

# **The BEST PRACTICES**

Newsletter  
Of

*The Interdisciplinary Council on  
Developmental & Learning Disorders*

*Vol.3, No. 1*

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## **SPECIAL EDITION: PART ONE**

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, LCSW-C, 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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The Interdisciplinary Council on Developmental and Learning Disorders would like to thank  The Unicorn Children's Foundation  for sponsorship and support of this newsletter.

## *Editor's Note*

Jo Raphael, MSW, LCSW-C  
Molly Romer Witten, Ph. D.

Once again The Interdisciplinary Council on Developmental and Learning Disorders (ICDL) has had a very exciting, productive year. We continue to move forward with the newsletter and journal, certification and training, research and fundraising. It is a very exciting time and we appreciate your interest, your suggestions and your commitment to our growing organization.

This is the first newsletter for this membership year and it contains the summaries of the first part of the Fifth International Conference of the Interdisciplinary Council on Developmental and Learning Disorders held in November 2001. The conference covered a broad spectrum of topics pertinent to working with children with severe disorders of relating and communicating. We had many special moments during the conference which were filled with new and interesting information and ways of looking at our children. This edition contains summaries from the following panels: *Assessment and Intervention for Emotional Functioning, New Approaches to Help the Most Challenged Children Learn to Communicate and Talk, the Parent Panel and Advances in Neuroscience and Biomedical Approaches.*

In our next newsletter we will complete our coverage of the conference with summaries from the following panels: 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, Ph.D., Serena Wieder, Ph.D., Barbara Kalmanson, Ph.D., Deborah Flaschen, Susan Norwell, MA, Monica Osgood, Christine Seminario, M.Ed., Sandra Taenzer, MS.

We welcome your comments and insights. 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](mailto:besobeso@enteract.com) or (Jo) [jo@icdl.com](mailto:jo@icdl.com).

Best regards,

*Jo and Molly*

## **Assessment and Intervention for Emotional Functioning**

### **The Assessment of Emotional Functioning in Infancy and Early Childhood and in Autistic Spectrum Disorders: The Clinical Applications of the Functional Emotional Assessment Scale (FEAS)**

*Presenter: Stanley I. Greenspan, M.D.*

Dr. Greenspan introduced the session by describing the work that he, Dr. Georgia DeGangi, and Dr. Serena Wieder, have completed on the standardization and empirical validation of the Functional Emotional Assessment Scale (FEAS), now in print. Dr. Greenspan linked the FEAS to work he and Dr. Wieder began 20 years ago at NIMH to identify better ways to assess individual differences in infants and young children in order to plan more effective treatments.

The FEAS is viewed as part of the DIR (Developmental, Individual-difference, Relationship-based) model of assessment and treatment. He noted **three insights** that led to the development of the FEAS and the DIR model.

- **Affect and emotion are critical not only to social development, but to intellectual and academic development.** This is true for all children, especially for the child with special needs. Why is affect so important? Feelings are the "generator" of thinking! Memory-based learning can occur without feelings, but more abstract thought cannot. Dr. Greenspan described two aspects to learning: the "*affective*" part - which promotes the generation of ideas based on personal, loved experiences and the "*analytic*" part, which involves the evaluation of

ideas. While Piaget held that idea generation emerged principally from sensorimotor experiences, Brazelton showed that affective experiences lead even very young infants to an early understanding of causality (e.g. reciprocal affective smile with a parent at 2-3 months) well before they engage in causal motor experiences (e.g. reaching for a string at 8 months). Dr. Greenspan illustrated the central role of affect through 2 examples: how children learn to say "hello" and how they understand the concepts of "a little" and "a lot". Saying "hello" is not generated learned as a script, but rather through the warm, loving "hellos" they encounter with someone they like. Similarly, a "little" is less than you emotionally want while a "lot" is more than you need. Conceptual development is rooted in affective experiences.

- **The importance of individual differences.** We must consider all of the child's sensory modalities, and understand how the child processes stimulation/information in each modality and discern whether the child is over or under-reactive in each. What emerges is the need to

construct a unique profile for each child.

- **The functional developmental level of the child.** Dr. Greenspan noted the importance of understanding how each child engages in relationships with pleasure and joy. He described the six levels of development described more fully in the FEAS. He placed particular emphasis on the importance of the reciprocal two-way communication system characteristic of the 3<sup>rd</sup> and 4<sup>th</sup> levels, and he reported that in viewing early

videotapes of children who were subsequently diagnosed with an autistic spectrum disorder (ASD), many did not engage in these early, sustained (15-20) reciprocal circles of communication.

The session ended with Dr. Greenspan sharing videotapes of his work with several parents and teachers in which his active coaching as part of a dynamic assessment system, helped elicit optimal functional levels in children.

Gerard Costa, Ph.D.  
Psychologist  
New Jersey

***The Research Applications of the FEAS, Including Reliability and Validation Studies and Videotape Demonstrations of the Scale***

*Presenter: Georgia DeGangi, Ph.D., O.T.R.*

Dr. DeGangi outlined the background, approach, and psychometric studies that went into the construction of the FEAS. She emphasized that in reviewing the utility of the major types of child development tests (parent report, observational scale of child and of parent), several measured some of the functional emotional stages but none measured them all. The FEAS was developed as a criterion-referenced instrument for children ranging in age from 7 months through 4 years. It was designed to measure emotional functioning in children with constitutional and maturational problems leading to a variety of symptoms such as anxiety, depression, impulsivity, etc. and children with pervasive developmental disorders. The FEAS provides a systematic assessment of the child's and caregiver's functional emotional capacities. For infants and young children, these functional emotional capacities include the child's ability to

organize play interactions with objects and persons, to self-regulate mood and organize attention, to form an attachment with the caregiver, to engage in reciprocal interactions and communications, and to represent feelings and ideas through play interactions. Caregiver behaviors are evaluated in relation to their capacity to support their child's development in each of these areas.

The FEAS then was created to build on these earlier measures and hopefully create a more comprehensive, valuable clinical tool. Both the FEAS child observation and parent-child interaction scales were created according to the functional stages to rate the child's specific skills as well as the parent's abilities to support these core capacities. Initial data gathering occurred in structured play observation sessions with parent(s) broken down into three brief (5 minutes) segments

with symbolic, tactile, and movement toys. Following this procedure allows assessment of the child's level of play and engagement across all three play modalities in order to focus on the contribution of sensory – motor maturation to social-emotional functioning.

Dr. DeGangi explained that the initial samples consisted of 94 poorly-regulated and 154 control infants ranging in age from 7 to 30 months. Ratings from observation and videotape distinguished the two Groups of babies, their parents, and the parent-infant interaction. Poorly-regulated infants showed more mouthing, noncontingent responses, fussing, aggression, and aimless wondering while displaying less affect, language and reciprocal play than typically functioning peers. Mothers of poorly-regulated infants had less

contingent responses, symbolic play, gestural (more language) communication, and flat affect. Interactive problems with poorly-regulated babies and their mothers included difficulties regulating affective and gestural cues, organizing planned, purposeful, and focused play, initiating contingent reciprocal interactions, and modulating responses to sensory stimulation.

Dr. DeGangi concluded that these discriminating features of the FEAS provide us the opportunity to more fully understand the child from a unique, multidimensional perspective for assessment and treatment planning.

Griffin Doyle, Ph.D.  
Psychologist  
Bethesda, Maryland

### ***Implications of the FEAS for Diagnostic Classification and Treatment Planning***

*Presenter: Serena Wieder, Ph.D.*

With an understanding of the FEAS as a system of functional assessment, Dr. Serena Wieder described a complimentary scheme for diagnostic classification: the Neurodevelopmental Disorders (NDD) of Relating and Communication classification system. This system extends the earlier scheme of Multisystem Developmental Disorders (MSDD) and its three subtypes first described by Drs. Greenspan and Wieder. Dr. Wieder underscored the need for a new and more useful classification scheme that could assist in differentiating among the individual differences and treatment needs observed in children with autistic spectrum disorders and other developmental disorders.

The NDD system was described as a classification and treatment-planning scheme, which significantly captures the range of observed individual differences, assessed using the FEAS. As such, the NDD system offers practitioners a framework for decision-making about the specific individualized strategies within the D-I-R approach that would meet a child's unique somatosensory and relational needs.

Through presentation and use of videotaped vignettes, Dr. Wieder reviewed the **4 types and subtypes of the Neurodevelopmental Disorders (NDD) classification scheme**, which were described in detail in an article by Drs. Greenspan and Wieder, reprinted in the conference manual. Each type offers a description of a child's

presenting profile along the six core functional developmental levels: Attention and engagement, purposeful behavior, problem solving, motor planning, imitative skills and symbolic capacities.

The NDD groups range from Type I to Type 4, with the severity of the symptom profile increasing from the first to the last group. The **Type I** group has four subtypes or patterns (**A, B, C** and **D**) depending on the profile of processing and motor planning difficulties, but all are seen as making rapid progress in treatment. Children who are best described under **Type II** have greater challenges but make consistent, albeit slower progress. Two subtypes (**A** and **B**) or patterns are described under Type II, with II-B children described as more self-absorbed and avoidant. **Type III** children are characterized by moderate to severe auditory and visual-spatial processing difficulties. These children often show very slow progress. No subtypes are described. The final group, **Type IV**, describe children characterized by very severe motor planning and significant auditory and visual-spatial processing difficulties. These characteristics interfere with higher functioning. In addition to greater severity in these processing areas and motor planning over children in Type III, children in Type IV often have oral-motor dyspraxia. Two subtypes (**A** and **B**) are offered, with children in group IV-

B showing patterns of regression and/or greater neurologic involvement, such as persistent seizures. Children classified within Type IV often make slow or no progress and are clearly the most challenging.

During the presentation, Dr. Wieder showed videotaped vignettes of children classified in the NDD groups, and emphasized several key benefits of the NDD system:

- The NDD system offers a complimentary scheme to use with the FEAS that together describes a child's unique profile and assists in treatment planning.
- The NDD system offers a good scheme for communication among peers and other professionals working with the child and family.
- The NDD offers a detailed descriptive system for the range of children observed with disorders of relating and communication.

Gerard Costa, Ph.D.  
Psychologist  
New Jersey

## ***New Approaches to Help the Most Challenged Children Learn to Communicate and Talk***

### ***Verbal Behavioral Therapy***

*Presenter: Vincent Carbone, Ed.D.*

Vincent Carbone, Ed.D. presented an operant conditioning model of language acquisition based on the work of B.F. Skinner. Dr. Carbone is a strong

believer in the early introduction of augmentative communication systems, with sign language being his top choice for the majority of children. This is because talking and signing require a

different word each time you communicate and you hear, see, and feel something different each time. The symbol exchange system is the same each time; i.e. you hand over a square card. Moreover, sign language may bring quicker acquisition of vocal responding in some children. With a picture exchange system, children may stay more focused on requests only. It is also not readily accessed, as you need just the right picture at just the right time. Research has shown that almost all children with autism can learn to sign despite motor imitation difficulties. However, if the child has a physical or neurological disability that makes the differential muscle control necessary for signing impossible, a pointing or selection based system should be immediately considered.

He recommends starting with expressive communication immediately, and to teach the children how to make requests (mands), rather than teaching them labels. This sparks their motivation for learning, as they can access desirable items (e.g. food/toys). First

signs should not include complex signs or confusing ones, such as please, more, help, or thank you. These are too easily over-generalized and it may be very difficult for the child to move on to other signs. He also noted that motor imitation should not be taught in isolation, but rather in the context of requests with good prompting and prompt fading. He explained that rather than requiring that a child sit in a chair and do drills, through reinforcement you get the child to come to you, and then gradually make the required response a bit more difficult.

Dr. Carbone presented videotape demonstrating the initial use of sign language and verbal language with several children. He also presented a video showing the success of a child who signs being included in a regular education setting where all of the children were required to sign when communicating with him.

Lori Jeanne Peloquin, Ph.D.  
Psychologist  
Rochester, NY

### ***New Systematic DIR-Based Dynamic Developmental Speech and Language Curriculum***

*Presenter: Diane Lewis, M.A., CCC-SLP*

Diane Lewis, M.A. presented a summary of the new Communication Curriculum that she is developing with Stanley Greenspan, MD, which is to be used with the more challenging children. It is appropriate for children who are functioning developmentally between birth – 48 months. Ms Lewis stated that the curriculum includes guidelines for Sensory-motor preparation, Oral Motor/Articulation work, Systematic Instruction, Applied Floortime, and, Floortime.

Ms. Lewis explained that the curriculum is divided into four levels. Schedules are suggested for each level which prescribe what order and how much time the child should receive sensory-motor input, oral-motor, systematic instruction, applied floortime and floortime. She stated that the more involved children require more sensory-motor preparation and floortime with less structured work (systematic instruction and applied floortime). Ms. Lewis feels that the middle two levels need to receive more structured work. She stated that the highest functioning

group of children need to receive less sensory-motor preparation and structured work and more floortime.

Ms. Lewis stated that the first step to implementing the curriculum is to fill in the Checklists to see exactly what skills the child has. The Checklists are broken down into four key curricular areas: imitation, receptive language, expressive language and play/pragmatics/social. The Kaufman Test of Speech Praxis should be used to gather basic oral-motor information. Once all of the data is in, a program is then formulated which prescribes exactly what needs to be taught to the child in each curricular area along with

how to schedule the activities (sensory-motor preparation, systematic instruction, applied floortime, oral-motor and floortime).

Ms. Lewis closed her remarks by stating that all of the work with the child, regardless of the activity or level, is to be done in a manner that supports back and forth pleasurable interaction with the child on the curriculum. She stated further that all the senses should be involved including visual, motor/tactile, and auditory.

Lori Jeanne Peloquin, Ph.D.  
Psychologist  
Rochester, NY

### ***Discrete Trial ABA Approaches***

*Presenter: Tristam Smith, Ph.D.*

Tristam Smith prefaced his presentation with the caveat that although many treatments may sound good, only research based approaches that document success are valuable.

Dr. Smith then presented Early Intensive Behavioral Intervention (EIBI), which he described as a labor intensive (20-40 hours per week. Two to three years of treatment) program for children under four, which is based on empirically validated approaches and proceeds in small, carefully planned steps.

The successes and limitations of EIBI were discussed describing the

characteristics of Best, Intermediate and Poor Outcome children. Pre-treatment predictions of Poor Outcomes were described. The audience was introduced to the behavioral concepts of manding and fading, which were used within the description of problems with imitation, labels, abstract labels and motivation.

Conclusions included encouragement for further study, particularly with low-IQ children and more interdisciplinary collaboration.

Paula Erdeyli, MSW  
Clinical Social Worker  
Louisville, Kentucky

## ***Parent Panel***

### ***Looking at Your Child Through a DIR Lens AKA: DIR Parent: Blessings and Challenges***

*Presenters: Deborah Flaschen, Michelle & Russ Geary, Sue Resnick, Shelley & Matthew Stravitz. Moderator: Amy Jackson*

At the end of a very long, rich day the Parent Panel presented on “Looking at Your Child Through a DIR Lens” aka “DIR Parent: Blessings and Challenges.” Amy Jackson acted as Moderator and did a wonderful job of helping the panel join together to present their different journeys with their children while focusing on the common themes of family and DIR.

The Stravitz family spoke first about the difficulties that they faced when they began to work with their younger son. Their older son, Matthew, was then fourteen and Shelley candidly talked about raising these two children together and how helpful Simon’s older brother was to him. The family moved to Atlanta just as their son was diagnosed and they had to try to figure out how best to help him in a new environment without too many external supports. Shelley talked about the difficulties they faced in having to create a program for her child. They began by utilizing concepts learned at the Options Institute and then integrated the DIR model. They found a few talented therapists and then together with volunteers had an excellent team to work with their son. It was not an easy journey but they approached it as a family with everyone pitching in and helping Simon with DIR and his therapies and Simon flourished. The family recently moved back to NY and is adjusting to being there at this time.

Matthew, now 22, spoke beautifully about what it felt like to have this brother in his life at the age of 14. He was warm and spoke of how difficult it was at

times to have so much time and attention given to Simon. He also said that he never felt left out and that now he has the brother that he always wanted. The boys enjoy one another and enjoy being together.

Sue Resnick spoke next about how the process informed her as a parent and that DIR doesn’t just change what you see in your child, it changes your outlook towards your child. She talked about finding out that her daughter had challenges and how difficult the process of discovering this was and then finding the right help. Her daughter is now a middle child with a brother on either side of her. Sue explained that they are a ‘floor time family’ and that ‘circles of communication’ have become a way of life for them. In fact, because of this level of awareness she was able to identify some learning challenges in her other child and secure the therapy he needed to address these issues before they became problematic.

Michelle and Russ Geary spoke about their family as “Life Under the Big Top”. They have triplets, all of whom have issues. Their son, Joey, has challenges with relating and communicating and they have also become a floor time family. Having triplets is challenging in itself. Having triplets with special needs can be overwhelming. Russ and Michelle have had rough times in their marriage and there has been tremendous strain on their family life. They have been able to work it through and utilize DIR with all their children and are constantly pushing for more and more. They have become strong

advocates for their children in school and in their therapies.

Deborah Flaschen spoke to how DIR becomes a way of looking at everyone in your family. She discussed the importance of family and siblings and read a beautiful essay that her 13 year old daughter had written for school. The letter was a poignant description of her very special relationship with her 11 year old brother.

The theme of this year's parent panel was how raising a child with special

needs affects the whole family. Each of the four families that presented have embraced the DIR model for their entire family and incorporated it into their way of life. Siblings are extremely important for the "special" child as well as for the typically developing one. Once again we thank the Parent Panel for the insight into the "real world" of DIR, for sharing their experiences, their knowledge and their expertise.

Jo Raphael, MSW  
Clinical Social Worker  
Baltimore, Maryland

## ***Advances in Neuroscience and Biomedical Approaches***

*Moderator: Ricki Robinson, M.D.*

## ***The State of the Evidence on GI Tract, Immunizations and Autoimmunity***

*Presenter: Tim Buie, M.D., Assistant Professor of Pediatrics, Tufts University and Harvard Medical School*

Tim Buie, M.D., a pediatric gastroenterologist, brought the cutting edge perspectives on the GI tract contribution and disturbances in autism spectrum children, recognizing that physicians all "practice heuristically", that is, "I've seen this before, and thus I've come to think of it this way..." From this beginning process, pooled knowledge begins, more complex data analysis occurs, empirical research is stimulated, ultimately giving rise to evidenced-based medicine's safe and effective treatments. Unfortunately, there is no clear and unequivocal data linking the GI tract and autism; yet here, new ideas bring a struggle against old heuristic beliefs, and await confirmations to new constructs of theory and study.

The cause of autism spectrum disorders remains unknown, yet clearly there are genetic risks and, perhaps, a "second hit" or insult. There appears to be general agreement of increasing

incidence. Although the studies are lacking, GI tract symptoms abound in children with ASD: constipation, diarrhea, pain, food sensitivities, and toileting difficulties. 30-40% of children with developmental problems have constipation. Diarrhea is also frequent, sometimes related to overflow from constipation (encopresis, when soiling). Abdominal pain appears to occur in up to 25% of children with ASD, and often seems to occur during eating or thereafter. Some children have been found to have gastroesophageal reflux, and when treated, there may be resolution of pain and mealtimes struggles.

Food sensitivities appear frequently in children with ASD, suggesting allergy or intolerance pointing to broader mechanisms of causation (Opioid theory?). As many as 50% of infants, who are later diagnosed with ASD, have "food allergy" by history and 1/3<sup>rd</sup> of

ASD children will remain with food intolerances and allergies as they mature. The symptoms of intolerance may be either non-specific including gas, diarrhea, hives, eczema or clearly, food specific. There remain conflicted empiric research findings: a recent study found a 70% association of food allergies and ASD compared to controls: another study found no association.

Immunological abnormalities abound in children with ASD raising questions of immunological mechanisms at work with food intolerances and allergies. In the case of food allergies, a year of struggle lowers the blood IgG level. This has generated a hypothesis that early GI food allergies may promote immunological problems over time, and may correspondingly be related to ASD symptoms. Additionally, the concept of "autoimmunity" has little empirical basis, thus far.

The issue of casein (milk) and gluten (wheat, rye, barley, malt, oats) intolerance has given rise to the "opioid excess theory." Basically, the breakdown products of these proteins have some opioid like, neurotransmitter-like, effects before they are excreted in the urine. The theory suggests that some of these products may be "drugging" ASD children, thus giving rise to symptoms of disengagement. The empirical studies of this phenomena have not substantiated an association of these breakdown products and autism symptomatology, despite clinical observations.

There are many exciting and new investigations underway linking the GI track and ASD. Some of the more recent work has focused on intestinal permeability, "the leaky gut theory". Abnormal permeability and protection within the GI track was felt to create weak defensive mechanisms allowing absorption of toxic compounds to the

CNS. It is within this context that the initial potential beneficial effects of secretin were explained. Unfortunately, more recent studies empirical studies on secretin have not shown strong support for a beneficial effect, yet some have shown stool and cognitive benefits, a parent perceptions of benefits, without researcher observed positive findings. Dr Buie encourages a "stay tuned" attitude for further research efforts including those from the Repligen manufacturer and others seeking biomarkers to suggest which children may benefit from the secretin product.

The original work of Andrew Wakefield and autistic enterocolitis can be found in the Lancet 1998 with a subsequent study in Am. Journal of Gastroenterology 2000. In the original observations, colonic lymphoid changes that suggest colitis were observed by colonoscopy in 11 of 12 ASD children with diarrhea. A subsequent study of 60 children found 93% of ASD children (compared to 14% controls) also had these findings pointing towards GI immunity issues. These findings are in a group of highly selected ASD children with diarrhea, and remain an unexplained finding. Embedded in these findings is the issue of vaccine injury from MMR and virus triggered immune reactions, and/or mercury toxicity. Dr. Buie cautioned that the movement to chelation for mercury toxicity and overload was building a treatment from little evidence like "shaky steps on shaky stairs". Yet the work by Welch on metallothionein deficiency, a genetically determined insufficiency of the binding protein for mercury, remains very interesting.

His Massachusetts General Hospital experience with GI abnormalities in over 400 ASD patients is by far the largest cohort study. By endoscopy of referred ASD children in his GI clinic, he finds esophagitis in 20% of his patients,

gastritis 12%, duodenitis 10%, eosinophilic inflammation 5%, pancreatic insufficiency ~10%, lactase deficiency 55%, colitis 12 % and lymphoid nodular hyperplasia 16%. This suggests that ASD patients have many multi organ system struggles and conditions, the GI tract, as observed, quite often significantly impaired. The etiologies and specific treatments for

these GI disturbances in ASD patients remains to be determined, yet symptomatic treatments have proven beneficial. Stay tuned!

David W. Willis, M.D.  
Behavioral-Developmental Pediatrics  
Northwest Early Childhood Institute  
Portland, Oregon

### ***Modern Therapy in Autism: Good-bye to Nihilism***

*Presenter: Michael Chez, M.D., Director, Autism and Epilepsy Services of Illinois  
Assistant Professor of Neurology and Pediatrics, Rush Medical School*

Michael Chez, M.D., a pediatric neurologist and previous ICDL presenter, discussed his emerging and important therapeutic experiences with autism spectrum disorders (ASD) that is leading towards increasing specificity for biomedical and neurological interventions. He views ASD's as a heterogeneous group of primary disorders of socialization and language function. Neurochemical dysfunctions have been noted in ASD's and focus predominantly on the serotonin, dopamine and acetyl-choline systems. Although with limited data, neuroanatomical studies are finding abnormalities in the cerebellum, pontine, temporal and frontal lobes, the etiology of which remains only speculative and currently still unclear. Electrophysiologically, many children have EEG abnormalities that mimic the findings in Landau-Kleffner syndrome, in which language regression is correlated with temporal lobe epileptiform activities. Until the various pathologies and subtypes of ASD's are well characterized and understood, "common sense" approaches still prevail to make biomedical decisions for treatment.

Meticulous history taking and documentation remain the cornerstone for beginning appropriate therapeutic

efforts: presenting symptoms, symptom specificities, regressions, inconsistencies, and co-morbid symptoms (i.e. aggressions, mood swings, self-stimulations, language patterns). Specifically, language system inconsistencies and regression symptoms often suggest Landau-Kleffner syndrome-like findings in the temporal lobes as observed during sleep on 24hr EEG's, despite the absence of clinical seizures (<10%) and < 50% abnormalities on office-based EEG's. In this group, valproic acid (Depakote) has been helpful in 60-70% of cases with improved expressive language over 2-3 months. In a similar group of children with careful monitoring, pulse dose steroid treatment have shown improvements in expressive and receptive speech patterns, supporting a view that ASD is a chronic brain disorder with inflammatory and immunological contributions. He is following over 400 children with chronic pulse steroid treatment and careful, frequent EEG monitoring, with 67% demonstrated benefit.

An exciting area of biomedical pursuit is the sleep disorders of children with ASD. There appear to be abnormalities of sleep architecture including

decreased delta sleep suggesting subcortical sleep disorders. Yet other causations including sleep apnea and GE reflux remain to be considered as contributing to sleep disturbances in ASD children.

Additional biomedical advances were described from his experience specific to individual symptoms. Regarding gastrointestinal symptoms, he finds many children having alternating constipation and diarrhea with GE reflux and encopresis (bowel accidents). He has not observed benefit from casein/gluten diets, nor from Secretin. Some children have benefited from SSRI's for obsessional symptoms, with the side effect of extreme moods sometimes noted when genetic histories of bipolar illness are present. Aggression and self-injury symptoms seem to respond to the atypical anti-psychoics, especially risperidol, but side effects of weight gain are often a significant problem despite true clinical benefit.

Since 1999, Dr. Chez has been studying the use of acetylcholinergic enhancement for "apraxia/frontal lobe syndrome". The use of Aricept in open-label and double-blind studies has been somewhat helpful with expressive speech and motor-planning functions in a small group of children. Further study is in progress.

In summary, biomedical interventions begin with the view of ASD's being a spectrum of different disorders, causations, symptom complexes and opportunities for interventions. Focusing first on EEG abnormalities with intensive pursuit by 24 hr EEG's is warranted, followed by biomedical treatments focusing on targeted symptom clusters. This individually tailored, "modification of the brain chemical environment" may have significant clinical and therapeutic benefit for many ASD children.

David W. Willis, M.D.  
Behavioral-Developmental Pediatrics  
Northwest Early Childhood Institute  
Portland, Oregon

### ***Chronic Pain in Adolescents with Autism/PDD Spectrum***

*Presenter: Lonnie Zeltzer, M.D., Professor of Pediatrics, Anesthesiology, Psychiatry and Biobehavioral Sciences, Director, Pediatric Pain Program, UCLA School of Medicine*

Little is known about the biomedical processes of pain and autism spectrum Disorders (ASD), although clinical observation suggests that many children with ASD's show pain hypersensitivity, inconsistent pain response or hyposensitivity. Dr. Zeltzer is a world's authority on childhood pain and the biopsychosocial aspects of pain response and experience and brought to the ICDL conference an important and emerging perspective for our autism spectrum children. Her presentation was a neurobiological overview of what

is known about pain and the regulation of pain perceptions.

What is pain? The answer is ever expanding from the initial views of a noxious sensation to a more comprehensive awareness of pain as the mind-body integration of cognitive and affective recognition of noxious and threatening body sensations that includes not only underlying neurobiological nociceptive circuits but also a conscious awareness of the experience of pain that derives from regulation between neurocircuitry for

pain facilitation and pain inhibition. Neurosensory data reaches consciousness and then is “perceived” as pain – a conscious awareness.

Pain transmission proceeds from the periphery (e.g. skin, muscle, etc.) and internal organs to the spinal cord and then up to the brain through many neurosystems that may intensify the transmission and perception of pain. There are also competing descending pain inhibitory systems that serve to dampen the nociceptive and pain signals. The pain facilitory system may be activated by infection, inflammation and learned safety signals which magnify the pain signals to the brain. Pain inhibitory systems may be activated by both intrinsic and extrinsic opioids, and by learned suppression efforts. Then, pain perception becomes the last stop in the pain transmission process and is significantly influenced by arousal/anxiety, memory, and attention and is interpreted with reference to teaching, culture, stress, parenting, relevance and coping styles, to name only a few.

Chronic pain syndromes seem to arise from dysregulation patterns of this integrative and processing system. “Pain begets more pain” – the longer pain goes on, the harder it is to turn off. Sometimes the ongoing experience of pain results in a downward spiral of increasing symptoms and disability giving rise to Pain Associated Disability Syndrome (PADS) that will require a full pain rehabilitation plan.

There is no literature on Autism Spectrum Disorders and pain! However, in the workup of chronic pain in children, undiagnosed cases of high functioning ASD/Asperger’s cases have been seen, bringing an interesting link between ASD’s and the differential diagnosis of chronic pain syndromes.

The treatment of chronic pain syndromes in children requires a thorough medical, developmental, family and psychological workup. Treatment is multi-layered including education, behavioral treatments, psychological management, medications, physiological interventions and complementary alternative medical interventions. The goals of treatment are to educate the child and family about “sensory signaling” and to reduce the focus on the “sensory self”. The effort at rehabilitation is the remediation of physical deficits, enhancement of socialization and communication with peers and the facilitation of problem solving. Many efforts are made to blend the mind/body split into a sense of holistic health and may require special communications with children and their parents. In this regard, helping them to understand pain through an “electrical engineer” approach in which pain is viewed as a “wiring and signaling dysregulation” disorder. With children on the autism spectrum, the pain treatment efforts are ever more complicated and must focus on the sensory processing and regulatory disturbances. Some children have found benefits from medical interventions like SSRI’s, typically in combination with other, non-pharmacological treatments, such as acupuncture, yoga, or massage. Unproven complementary alternative medical interventions like acupuncture, biofeedback, yoga, and therapeutic touch may have a place. Much remains to be learned for patients with ASD’s from the biopsychosocial perspective toward the development of healthy regulation of pain threshold, perceptions, and suffering.

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