

The BEST PRACTICES

Newsletter
Of

*The Interdisciplinary Council on
Developmental & Learning Disorders*

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SPECIAL EDITION: PART TWO

Summary of ICDL Fifth International Conference
November 9, 10, 11, 2001

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The Best Practices Newsletter of the Interdisciplinary Council on Developmental and Learning Disorders, sponsored by the Unicorn Children's Foundation, 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, phone or fax at (410) 486-1251. *Thank you.*

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Editor's Note

Jo Raphael, MSW
Molly Romer Witten, Ph. D.

As promised, here is our second newsletter for this membership year which contains summaries of the second part of the Fifth International Conference of the Interdisciplinary Council on Developmental and Learning Disorders. The conference covered a broad spectrum of topics pertinent to working with children with severe disorders of relating and communicating. This edition contains summaries from the following presentations:

Early Detection and Early Intervention
Making Educational Interventions Work When They Haven't in the Past

These panels were exceptional as speakers included T. Berry Brazelton, MD, Joshua Sparrow, MD, Phillip Teitelbaum, Ph. D., Osnat Teitelbaum, Stanley Greenspan, MD, Stuart Shanker, D. Phil., Serena Wieder, Ph.D., Barbara Kalmanson, Ph.D., Deborah Flaschen, Susan Norwell, MA, Monica Osgood, Christine Seminario, M.Ed., Sandra Taenzer, MS.

In April many of us attended the Infancy and Early Childhood workshop where ICDL sponsored a Parent Networking Reception. Over 200 parents came to this impromptu get together to share information about their children and their regional resources-or lack thereof. As the ICDL moves forward with its training and certificate programs we hope to create a venue for parents and professionals to be able to meet regionally to share information and create support networks.

Many people talked with us about the new and innovative things that are happening in their region. If you have started a regional group or would like help in starting one please contact Jo at: jo@icdl.com.

We are looking forward to the next newsletter where we will return to our regular features including updates from regional networks, the parent network, clinical insights, medical updates, biomedical updates and education.

Please write to us to post information, to submit an article for consideration or to share your thoughts.

You can reach us by e-mail at (Molly) besobeso@enteract.com or (Jo) jo@icdl.com.

Best regards,

Jo and Molly

Early Detection and Early Intervention: Red Flags in the First Year and What to Do About Them

What Infants Tell Us:

How to Assess Risks and Strengths to Harness Potential and Mobilize Growth and A Framework for Identifying Individual Differences in Infancy

Presenters: T. Berry Brazelton, M.D. and Joshua Sparrow, M.D.

Dr. Brazelton began by providing an historical context for understanding how the Touchpoints™ model evolved. He observed that “what I went through in the fifties was that both pediatrics and psychiatry was a pathologically driven model.” When Dr. Brazelton talked with parents he experienced a conflict between what he knew and was trained to talk about (pathology) and what the parents of each of his little patients wanted him to talk about (the baby’s strengths). He stated that he and others attempted to resolve this conflict by devising principles of development that would help parents see their newborns as competent babies.

Dr. Brazelton designed the Neonatal Behavioral Assessment Scale (NBAS) as an attempt to create categories of competence that parents could easily identify and observe themselves. He wanted to create a way for looking at the neonate’s best performance. What the NBAS provides is not a ‘score’, but a way of looking at the baby as an individual with definite strengths and vulnerabilities. He stated that what is most important is to help parents understand what their baby can do. He believes that after the parents can readily accept their baby’s strengths, they can more readily accept their baby’s individual differences; that may impede developmental progress, or derail development altogether. The NBAS allows parents to perceive their baby coherently. Along the way, as Dr. Brazelton’s research was documenting the range of newborn behavior, he organized his perception of indicators of fragile babies. Altogether these indicators of developmental process constitute the Touchpoints™ of development during the first three years of life.

One behavioral marker that Dr. Brazelton uncovered was the baby’s capacity to habituate to both external and internal stimulation. He explained that there are three forces involved: the emotional life; the environment; and the neurodevelopmental biological forces provided by the baby’s physiological individual differences. Dr. Brazelton stated that the forces that drive development occur within the internal feedback system and that this plays a central role in the emotional life of the infant. He observed that fragile babies shut out too much stimulation because the stimulation overwhelmed them. The cost to the baby of shutting out stimulation was that he/she became dysregulated. Dr. Brazelton found that the baby was working very hard to keep the environment from overloading a hyper-sensitive nervous system.

Using video tapes of premature infants under four months of age, Drs. Brazelton and Sparrow illustrated how we can help ourselves and parents think about each infant’s abilities. They described some strategies that can help professionals support the parents to build on those abilities, as well as alert the parents to specific sources of vulnerability that their baby expresses during dyadic interactions. They emphasized these important points:

- 1) Development is a process, not a goal.
- 2) It is important that there be ‘negative’ experiences in life, as well as ‘positive’ experiences. Rather than perceiving a baby as ‘regressing’, we can reconceptualize ‘negative’ behaviors as part of the larger developmental process. Just looking at discreet behaviors without having the larger developmental context prevents us from finding the inherent developmental logic

in the baby's behavior. Behavior that seems to be regressive may tell us about a baby's unmet need. 'Negative' behaviors can also serve as a signal that the baby is getting ready to make a developmental shift. Finally, behaviors that we perceive as 'negative', because they make us engage more with the baby, or engage in a different way with the baby, may not be experienced by the baby as negative.

Both speakers emphasized and illustrated the Touchpoints™ model of assessing the developmental process that respects individual differences for each infant, and each family. As Dr. Sparrow explained, "Touchpoints™ is a relational framework for joining families as professionals. It is a paradigm shift from looking at negatives to looking at positives, abandoning prescriptive practices and embracing a collaborative approach of empathic involvement. It's about embracing a full range of human experiences, rather than viewing them as hierarchical.

Here is a set of attitudes to check in with when you are 'stuck' as a professional. Professionals may also find that these attitudes assist them in reflecting on their reactions to challenging clinical situations:

- Use the behavior of the child as your language for communicating with parents about their children. As you attempt to help the parents understand their child, use

language that the parents themselves use to describe their child.

- Go beyond traditional professional roles, without creating boundary violations. When you are crossing a boundary to make yourself less powerful and parents more powerful, it is probably ok. When you cross an interpersonal boundary in order to assume more authority, then you may need to stop yourself.

- Stop thinking in terms of the dichotomies of negative and positive. Regression can be a positive, not just a negative, and understood as an inherent part of our development. Also, within relationships, we have to value our mistakes as an opportunity for learning, and as guideposts for our own development. By embracing our own developmental cycles and struggles, we will be open to the same in the babies and families that we hope to serve."

Dr. Brazelton ended with these lovely remarks: "If one modality is knocked out, it is most certainly the case that the others are hypersensitive. From the newborn baby is the future of the world. A mother should hold the baby close so that the baby knows that the world is his. The father should take it to the highest peak to show it how wide the world is. That it is his."

Molly Romer Witten, Ph. D.
Clinical Psychologist
Chicago, Illinois

Red flags in the First Year

Presenters: Osnat Teitelbaum & Philip Teitelbaum, Ph.D.

This talk explored an early identification strategy for autism based on motor patterns common to children later diagnosed as having autism. Dr. and Mrs. Teitelbaum invited us to consider motor capacities as the first site for individual differences for babies later diagnosed with autism spectrum disorders. They emphasized that no single motor behavior can serve as an indicator of a condition definitively or predictively. They used videotape to illustrate how we can observe a pattern of developmental

individual differences in motor functioning in the following milestones:

1. Rolling over: There is a movement pattern characteristic of this group of infants that identifies their developmental as different from typical development. There is inadequate rotation of their torso in relationship to their head.
2. Sitting: At six months children later identified as having an autism

spectrum disorder demonstrated instability when sitting and reaching, unlike babies developing typically. The protective reflexes seem to be absent and the baby may fall over without a righting or self protective response when trying to reach from a sitting position. A baby with these motor patterns doesn't protect his head in falling over, and doesn't bring the body to midline when trying to sit up.

3. Crawling: In the baby later diagnosed as having an autism spectrum disorder, there is an asymmetry in crawling. There is persistent asymmetry throughout development from crawling to walking, to running. At the milestone of crawling, the asymmetry takes the form of an unusual crawling pattern in which the baby crawls with on one knee, but puts his foot on the floor with the other leg, rather than using the other knee.
4. Walking: In children who were later identified as having an autism spectrum disorder, weight shifting is also atypical. For these children the arms are horizontal, and the baby does not roll his foot. It looks like a goose walk. The position of the arms is infantile and asymmetrical.
5. Children later diagnosed with autism spectrum disorders show problems getting up from chairs because of

the collection of motor issues that accumulate before the stage of getting up from chairs independently.

Two things to look for in the motor capacities of children at risk for autism spectrum disorders are:

- 1) Reflexes such as infantile reflexes that last too long, (e.g. tonic neck reflex) or 2) Reflexes that don't come in when they should. (e.g. lack of protective response).

They hypothesized that there is a defect in the functioning of the vestibular system at the core in autism spectrum disorders. Using the motor patterns and development of motor milestones in children later identified as having autism, they described a screening tool based on their hypothesis of vestibular involvement in autism. For some babies later identified as having autism, the head stays in line with the midline of the body, rather than righting to a vertical plane, when the baby is held in a horizontal position. Head verticalization is normal at 6-8 month in typically developing babies. In infants with autism, there is no head verticalization. They hypothesized that this individual difference in head verticalization may be a useful diagnostic indicator for pediatricians to use in screening the child in a family with a history of autism. They stated that they believed that pediatricians could detect a subgroup of autistic children using the head tilting reaction.

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Clinical Psychologist
Chicago, Illinois

New Affective and Perceptual Motor Indicators of Autistic Spectrum Phenomenon in the First Year and Related Early Intervention Strategies

Presenters: Stanley I. Greenspan, M.D. and Stuart Shanker, D. Phil.

Dr. Greenspan began this presentation by explaining that while his co-panelists laid the foundation for work in individual differences and in the motor system, tilting and difficulty with coordination, he and Stuart Shanker would discuss the affect system. "Imagine what would happen if we could identify infants vulnerable to a wide range of neurological differences early on before their

behaviors became stable patterns of relating to the world."

Dr. Greenspan explained that in their research they had two questions they wanted to explore:

- What are the indicators of autism early in infancy that we can identify so that we can find the children at risk as early as possible?

- What is the right way to intervene on behalf of the development of these children?

They then focused on three possible indicators that build on the concepts of the DIR model.

1. Reciprocity, back and forth signaling
2. Affective and Motor Rhythm between the baby and the caregiver.
3. Facial expressions of affect

Dr. Greenspan provided background theory explaining that there is a school of thought that posits that facial expression and affect are stereotypical behaviors that have evolutionary origins and are primitive and rigidly organized at best. What they have learned through their research calls that theory into question. Drs. Greenspan and Shanker are trying to develop measuring tools within the context of a dynamic systems theory of interaction. A dynamic systems theory places the focus on the dyad, rather than only looking at the child's behaviors out of context. It focuses on the child's interactive behaviors within the context of co-regulated behaviors with the parents or other caregivers and they are trying to develop the same sort of measurement in dyadic rhythmicity and facial expression.

Rhythmicity involves a timed interaction between the partners of the dyad. At the University of Utah, Alan Fogel showed how an infant's facial expressions of emotion are fleeting and change in response to equally swift reactions on her mother's part, and how it is out of this fast-paced interactional matrix that more stable, recognizable expressions develop. The mother's facial expressions significantly influence the development of the baby's development of the facial expressions for the same emotions. This indicates that they are not genetically predetermined phenomenon or hardwired. In their research Drs. Greenspan and Shanker are looking at specific characteristics of facial expression:

- Complexity: Is there more than one element of the emotion in the child's facial expression of the emotion.
- Detail: How much of the face is active? They have mapped the face into four regions. How many regions are involved in a given facial expression?
- Symmetry: Does the facial expression occur across the whole face or in an isolated way on only one half of the face?
- Duration: How long does the expression last?
- Transitions: Does the child go from one expression to the next gradually, or does the child go from one expression to the next in a discontinuous manner, like an on and off switch?

When they observed the facial expression of children identified as having autism spectrum disorders, they discovered that the children showed mostly flat affect. There was no responsiveness to the caregiver's facial expressions of affect. Another characteristic difference for children identified as having an autism spectrum disorder was that the appearance of these facial expressions (e.g. smiling) occurred with a quality of an abrupt transition. Imagine, for children later identified as having autism spectrum disorders, their parent doesn't get the warning signals that parents usually use to monitor the baby's mood. Asymmetry was also observed: the children smile on only one side of their faces. There is no movement in the upper part of the face, but in the nose on down. The smiles are short, they go on and off unpredictably, and the intensity is low.

For dyads with typically developing infants, there is a nice rhythm going in at least two modalities, and there are no gaps in the chart of coding the caregiver and baby. Every caregiver initiated behavior evokes a contingent response. Even when they got the rhythmicity going, the facial expressions did not pick up in children with autism spectrum disorders. The child can be totally engaged, and attending to the caregiver, but even though engaged, and seeming to be enjoying the interaction, they got low scores, blanks, and poor rhythmicity. This led them

to see that the facial expression of emotion in children with autism spectrum disorders can be marked by five deficits: Low intensity, low detail, sudden on-off transitions, asymmetry of facial expression and lack of rhythmicity between the parent's facial expression of emotion and the baby's.

This was done by using Robert Ekman's coding system. Ekman studied what are known as 'Duchenne' smiles and recorded what parts of the face moved. In big smiles there are 4 areas of the face highly engaged. The four areas of the face are: 1) the area around the eyes, 2) upper cheeks 3) the mouth opening and lips parting and 4) the jaw dropping. Greenspan and Shanker looked for a noticeable deficit in at least three of the measures: i.e. low reciprocity, low intensity, little detail, sudden on-off transitions, and asymmetry of facial expression. It is the cluster of factors that give a potent warning sign.

In the second part of their research, they applied this coding system by looking at children over time, through longitudinal studies. Persistence of these traits is seen using a dynamic approach, when these children haven't had DIR intervention. In the old theory, since emotions were considered hardwired, if the affective processes were broken this couldn't get fixed. However, Drs. Greenspan and Shanker showed videotapes of children after intervention with DIR. The

tape showed a transformation in facial expression, rhythmicity, intensity, and with an asymmetry persisting. The depth of facial expression of affect *can* be affected and this is considered impossible according to theory of hard-wired emotions. What they are seeing is that the affective system is flexible in response to the environment. If you work with the child without working with the affect system the child becomes less able to access affective expression. Some children do okay with structured approaches if it is part of a larger program in which you get affective practice. The precursor systems to the full fledged symptoms have to do with reciprocity, asymmetry, facial expressions of affect, that don't develop into reciprocal development.

The essential thing is that the children with autism spectrum disorders initially show some responsivity, and they can be cuddly and interactive around 10-12 months. By 15-16 months however, there is a lack of social problem solving because they don't have multiple affective relationships, and they are lost in events with their peers. So loss builds upon loss of affective tone and range. This loss phenomena continues as the children can't handle complex social environments.

Molly Romer Witten, Ph. D.
Clinical Psychologist
Chicago, Illinois

Making Educational Interventions Work When they Haven't in the Past

Dr. Serena Wieder opened the educational intervention program Sunday morning citing the results of a study conducted by the Academy of Educational Sciences. She highlighted some recommendations that the Academy supported in determining what "best programs" for children incorporated. They were: 1:1 educational programs and incorporating a broad range of capabilities.

Furthermore, the study stated that there is no definitive evidence that any one approach is better. Finally we only help about one third of our children so we need to

work on conceptualizing what the current research is telling us.

Dr. Wieder went on to discuss four direct education programs that incorporate the DIR model. Two of the programs are funded by the public education system (Celebrate the Children, New Jersey and School District 54, Schaumburg, Ill.). The third model is a hybrid program where children's needs are met individually and then they attend public school. Finally, there is a private school (Barbara Kalmanson, Ph.D., San Francisco, California) which is a parent-initiated model.

Essential features of these educational programs were highlighted:

1. The programs were designed for children rather than fitting a child in the program.
2. Comprehensive-A full range of services are included, i.e.: inclusion, social groups, speech, OT.
3. Teachers are trained across all learning contexts.
4. Training and mentoring is an ongoing process.
5. Includes peer role models for play and thinking.
6. Program has built in adaptability and flexibility as the child changes.
7. Programs include parents as part of the educational process.
8. Programs are not designed on the basis of a diagnosis.
9. Programs embrace the law.

Dr. Wieder went on to share the important processes of learning:

1. Affect is central to all learning. It allows children to find meaning and become symbolic
2. A continuous flow of interactions allows the child to become

3. intentional and capable of generalizing and abstracting. Process is more important than content.
4. Long periods of spontaneous floortime get children to think and problem solve.
5. Children have to bring different processing skills across all modalities.
6. Children must apply thinking to multiple contexts.
7. Children must be challenged to reach the higher levels of symbolic thinking.
8. Activities must be flexible and experience based so learning will be dynamic.
9. Work must be done at the child's developmental level. Don't skip over basic foundations.
10. Group activities should meet the needs of children at different levels.
11. Relationships and pleasurable interactions are essential for learning.

After the core components were described, Dr. Wieder introduced the four educational programs.

Sherri Cawn, MS.SLP-CCC
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ACCORD

Christine Seminaro and Sandy Taenzer presented experiences; and was both interdisciplinary and ACCORD, a program developed for the public interdisciplinary. Ms. Seminaro and Ms. Taenzer school system in Schaumburg, Illinois, a middle shared that a long vision (3-7 years) was necessary, class community. ACCORD (Affect, Connecting, as well as flexibility, creativity, providing supporting Communication, Organization, Relationships, and data, and a willingness to scout out funding from a Development) serves 200 pre-school children, variety of resources. Each of the program including 20-25 children with ASD. They classrooms includes sixteen children ages 3-5 who emphasized that the majority of families in their are enrolled 10 hours per week in an integrated community were unable to afford private services. setting (typically developing children, children at risk, Their goal was to organize all of the community and children with challenges). Related services are resources available (including the library, park provided, as well as 2-15 hours a week of additional district, and volunteers) so that the program services, including parent-child sessions teaching reflected the ICDL clinical practice guidelines; the DIR model. Staff development is provided on a provided family focused-parent involvement, regular basis and team meetings are held weekly. education and support; gave the children authentic

CELEBRATE THE CHILDREN

Monica Osgood was asked by the Mt. Arlington, focus is present, the child can be engaged in an New Jersey public school system to develop a interaction, which leads to thinking, and program for children ages 3-10 who have a broad subsequently to learning. The goal for all children is spectrum of challenges. Celebrate the Children independence. This progression can be seen as a includes a pre-school disabilities classroom, a social long term goal, but may be repeated throughout the skills/sensory room, full inclusion, and mainstream child's day as he/she is confronted with the structure support for children in grades K - 3. Related of the classroom and the challenges that structure services and Individualized home programs are presents. Ms. Osgood also discussed the available. A six week summer camp open to all importance of looking honestly at the pace and children ages 3-15, which focuses mainly on social structure of the mainstream classroom prior to skills, is also offered. Ms. Osgood discussed a including a child who has challenges. Sometimes a progression she finds important to keep in mind self-contained program for children with learning when working with children who present behavioral disabilities, or another small program can bridge the challenges. Instead of seeing "behavior" as a cause transition from the pre-school program to the that stands by itself, she looks at a child's behavior mainstream classroom. She also emphasized that a and asks "What are the developmental weaknesses child may need individual intervention on a flexible responsible for the behavior?" She then uses the basis when participating in a mainstream class so as DIR model to effect change. Regulation needs to be to maintain regulation and self-esteem. established before focus is to be expected. When

HYBRID-HOME + SCHOOL

Deborah Flaschen and Susan Norwell, educational Deborah assigned numerical values to these, and consultant, developed a "Hybrid Program" to meet subsequently kept some segments and discarded Ms. Flaschen's son's needs. D.J. Flaschen is another. They then collaborated with their school exuberant child who thrives within a relationship. He district to identify key needs and goals. The result is resilient and creative, with a strong visual memory, was a program in which D.J. was home schooled for motor skills, and a great sense of humor. He is also academic, motor and sensory needs, and dynamic challenged by dys-regulation, auditory processing cognitive work for 3 1/2 hours. He also attended a difficulties, motor planning and sequencing mainstream classroom for 2 hours a day with a 1:1 difficulties, and by difficulties in word retrieval, which aide, which focused on social relationships, can make group social experiences challenging. maintaining regulation within a group, receptive D.J.'s development is also uneven, so that teaching conceptual language, and expressive, social him at one level does not meet his needs. communication. While there was skepticism on the Historically D.J. participated in a variety of program part of the school that this could work, by using the "models". At the end of first grade it was clear to the school curriculum content as a basis for home Flaschen's that they were trying to fit D.J. into a schooling and by having weekly planning meetings, program, rather than developing a program to fit D.J. D.J. made significant growth, including seeing Following Dr. Greenspan's suggestion, they looked himself as a learner. Now in the second year of the at D.J.'s program in 1/2 hour segments, and program, the team has revised approaches that did evaluated each segment using these criteria: 1) How not work and D.J. participates in a typical 3rd grade much pleasure was he deriving?; 2) How much classroom, 3 hours a day, with a 1:1 aide. Ms. social interaction?, Back and forth?, Sharing of Flaschen and Ms Norwell emphasized that this ideas?; 3) How much abstract thinking is promoted?; approach is a continual "work in progress". and 4) How much content is being promoted?.

THE OAK HILL SCHOOL

In the last presentation, Barbara Kalmanson presented Seven Domains of Functioning which "make and shape" the decision for full inclusion of a child with developmental challenges.

1) Can the child keep pace with the academic program either independently or with minor modifications and support?

2) Can the child regulate attention and modulate arousal states to sustain focus and concentration in a classroom setting?

3) Can the child initiate and sustain social contact with peers independently or with minimal adult support?

4) Can the child make transitions on demand?

5) Does the child have enough flexibility to cooperate with unpredicted changes in routine?

6) Can the child process information at the speed, difficulty level and with the amount of repetition presented in class?

7) Can the child navigate around the school facility independently?

Dr. Kalmanson described these domains and presented a variety of methods for facilitating success or modifying the demands or environment to meet the needs of the child. Critical to any inclusion program is the school personnel's willingness to meet each child's needs.

For some children, a full inclusion environment is not the intervention of choice. Dr. Kalmanson presented a model DIR school, Oak Hill, located in Marin County, California. This school was established by a group of parents to meet the needs of their children. These children were losing ground academically, they were overwhelmed in the typical classroom, and

felt chronically socially disconnected at the schools they had previously attended. Oak Hill follows a DIR model of relationship-based education. Students participate in individualized academics through semi-structured problem solving activities; sensory, motor and visual-spatial activities; and spontaneous play activities including floortime, music and drama therapy. Oak Hill offers an afterschool program in which day students play and interact in organized science, sensory-motor, art, drama and social activities with students from the broader community who attend the afterschool. In this way, inclusion experiences are taught and paced by professionals who understand the special developmental needs of the students.

Each of these programs emphasized the need for recognizing and honoring individual differences, for teaching through a relationship based approach, and for working within a developmental framework that avoided splinter skills and rote learning. All of the presenters acknowledged both the initial and continued efforts needed in order to do this. As parents and professionals we must be willing to both think outside of the box, and to act upon our thoughts.

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