



# **The BEST PRACTICES**

Newsletter  
Of

*The Interdisciplinary Council on  
Developmental & Learning Disorders*

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*The Best Practices Newsletter of the Interdisciplinary Council on Developmental and Learning Disorders is written to provide regional updates and networking opportunities to professionals and parents working with young children with communication and relating challenges. We hope to provide information and support and welcome any feedback or contributions that you may have. Please address your comments to Jo Raphael, MSW, Editor at: 3213 Midfield Road Baltimore, MD 21208, E-mail at [JO@ICDL.COM](mailto:JO@ICDL.COM), phone or fax at (410) 486-1251. Thank you.*

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## EDITORIAL NOTE

*Molly Romer Witten, Ph.D.*

Often parents ask us (clinicians) "at what age should my child be able to do \_\_\_\_\_". Recently when one of my close friends and colleague, who had a child with a regulatory disorder asked me this question, I became mystified. My first thought was 'he should know better than to ask this sort of question'. However, he was asking the question sincerely, so it was more than appropriate for me to answer the question asked, sincerely. I was uncomfortable with his question because since his child was also my friend, and I didn't see my friend or his child simplistically, I didn't understand why he would choose a simplistic view of his child's growth. I wanted to understand why he would pin his sense of his child's growth on such incomplete evidence as a developmental milestone.

When a professional talks about the DEVELOPMENTAL PROCESS for any child, the concept of 'developmental milestones' function as a sort of short hand, a snapshot of a child's capacities at any given moment in time. Milestones neither convey the richness of a child's growth, or the individual differences that occur in the course and sequence that most children's growth takes. Really, ALL development occurs within a child's most satisfying relationships. This principle is one of three core tenets of the DIR paradigm. Yet, out of our deep concern for a child's welfare, we, professionals as well as parents, ask anxiously about isolated milestones all the time: "This child walked/talked/jumped/potty-trained (you name it) at this age, is that normal?"

Developmental steps, stages, tasks and goals hold us accountable for our interventions, as well as the child's

growth in specific sensory, motor, cognitive, social or intrapsychic capacities. When parents speak in terms of this sort of accountability, or professionals speak with parents about their child in this sort of language, there is an insidious danger of equating milestone tracking to good-enough parenting as if it were also an 'intervention'.

Parenting requires relational availability, continuity, and empathy. Parenting does not require an academic knowledge of developmental milestones. □□ Whether a child has achieved a developmental task by a certain age is less important than if parents feel joyfully related with their child. Any parent will confirm what Clinical experience and research have informed us; namely that the child's most important and satisfying relationships are the least intrusive, most powerful vehicles for delivering interventions that support optimal developmental process. Development will happen if the relationship feels satisfying, if the parent is consistently available, and if there is an empathic appreciation for the child's experience and perspective.

Use of developmental milestones as a currency of conversation between parents and professionals issues from the anxiety and best hopes we all have for children. It seems to be a covert way of controlling our anxiety in our professional roles. However, developmental accountability is less important than continuity of relatedness and empathic responses in parenting. It is imperative that, as we acknowledge parents as authentic leaders in the intervention of their children, we also nurture their language for talking about



their child and not supplant it with our own professional shorthand.

As professionals, clinicians who see many children in our work, we need to track developmental milestones as a means of tracking our own effectiveness. Although we, as clinicians sometimes will ask parents about this or that individual capacity in their child's behavioral repertoire, the concept of developmental milestones remains our professional, technical, tool much like a carpenter uses a measuring stick or tape measure. We must be careful not to impose the anxiety of our dim awareness that we do not know the child as well as the parents do, by trotting out our descriptions of developmental stages and pushing the parents become precociously 'Professional'. Our desire to do our jobs well by continually reminding parents of the next developmental milestone or task that their child needs to attain, achieves neither best clinical practices, nor really helps parents focus on what can help their child the most. Human growth is not a speed-trial it is not a premeditated competition in a race, or a set of discrete growth objectives with 'empty waiting' in between the

accomplishments of developmental tasks. Human growth is a process involving satisfying, empathic, continuous, often joyful moments of relating. The other day I saw a tee shirt with the inscription "fun is free" written on it. On the back of it I wanted to print the addendum "so is your relationship with your child...priceless".

We can well afford a large degree of diversity and individual difference in developmental process if we, as parents teachers and other professionals value relatedness, empathy and the capacity to 'stick with' our job as whether as parents, as therapists, or as teachers, and desire to share with our children a sense of community. To the extent that we label, isolate, relegate, inculcate, and reduce our children to standardized expectations, we cope with our own anxiety and worry, at the risk of unwittingly supporting reduced complexity and increased disability for our children individually, and our human family globally. Without relatedness and empathy, we dismantle the potential for an interdependent, collaborative, enlarged sense of belonging and community so desperately needed right now in our world.

## Accessing Behavioral Health Treatment Services for children in Pennsylvania and elsewhere

*Steven A. Kossor*

*There are no obstacles, only hurdles of varying heights. None is so great that it cannot be overcome, gotten around or gone under. Even mountains disintegrate with time.*

Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services were created in the 1960's and expanded by the Congressional Omnibus Budget Reconciliation Act of 1989 (OBRA'89) to provide "necessary health care, diagnostic services, treatment, and other measures described in [the statute] to correct or ameliorate defects

*and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan."* 42 U.S.C. § 1369d(r) (5).

The U.S. Congress made this funding source available in **EVERY** state in the United States, in 1989. Pennsylvania



put its program into place in 1992, (but only after the federal oversight agencies threatened to cut-off HCFA funding if they did not create an implementation plan). The same threat was made to every state, and according to the Center for Medicaid Studies (CMS), the programs that I describe (including "TSS" services) in Pennsylvania are, in fact, possible in every state in the nation. NJ has just begun implementation. The program goes under different names in every state. When you read the Omnibus Budget Reconciliation Act of 1989 (see the reference I cite in the article), you'll see that it states that these services **MUST** be available to children if they are prescribed for them by a licensed practitioner **REGARDLESS** of whether or not the prescribed services are part of any "State Plan" for services to children. These services may be referred to as "wrap-around" services in other states. TSS services are provided by people with Bachelors degrees -- they do the most work, and achieve the greatest gains -- all under the supervision of Masters level clinicians. In my practice, licensed psychologists supervise the clinicians, and I'm exploring how to become eligible to deliver these services in NJ as well.

It seems that "everybody" does engage in some form of the "wrap-around" (or "EPSDT") services, but each state may do them in a different way. The federal law that made it come into existence definitely, positively, unequivocally allows "TSS" service to be forced into existence in every state in the USA.

Among the measures cited in the OBRA '89 legislation are *psychological outpatient services* and *behavioral habilitation and rehabilitation* services. If a child is has an "Axis I diagnosis" such as Autism or PDD via the most recent edition of the Diagnostic and Statistical

Manual of the American Psychiatric Association (DSM IV), and it can be shown that the child can benefit from behavioral habilitation or rehabilitation services, then that child is entitled to these services, even if the necessary services are not part of any "State plan." The OBRA '89 legislation created a legal *entitlement* to early and periodic diagnosis and treatment to any person under age 21 who has a "medical necessity" for such services. It is applicable throughout the United States and its territories.

In Pennsylvania, the "medical necessity" of EPSDT services is determined by a licensed psychologist or a licensed psychiatrist, based on a face-to-face evaluation of the child and an assessment of the child's strengths, weaknesses and needs. The "core principles" of the Child and Adolescent Services System Program (CASSP) are used to guide treatment: Services must be child centered, family focused, community based, culturally competent, least-restrictive, least intrusive and involve the collaboration between service systems (school, family, medical services, etc) – all working to address the needs of the child in a collaborative, cooperative effort to prevent long-term hospitalization, institutionalization, incarceration, psychiatric medical treatment, or other *highly* restrictive interventions.

In Pennsylvania, "Therapeutic Staff Support" (TSS) services were created as part of the OBRA '89 implementation of the EPSDT entitlement. The most qualified TSS providers have Bachelors degrees, and can deliver all sorts of intensive behavioral treatments including the Developmental, Individual difference, Relationship based (DIR) treatment model developed by Stanley Greenspan, and a wide variety of other



intensive behavioral treatment programs. All EPSDT services are delivered in the child's home or school, at no cost whatsoever to the child and family receiving the services, *regardless* of parental income.

In Pennsylvania, Mobile Therapy and Behavior Specialist Services are also available under the EPSDT entitlement. Through these services, a child and/or members of the child's family can receive psychological counseling, psychotherapy, behavioral counseling and assistance with the implementation of the child's treatment program in the home, a school or other community setting. *Any* adults who interact with the child can be brought into consultations with one or both of these professionals (a Masters degree is required to perform either Mobile Therapy or Behavior Specialist services), and the child's treatment program can be enhanced and expanded to include the child's school teacher and classroom, day care provider, church youth group, or any other community resource. Every state is responsible for implementing the OBRA '89 legislation in its own way, and no other state has implemented it with the vigor and scope that Pennsylvania has. In Pennsylvania, substantial assistance was obtained from the Robert Wood Johnson Foundation via a grant. Through this grant, the CASSP principles were used as the basis for developing the EPSDT system. Since 1992, the Departments of Public Welfare and Education in every state have collaborated to an unprecedented extent to create a system whereby EPSDT services could be delivered by school districts themselves!

Whether it is advisable or permissible in the context of compulsory education laws for school districts to also deliver Mental Health services to children, and bill Medicaid privately for

reimbursement, is a pointed question. Nevertheless, every school district in America is eligible to enroll as a Medicaid provider to deliver and bill for EPSDT services, along with licensed psychologists, community mental health centers, and other entities that are clearly more qualified to deliver mental health and behavioral treatment interventions to children. In 1989 it was projected that \$4 million to \$20 million dollars could be reimbursed to Pennsylvania via the Medicaid program, and the program has grown *terrifically* since then. In order to manage this huge financial responsibility, Pennsylvania's governor signed an Executive Order in 1996 mandating Managed Care for all recipients of EPSDT services. All states have managed the federal mandate for EPSDT services in one way or another, but access to funding for EPSDT *mental health and behavioral treatment* obviously cannot and should not be limited to *schools*. Licensed practitioners with appropriate training and experience should be able to prescribe necessary treatment, and supervise its delivery in every state, just as they are in Pennsylvania.

EPSDT services were recently re-named "Behavioral Health Rehabilitation" (BHR) Services in Pennsylvania. In Pennsylvania, applying for Medical Assistance benefits for a disabled child is easily accomplished by contacting the County Assistance Office to request an application for Medical Assistance benefits. By indicating on the Medical Assistance application that the application is for a "**disabled child only**" (by writing these three, exact words on the application cover) the OBRA '89 legislation makes it possible for the disabled child to receive BHR Services without any cost to the family whatsoever, *regardless* of the family's level of income. An application for Social



Security (SSI) benefits must be made, and if the family's level of income is above the minimum cut-off for SSI benefits, then the Medical Assistance benefits must be granted, if the child has a need for treatment for a mental disorder (in many cases, this can be easily diagnosed by the child's pediatrician based on the child's behavior in the doctor's office, or parental reports of the child's behavior at home or at school).

In Pennsylvania, for a short time (usually about 15 days) after a child becomes a recipient of Medical Assistance benefits, the child's case is not assigned to any Managed Care Organization (MCO) and BHR Services can be initiated without asking the permission of any MCO authority. If BHR Services are implemented in this brief window of time, the MCO is

required to continue to fund the delivery of those services for approximately four months. Any subsequent reauthorizations of services must be done in accordance with MCO policies and procedures, but national standards exist to guide treatment prescription practices (including the 2001 report of the *National Academy of Sciences* documenting that 25 hours of "intensive, individualized treatment" is the minimum amount of treatment necessary to realistically expect significant improvement in a child with an autistic spectrum disorder).

You will find additional information, including the exact citation in the Federal Register where the OBRA '89 legislation appears to create the EPSDT programs nationwide at my website: <http://www.ibc-pa.org>

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<p><b>Two Treat or Not</b> <i>Sherri Cawn, MA, CCC-SLP</i></p>
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When there is a concern about a child's development, it is well known that a speech pathologist is often the first call that a parent makes. It is at this very important initial consultation that knowledge of the child's sensory processing development will service the Speech and Language Pathologist's understanding of the child's vulnerabilities as well as what impact that they maybe having or will have on the child's communication .

Parents often express concern about "when their child will talk"; it is often hard to convince them of the importance of *process* and not *product*—which to a parent of a nonverbal child is a 'word'.

Those who are informed by the DIR® model understand that affect is biologically driven and lays the foundation for intentionality. It requires a skilled therapist to be able to impart reliable yet comforting information to parents about the developmental communication process, and that understanding the child's full developmental potential is a better predictor of his communication, than the production of words.

The 'I' (individual) in DIR® reminds us how important individual differences are in the developmental process: Often the examiner/therapist is called upon to explain why a child who is not able to



maintain regulation around sight, sound and movement in his environment, will not be ready to communicate. Our understanding of the biological process as it relates to the process of communication becomes a critical component of the therapeutic process.

The DIR® philosophy is steeped in research in infant and early childhood mental health, but in many ways it remains an art because of its emphasis on the child's unique profile. Each time you meet a family for the very first time you begin the process of understanding the child's exceptionality—within that understanding is the development of the art of 'floor time'

That said the DIR® model recognizes that the development of infants and young children is complex and requires an acknowledgement of the child's abilities within a functional context. The occupational therapist is a key player in helping to assess the sensory characteristics of the child that are interfering with their ability to interact with significant others; interact with the environment; and understand the child's neurobehavioral state (Long p, 207, 2002).

Relying on information from Anzalone & Williamson (2002) and DeGangi (2000), regulation for some of the children we work with may be characterized by a lower threshold for physiological and emotional reactivity which may in turn cause a child to be over-reactive; this can take the form of anxiety, agitation and a limited ability to be "present" for learning. Children who are under-reactive may also demonstrate characteristics of self absorption, lethargy, passivity and a similar pattern of not being 'present' for social experiences. Without the ability to maintain regulation, it will be difficult to connect the sound to its meaning,

especially if the child has a hypersensitivity to sound at certain high frequencies (speech happens at the higher frequencies 2000-4000HZ).

During the pre-intentional and intentional stages of language development (Gerber/Prizant, 2000) children not only respond to sound but can develop the ability to localize sounds close to them (proximally) and father away from them, at a distance (distally). This requires an intact neurological system to help move that sound (starting at the cerebellum, which is rich with auditory neurological fibers) along the appropriate auditory pathways to be discriminated, recognized and interpreted. More importantly, the child has to be able to be regulated, attentive and "present" in the context so he can attach affect to the meaning of the sound. That, of course, will become more differentiated as the developmental process occurs, but even more importantly it sets the foundation for joint attention.

Emotional regulation is a core process underlying attention and social engagement (Prizant, Wetherby, Rubin, 2003). Without our ability to maintain regulation, communication is at risk. Think about an infant who has challenges in maintaining self-regulation around auditory stimuli (as so many of our children have hypersensitivity to auditory input): Imagine how difficult it will be to set the groundwork for early communicative functions if you can't be soothed by the sound of the human voice. The OT's role in this early developmental treatment is critical for the child: their expertise guides the rest of the team's understanding of the child's sensory processing development.

As Speech and Language Pathologists we need to understand the child's self regulatory patterns *before* we think



about working on developmental communication goals, including the kind of mutual regulation that sets the foundation for joint attention. The importance of motor planning and imitation for children with developmental challenges has been well documented, and an understanding of its components and the profound effect it has on a child's rhythmicity and timing—which in turn effects communication—cannot be emphasized enough.

To understand how motor planning effects communication, think about an important nonverbal gestural marker such as pointing—this ability not only requires motor planning, but intentionality. This doesn't happen alone; it is one part of an integrative process that takes into account the child's affect, the amount of effort the child can commit, and the ability of that child to understand and share jointly with a significant other what their desire is. If there are challenges with motor planning or visual spatial processing, the end product of pointing will be challenged because the goal to get there can't be accomplished. Without an understanding of the body piece, and the child's ability to integrate intention with action, the goals of a treatment session may be lost. (Dr. Greenspan eloquently explains his affect diatheses model in the *Journal of Developmental and Learning Disorders*, Vol.5, Number 1, 2001).

The OT understands the concept of motor planning as it relates to learning and other adaptive behaviors; however, they need SLPs to make the "language connection", to bring the communication process into the bigger picture. An understanding of a child's motor system helps planning and the development of communication goals (affect cueing, non-verbal gestures, verbal organization, developmental

apraxia of speech), particularly social communication.

Although SLPs are trained extensively in anatomy and physiology of both the speech and hearing mechanism, they do not get extensive training in how the vestibular and the auditory system work together to set the foundations for language. These two sensory systems share the same home and are innervated by the same cranial nerve: The vestibular system processes big movement of sounds, directionality, balance; the auditory system processes small movement of sound, i.e. speech. The vestibular and auditory systems are intact at birth—the millions of auditory connections in the cerebellum allow the young baby lots of opportunities to be stimulated by sound from birth on.

Thus, a little seen connection develops: If a child has gravitational insecurity, the amount of effort a child uses to compensate for a lack of balance uses up some of his ability to engage in a higher order processes like speech. We see such an example in the baby that doesn't turn when he hears the phone ring, or falls over in response to a loud noise or quick movement. What will happen to that intent? The signal could be diminished because of the baby's inability to sustain regulation; because a biological vulnerability (such as arousal, auditory processing, timing and rhythmicity) was diminished, the moment of connection is fleeting or lost. In order to be able to use words as symbols of their ideas, infants need to have perfected the suck-swallow-breathe rhythm and maintain postural control and air flow to begin the process of differentiating speech sounds. The young child's ability to co-ordinate and time this pattern can be very important in their later development.



Co-treating with an OT is useful in such instances because maintenance and development of postural control fall under the radar screen of OT and the sound system falls under the developmental domain of the speech pathologist.

Recently, I was on an out-of-state consultation with my favorite OT; we were doing group supervision around a case and discussing affect cueing. Each of us took a turn in discussing how we saw the affective system within our discipline. Then my favorite OT said that although speech and OT can sometimes look very similar during the early stages of Floortime, what separates us is the expected response of the child. She went on to explain to our group that while she was invested in the affective/action of the signal, she also wanted to be able to create the opportunity to help that signal happen again; likewise, as an SLP, I respond to the signal (non-verbally), woo the signal, and tempt the environment all the while waiting for a reaction to the affect.

I could go on with example after example of the importance of co-treatment between the SLP and OT, but the critical piece to remember is that the ability of two disciplines, dependent upon each other's depth and breath of knowledge about the child's individual differences, supports the DIR® model in the best possible way. It lays the foundation for parents in their understanding of dynamic systems, in team work, and in understanding individual differences, as well as supporting the child's development in co-regulated affective reciprocity as they make their way through the six developmental stages.

In closing, I'd like to share a personal moment with you. Several weeks ago I had a visitor to my clinic from Mississippi who was interested in seeing

how the DIR® model informs my work. Since I wasn't seeing clients in my office, I drove this colleague down to Beth Osten's Occupational Therapy Clinic where one of the speech therapists from my office co-treats—this way the guest could watch a co-treatment of speech and OT, and I could monitor what she was seeing.

As we were observing, Beth (OT) came in to work with a five year old boy and Gwen (the SLP from my office) was treating a three year old boy with another OT, as well as the dad. From across the room, I noticed that the younger of the two children was signaling in a subtle way (eye gaze shifting downward into the ball pit) and no one had picked up on it. I went over to whisper to Beth on what I had noticed; we seamlessly began to treat together. What started out as two children receiving OT and speech in a large gym turned into a rich interaction involving a parent, an OT and an SLP.

What was amazing about what happened was how the mutual regulation was maintained, such that both children—although at different levels—were able to maintain affective reciprocity. You could've heard a pin drop: The room was charged with energy, rich interactions and floor time at its best. The rest of the professional all knew something quite exciting was happening and before we knew it the room was filled with OTs—and yet the "interactions" continued. We were in the "groove".

Occupational therapy and Speech pathology—they are the science that helps define the art of the DIR® model. So the next time you're at your clinic, school, or office, go in and say to your favorite OT or speech therapist, "Hey you wanna co-treat today?" Then see what happens.....



## A Sister's Reflections

*This was written as a college essay by the sister of one of our kids.*

My brother just dropped by for a visit. Deeming the moment right, he quit his in-depth perusal of the newest Lego Magazine to visit me in my basement sanctuary and apologize for giving me a cold. Pleasantries dispensed with, he plunged into the topic he really wanted to discuss—whether or not I was still working at the lab. Upon receiving my negative response, he replied that at least I'm not a waitress. Immediately launching into a detailed description of what the job entails, he balanced imaginary trays over his head. Laughing as he pretended to slip and drop his full trays, I abandoned my calculus homework for the entertainment my brother was providing in an attempt to cheer me up. With a wry smile twisting his lips and mischievous delight gleaming in his hazel eyes, he chuckled the imaginary trays at an intransigent customer, bowed, and sidled out of the room.

He was born on March 20, 1991, the night of my Elementary School Annual Musical Presentation for Parents, in which my second grade class, decked out in pajamas and grasping flashlights in sweaty palms for the surprise ending, performed a rendition of "Mr. Sandman." Had anyone else been responsible for causing my mother to miss this momentous occasion, I would have had his or her head on a silver platter, but I don't remember feeling any resentment towards the writhing, bald, blanket-wrapped bundle that immediately grabbed a lock of my hair as I bent over the hospital crib. Eight days later, family and friends gathered in our house for the Brit, and I, knowing full well what a circumcision entailed, hid in my room with my sister as my brother was officially named. Time flew forward and the little bald bundle grew some blond

fuzz, astonishing my brunette family, until my father reminded us that he had been blond as a baby.

Two and a half years later, our idyllic world came crashing down when my baby brother was diagnosed with Pervasive Developmental Disorder (PDD). While he was struggling with occupational, play, and speech therapy, I was grappling with what I perceived at the time to be a dark splotch on our family's average middle class American family image, an abnormality to be kept secret. Accepting the challenge of living with someone with PDD is difficult, but for a ten year old whose classmates regularly made retard jokes, the blow was particularly fierce. For months, I stifled my emotions, as not to trouble my parents further, confiding my feelings only in my diaries and crying in secret. One day I overheard my father telling his sister about my brother's recent progress. Furious, I fled back to my room and poured hostilities into my diary. How dare he tell someone else our secret? This was the brand of Cain, in my eyes. This was something to be dealt with and solved in secret. It didn't mean that I loved my brother any less, but I was terrified of what other people would think of him, of me, of my family if they ever found out.

As my brother progressed, so did I. Slowly and painfully I grew to accept his unique and wonderful qualities. I learned to be proud of his achievements; some of the most satisfying moments of my life were receiving letters from my parents while in summer camp, telling me that he had learned to brush his teeth, or tie his shoes. My parents infused their hope into our family, allowing us to heal and



to work as a family to get our brother back. The experience strengthened us as individuals and forged a family unit, weathered by the journey and enriched in the process.

I remember waking up early on weekends and falling back asleep in the doorway of my brother's room, so he'd have to wake me up instead of waking up my parents. Then we'd sneak down to the kitchen and cook pancakes, and my parents would wake up at 7:30 feeling that they had slept in. One of my favorite memories is of all of us dancing around the living room to "Van Morrison's Greatest Hits" and singing at the top of our lungs on Saturday mornings. Our living room has huge windows and anybody could have seen us, but none of us cared.

My brother is nine years old now, with startling intelligence and perceptiveness for someone his age—recently over breakfast he had me explain the concept of the first, second, and third dimensions, and then told me that the fourth dimension is time. He seems to have inherited my father's sense of humor, but whether that is a gift or not, I have yet to figure out. Resulting from hours of running around and jumping on the trampoline, muscles bulge out of his legs and I would loathe getting into a physical fight with him. And he has an evil laugh to rival that of Cruella DeVille and other famous bad guys. My brother is destined for greatness, but sometimes I look back and wish that we still danced on Saturday mornings after pancakes.

**WEB-BASED RADIO SHOW**  
**WITH**  
**STANLEY I. GREENSPAN, M.D.**  
**TUNE IN THURSDAYS FROM 10:30 TO 11:30 a.m. EST**

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A new call in, web-based radio show with Stanley I. Greenspan, M.D., featuring discussions and answers to questions on infants and children with special needs and learning disabilities as well as on facilitating development in all children (those with and without special challenges). The broadcast will include in-depth discussions of critical topics such as language, intelligence, peer relationships, and handling aggression.

Periodic video illustrations will be provided.

Listen as Dr. Greenspan interviews colleagues on new discoveries and programs and offers practical advice for parents and clinicians.

Tune in live to each broadcast or view archived shows at: [www.floortime.org](http://www.floortime.org).



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