *PEDS® Tools* are printed in color and several are also laminated. Best to purchase our test protocols and attach to those for your study. We license many of our translations and provide digital copies but these too need to be attached in full to research protocols.

Please go to the *Translations Request Form* located under the "*Resources"* tab for research and licensing translations.

My research project using PEDS® Tools is not funded. Are you able to help me?

Probably. Please go to the *Translations Request Form* and fill out the form, describing your project.

I need more information on PEDS-R® Psychometrics.

Please download the *PEDS-R® Psychometric Research* paper *here*.

We are in the middle of a study using PEDS®, not PEDS-R®. How do we reconcile our existing data?

Assuming you have captured parents' and professionals' verbatim concerns categorized by domain, along with *PEDS® Paths*, we can advise you on how to reprogram your existing data and switch to *PEDS-R®* for the rest of your study. Please contact us at *research@pedstest.org.*

Help for Existing Customers of *Parents' Evaluation of Developmental Status® (PEDS®)*: Transitioning to *PEDS-Revised® (PEDS-R®)*

PEDS-R® is a new edition of *PEDS®* that improves questions to parents, facilitates provider input and enables detection of risk for:

- Developmental Disabilities and Disorders (DD)
- Mental Health/Emotional and Behavioral problems (MEB); and
- The combination of both: (MEBDD)

Comparison of PEDS® and PEDS-R®		
PEDS® Required Materials: 3 separate parts*	***PEDS-R® Required Materials: All in one***	***Comment on PEDS-R®***
• 1 *PEDS® Brief Administration/Scoring Guide*	*PEDS-Revised®* includes all *Forms*, directions, plus a section for documenting current findings and action steps (pack of 50)	• Adds two new questions • Encourages provider comments/concerns • Revises scoring to better detect DD, MEB and MEBDD • Enables clinics to bill for screening via 96110 • Helps quality screening become a profit center for practices • Better compliance with Medicaid /insurance audits • Improves detection of children at risk via adherence to AAP Policies
• *PEDS® Response Form*s (pad of 50)		
• *PEDS® Score/Interpretation Forms* (pad of 50)		

**Because PEDS® materials were sold separately, Directions and Score/Interpretation Forms were often unused. Thus referrals based on PEDS®, despite its higher detection rates, were lower than other screening tools. Not good!*

PEDS-R® rectifies this problem and improves your clinic's ability to implement quality early detection and to survive an insurance/Medicaid audit.

Because questions and scoring have changed, existing *PEDS®* users will need to purchase new *PEDS-R® Forms.*

Please avail yourself of *PEDS-R®* training and certification by signing up at *Training*.

After you have tried *PEDS-R®,* we welcome your feedback! *(Training@pedstest.com)*

HOW TO REFERENCE *PEDS® TOOLS*

Reference Citation for the *PEDS-R®* Handbook: Glascoe FP, Mills TD, Woods SK. *Parents' Evaluation of Developmental Status–Revised® (PEDS-R®): Handbook*. Nolensville, Tennessee: ©*PEDStest.com LLC, 2023*. www.pedstest.com

Reference Citation for *PEDS-R®* Psychometric Research: Glascoe FP, Vishnubhakta V. *Parents' Evaluation of Developmental Status–Revised® (PEDS-R®): Psychometric Research*. Nolensville, Tennessee: ©*PEDStest.com, LLC, 2023*. www.pedstest.com

Reference Citation for *PEDS-R®*: Glascoe FP. *Parents' Evaluation of Developmental Status–Revised® (PEDS-R®):* Nolensville, Tennessee: ©*PEDStest.com, LLC, 2023*. www.pedstest.com

Reference Citation for *PEDS:DM®*: Glascoe FP, Robertshaw, NS. *PEDS:Developmental Milestones®:* Nolensville, Tennessee: ©*PEDStest.com, LLC, 2016*. www.pedstest.com

Reference Citation for *PEDS:DM® Professionals' Manual*: Glascoe FP, Robertshaw NS, Woods SK. *PEDS:Developmental Milestones®, Professionals' Manual, 3rd Ed*. Nolensville, Tennessee: ©*PEDStest.com, LLC, 2016*. www.pedstest.com

Reference Citation for *PEDS:DM—AL®*: Glascoe FP., Robertshaw, NS. *PEDS:DM—Assessment Level®*. Nolensville, Tennessee: ©*PEDStest.com, LLC, 2016*. www.pedstest.com

PEDS-R® RESEARCH AND PSYCHOMETRIC SUMMARY

Description

Below is a summary of psychometric support for *PEDS-R®*. The complete and voluminous studies supporting *PEDS-R®* are housed within: Glascoe FP, Vishnubhakta V. *Parents' Evaluation of Developmental Status – Revised® (PEDS-R®): Psychometric Research*. Nolensville, Tennessee: ©PEDStest.com, LLC, 2023. The document is freely downloadable at www.pedstest.com.

Standardization

- *PEDS-R®* was standardized in English and Spanish on a nationally representative sample of 262,310 North American children, whose ages ranged from birth to 8 years.
- Families with psychosocial risk factors (e.g., limited education, poverty and non-English-speaking) were as able as those without psychosocial to raise concerns. Those with psychosocial risk tended to have children with higher DD, MEB and MEBDD risk.
- Risk rates on *PEDS-R®* varied considerably by age of child. Children 4 ½ years of age and older had 4 times the risk compared to children less than 18 months of age.
- The much higher risk rates in older children, compared to prior norming studies, seem due to the adverse impact of the COVID-19 quarantine. Even so, younger children were also affected. For example, MEBDD risk was three times higher for 3-year-olds in 2020 as compared to 2-year-olds in 2019, and 3-year-olds had much higher MEBDD risk in both 2020 and 2021 than in 2018 and 2019.
- In comparing the performance of boys to girls on *PEDS-R®*, boys had 1 ½ times the risk for DD, MEB or MEBDD than did girls. Psychosocial risk rates were comparable across gender.
- Gender of caretaker/informant on *PEDS-R®*, did not result in performance differences. Fathers, step-fathers and grandfathers were as capable of identifying risk as mothers, step-mothers and grandmothers.
- After adjusting for age-differences in the Spanish-speaking sample (which had many more very young children), there were no differences in identification of risk on *PEDS-R®* whether administered in English or Spanish.

Reliability

- ***Internal Consistency*** among *PEDS-R®* items revealed modest to moderate intercorrelations, i.e., no highly significant correlations reflecting redundancy. This means that each item contributes uniquely to the measure as a whole.
- ***Test-retest Reliability*** was 93% for re-administrations within 1 week, and 88% for administrations between 1 week and 4 weeks. Note that *PEDS-R®* is interactive: When professionals are able to effectively address parents' concerns, there are often fewer issues raised at the subsequent administration, which lowers test re-test agreement. Thus results are in keeping with prior reliability studies.
- ***Inter-rater Reliability*** was 82% for re-administrations within 1 week and 86% for administrations between 1 week and 4 weeks. Again, because professionals are often able to effectively address concerns, inter-rater reliability is expected to have lower agreement between first and second administrations. In addition, when parents do not speak English, repeat screens often involve a different examiner who is bilingual -- also leading to lowered inter-rater agreement.
- ***Inter-method Reliability*** compared professional scoring to parent reporting, specifically when parents raised concerns whether they marked "a little" or "concerned". In only 6% of cases did professionals need to change "not concerned" to "concerned". The remaining 489 cases were correctly reported by the parents and clinicians completing *PEDS-R®*. Thus inter-method agreement was 94% (N = 489/515).
- ***Stability.*** Comparing risk levels on *PEDS-R®* when rescreening over longer time intervals had 80% agreement for younger children and 82% agreement for older children. Lowered risk levels in subsequent administrations illustrate the effectiveness of interventions including professional advice. As a consequence, improved status was found in 49% of younger children and 30% of older children

who were initially at risk. Even so, developmental/mental health risk remains a "moving target", i.e., risk of developmental and mental health problems increase the older the child.

Validity

- ***Content Validity.*** *PEDS-R®*'s content validity derives from questions eliciting parents' comments in each of well-established developmental-behavioral/mental health domains.
- ***Concurrent Validity.*** *PEDS-R®* has close associations with comparable sub-domains on an assessment level measure.
- ***Construct Validity.*** *PEDS-R®* factors were closely associated with similar factors on mid-level assessment and diagnostic measures. Social-emotional and behavioral concerns on *PEDS-R®* were correlated with a range of deficits on in-depth tools – suggesting that when referrals are made, professionals should measure children's skills across multiple domains.
- ***Discriminant Validity.*** Findings from several different studies illustrate that: a) parents' concerns reflect problems in the same domain on in-depth, milestones-focused measures, b) Risk on *PEDS-R®* also served as an indicator of other DD/MEBDD risks; and c) there are unique performance patterns on *PEDS-R®* for various categories of disabilities (e.g., ASD, motor impairment, learning disabilities). Nevertheless, speech language impairment and mental health diagnoses shared the same pattern, confirming prior research: Children with ongoing language disorders are at greater risk of mental health problems.
- ***Predictive Validity/Predictive Sensitivity.*** Among children who eventually received a diagnosis and thus enrolled in IDEA/special education, prior screening with *PEDS-R®* revealed risk in 82%. *PEDS-R®* detected problems on average 21 months earlier than age at diagnosis.

Accuracy

- *PEDS-R®*'s sensitivity is high, 93%, as is specificity, 92%, especially when applying to Path B: Moderate DD risk results, additional predictors such as *M-CHAT-R* or *PEDS:DM®* (screener) results, minority status and child's age.

Utility

Readability. *PEDS-R®* questions were assessed for readability via different formulas. Response options were omitted because including these can falsely lower indices of reading difficulty/intelligibility:

- Flesch Reading Ease score: 88.2, i.e., easy to read
- Gunning Fog: 3.7, i.e. easy to read
- Flesch-Kincaid Grade Level: 2.9 (high second to early third grade level)
- The SMOG Index: 2.7 (high second to early third grade level)
- Automated Readability Index: 1.4, Grade level: 6-8 yrs. old (First and Second graders)
- Linsear Write Formula: 3rd Grade level

Administration Time. Answering questions on *PEDS-R®* takes an average of 2 minutes (range = 1 – 11 minutes). Parents with few or no concerns complete *PEDS-R®* in 1 – 3 minutes while parents with abundant concerns often require 9 – 11 minutes. If using the *PEDS® Online* Parent Portal, 0 minutes of professional time are needed.

Scoring Time. In print, *PEDS-R®* takes 2 minutes to score. With *PEDS® Online*, 0 minutes are required due to automated scoring.

Time Required to Write Referral Letters and Take-Home Parent Summaries. A scant minimum of 5 minutes is needed for each of these tasks when using *PEDS-R®* in print. With *PEDS® Online*, 0 minutes are needed because referral letters and parent summaries are automatically generated.

Material Costs.

- In print, *PEDS-R®* costs $1.04 per administration. Unlike past iterations of *PEDS®,* which had two separate pads of forms plus a separate booklet of directions, *PEDS-R®* combines all components into a single perforated fold-over protocol. Within are directions for administration, the *PEDS-R®* questions/space for parents' comments, *Score and Interpretation Form* [including how to incorporate findings from the *PEDS:DM®* (screener) and *M-CHAT-R*], and a *Current Findings* table for documentation of results and selection of recommendations.
- *PEDS® Online* costs $4.00 per administration and includes the *PEDS:DM®* and *M-CHAT-R* along with automation of scoring, results, referral letters and take-home parent summary report.

Reimbursement/Billing. *PEDS-R®* [as well as the *PEDS:DM®* (screener) and *M-CHAT-R*] are eligible for payment from Medicaid/private insurance via the 96110 code (multiplied by 3 if all measures are given). The average reimbursement per screen is $8.00, rendering a substantial profit margin for practices.

Integration with Electronic Records. *PEDS® Online* can be seamlessly and securely integrated with electronic records via an Application Programming Interface (API). Because sophisticated programming skills are needed, professionals wanting integration will need to prompt vendors at the national level to contact us: *Amy@pedstest.com*.

Other Benefits and Guidance

Impact/Stakeholder Uptake.

- Eliciting and addressing parents' concerns is an essential component of caring for children and their families. Prior studies show that parents much appreciate professional attention to their worries and thus are far more likely to keep future appointments.
- Professionals find that use of *PEDS-R®* reduces late-arising concerns. These disruptions leave no time for preparation or for gathering information handouts/brochures about referral resources. The time allotted for encounters is often exceeded, and this results in irritation to other families who must wait longer than expected.
- When parents' concerns are elicited, professionals find it easier to deliver difficult news because parents' worries can be confirmed thus providing motivation to seek intervention.

Compliance with Policy Recommendations.

The combination of *PEDS-R®*, *PEDS:DM®* (screener) and the *M-CHAT-R* offer evidence-based compliance with American Academy of Pediatrics' recommendations to: Elicit and address parents' concerns, measure milestones and periodically screen for autism spectrum disorder.

Compliance for Medicaid Patients.

The Centers for Medicare and Medicaid Services (CMS) requires evidence that billable screening tests were administered, scored, interpreted and appropriate action steps taken. To successfully survive a Medicaid audit:

- Print users can scan or print out the completed (front and back) for patient records. This shows parents' comments on the *PEDS-R® Response Form* and *Current Findings,* i.e., results and action steps.
- *PEDS® Online* users can paste or attach results to each patient's electronic record.

Translations.

PEDS-R® is printed in English and Spanish. *PEDS® Online* is offered in English, Spanish and Chinese. These and nearly 65 other translations have been thoroughly vetted and shown to work well. Translations are freely offered to *PEDS® Online* users and can be licensed by print users. Contact: *Translations@pedstestonline.com*.

COPYRIGHT

PEDS-R® is copyrighted. Just because you have acquired a copy of *PEDS-R®* does not mean you have the right to freely distribute it. It is illegal to photocopy blank protocols, imbed any elements of the *PEDS-R®* into other questionnaires, display on websites, or include in electronic records. Only completed forms may be scanned.

Training for *PEDS-R®* is also copyrighted and may not be recorded, reproduced, or shared.

The original *PEDS®* version is still under copyright and is not public domain. The same terms apply to the reproduction of the original *PEDS®* materials.

Copyright infringement is theft. Copyright infringement is taken seriously and will result in litigation. Infringement also starves future development of *PEDS® Tools*.

The *PEDS® Tools'* team who provide customer support, ship materials, facilitate translations, improve its website, create training, and write programming for *PEDS® Online*, are all parents with children to support. Copyright infringement hurts real people and their families. You can see who we are at at this *link*.

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No person shall, without the authority of the copyright owner or the law, intentionally remove or alter any copyright management information knowing, or, with respect to civil remedies under section 1203, having reasonable grounds to know, that it will induce, enable, facilitate, or conceal an infringement of any right under this title.

The damages for violating 17 U.S.C. § 1202 alone range from $2,500 to $25,000 per violation, in addition to any damages for copyright infringement.