

The BEST PRACTICES

Newsletter
Of
*The Interdisciplinary Council on
Developmental & Learning Disorders
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SPECIAL EDITION: Summary of ICDL Fourth International Conference November 10, 11, 12, 2000

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, Managing Editor at: 3213 Midfield Road Baltimore, MD 21208. E-mail at JO@ICDL.COM, phone or fax at (410) 486-1251. *Thank you.*

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.

Welcome to the new *Best Practices* newsletter! *Best Practices* will be available on the web at www.icdl.com and in hard copy through subscription.

We've had a very exciting autumn filled with some changes in our growing organization. ICDL is now a membership organization and to date, over a thousand people have joined. We are dedicated to raising the bar for each and every child. We also held the Fourth 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. In order to share the conference with you we our first two volumes are **Special Editions** in that we have included summaries from each presenter to give you an overview of the three-day conference. This edition contains summaries from the *Redefining Standards of Care*, *The Frontiers of Biomedical Treatment in Autistic Spectrum Disorders*, *Parent Panel: The Role of the Parent: Facing the Challenges of Raising a Child With Communication and Language Difficulties*, and half of the panel entitled: *Autism: The Causes and Increase in Cases*. Our next edition, Vol. 2 No. 2 will include summaries from the rest of the conference including: *Autism: The Causes and Increase in Cases* and *Raising the Bar: Increasing Abstract Thinking, Empathy, Peer Relating and Academic Achievement in Children with Autistic Spectrum Disorders and Other Special Needs*.

The editors used the opportunity to meet in November, which resulted in some new ideas and some changes in personnel. Our newsletter will continue to be available quarterly on the web and in hard copy for subscribers. We will have a Special Edition following each November and April conference. Regular columns will be Regional Networks, Biomedical, Medical, Parents, Clinical Insights, Education, Updates and Advocacy. In addition we plan to add an interview column where we interview folks in the field-either professional or parent. We've also had some editorial staff changes. Lori Jeanne Peloquin, Ph. D. and Ricki Robinson, MD, will continue to be active within ICDL but no longer involved in the newsletter. Rick Solomon, MD, and I (Jo Raphael) will assume their columns. We thank them for their time and energy and devotion to our growing organization.

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

*The Interdisciplinary Council on
Developmental and Learning Disorders
Fourth International Conference*

**AUTISM:
What are the causes?
Why the increase in cases?
Redefining Standards of Care**

***Redefining the Standards of Care:
The New ICDL Guidelines for
Infants, Children & Families with Special Needs***

Molly Romer Witten, Ph. D.

Principles of Assessment and Intervention
Presenter: Stanley I. Greenspan, MD

Dr. Greenspan opened the conference with an overview of the characteristics of an effective assessment that can be used as a roadmap for treatment planning and implementation. He described the assessment as needing to be process oriented, not score oriented, and focused on elucidating each child's individual differences, rather than figuring out how to clump a child into one or another category of disorder. He spoke of four domains in which each child has unique individual differences: sensory and motor characteristics, characteristics of impulse and affect expression, family characteristics, and medical history. Each of these domains must be exhaustively explored in order to understand the circumstances of the child's functioning.

Importantly he hypothesized a "diathesis model" of autistic spectrum disorders (ASD). In this model, he proposed that typically, humans have a simultaneous double coding of every internal and externally perceived event. In the case of children who have autistic spectrum disorders, he explained it may be that this double coding does not

become neurologically engaged at the appropriate time. If this is the case, the child with an ASD does not have the influence of the affective coding to develop discriminative power between various sensory events (both internal and external in origin). Sensation remains coded at the most basic level of pain, not pain, pleasure, and neutral. When a child develops without the affective component of the double coding process, s/he cannot develop learning strategies. Gregory Bateson indicated that what connects people are salient patterns of interaction. If the child cannot come to comprehend the patterns of his/her culture such as communication, which stimuli are important to attend to, or how to connect his/her own actions to the actions of other people or objects in the external environment, the child will not develop a set of internal expectations. Without the relational pleasure that occurs during interaction, a child without affective coding cannot develop effective anxiety modulation, or motor modulation. And, without this important regulation capacity, the child cannot evaluate risk, or seek help from others. He suggested that interaction is

the mediator of sensory integration, and that it creates and facilitates the fine-tuning of child's innate and constitutional factors with the surrounding cultural preferences and

mores. Interaction is the glue that connects each of us to the larger world outside ourselves.

A Functional Developmental Approach to the Education of Children with Special Needs
Presenters: Serena Wieder, Ph. D. and Barbara Kalmanson, Ph. D.

Dr. Wieder began the second talk by critically evaluating the current capacity of our educational system to meet the needs of preschoolers who experience ASD. She stated that it is inappropriate for schools "adapt down" programs for older children to young preschool children between the ages of 2-5 years. These preschoolers have different and unique developmental needs for affective, cognitive, and relational experiences not built into programs for older children. She emphasized that what is needed are unique interactive and affectively lively preschool classrooms. Although children with ASD have widely varying sensory profiles and constitutional factors, it is important to organize *around* their functional capacities, and create educational environments that support continued developmental progress. While children with ASD vary widely in their individual differences, and sensory capacities, they need similar social and emotional relationship building experiences that children in the typical range receive in typical preschool settings. The emphasis needs to be on spontaneous and mediated interactions that develop mutual attention and engagement, joint problem solving, symbolic play and social games in an enjoyable and enticing environment.

Children with ASD need to develop their identity as a member of a classroom *and as a friend*. No amount of individual therapies can substitute for classroom experience and the play dates that can precede and follow school. Different models need to be considered ranging from full inclusion (with necessary support) whenever possible, to mainstreaming, to special education classes which include a range of abilities. Therefore, the school programs must be adapted to the needs and strengths of the children, taking into account individual differences and sensory processing needs, while continuing to meet the needs of typical classroom peers and affording them the

wonderful opportunity to relate to children who are different. A video illustration of a nonverbal child with very significant challenges surrounded by typical peers doing a drawing together, illustrated the great pleasure the child experienced when he noticed the children were imitating his tapping his pencil. This led to a long chain of mutually enjoyable interactions where he could communicate through rhythmic patterns his peers understood and reciprocated, and then went on to do a mutual drawing.

Dr. Barbara Kalmanson suggested that the characteristics of an appropriate classroom environment rest with the teachers' pacing, focus, and flexibility. She demonstrated this proposition by showing videotape illustrating an effective circle time. This circle time experience involved all children at a sensory motor level; the pacing was slow, with time built in to create a responsive flow between the teachers and children. The experience seemed inherently enjoyable for the children. The final characteristic was that the activity progressed full of high affect exchanges between the teachers and children. Dr. Kalmanson also highlighted that teacher flexibility is a necessary characteristic because, often the teacher's flexibility will lead her/him to reverse his/her intention in the service of facilitating interaction. In the clip shown, the teacher initially wanted to entice the spectrum child to join a group. However, when it became clear that the child was unable to do so, the teacher reversed his intention and wooed the other children to engage in interactive group exchanges doing the activity that the spectrum child was engaged in. Ultimately the child with an ASD became engrossed with the other children and participated in a group activity with his peers. He did this without age appropriate language, or developmentally appropriate motor planning capacity. The teacher functioned initially as the affective draw for

children to notice the child with special needs, and then transformed the activity by commenting on all the children's actions. He then raised the developmental level of the activity by refocusing the children within the same environment.

In a second video illustration, Barbara Kalmanson showed how teachers and specialists at the Oak Hill School implement a transdisciplinary program to meet the sensory processing needs of school age children while supporting their academic needs. The video showed a teacher and OT working with a child on a swing in order to stimulate the vestibular system to enable the child to work more effectively learning math skills. The program focused on reciprocal affective cuing in a highly active and engaging sensory intervention, which enabled the

child to regulate himself and focus on an academic task.

Last, Dr. Wieder showed a video illustration of an outstanding public preschool program using the DIR approach called Celebrate the Children developed by Monica Osgood and Julie Frank demonstrating the individualized work within a group program for children at different levels. This program combines home based Floor Time as well as a school based program which uses spontaneous interactions to join children together as well as semi-structured activities where emphasis is always put on relating and communicating. The range of children ensured appropriate models for each child to learn from. Dr. Wieder then described DIR the *principles of a comprehensive educational model*.

<p><i>Developmental Approach to Motor and Sensory Functioning</i> <i>Presenter: Marie Anzalone, Sc.D., OTR</i></p>
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Dr. Anzalone emphasized that in working with children with autistic spectrum disorders, the evaluation should result in a process, not a product. In saying this, Dr. Anzalone meant that the evaluation should become the prototype for the intervention organization. She made a strong distinction between sensory input and sensation. She made it clear that sensation is the subjective experience of sensory input. She explained that this is an important distinction because in that subjective experience there is the addition of affect to the sensory input.

There are different aspects of motor behavior that should be included in evaluation:

- 1) Neuromotor;
 - 2) Gross motor function;
 - 3) Fine motor function;
 - 4) Oral motor; and
- Praxis.

She referred to Praxis as really more than just motor planning. It is the flexible ability to engage in novel goal directed behavior. It is not a discrete skill of the child, but it is an emerging relationship between the child and

the environment. It changes from moment to moment, depending on the changes within the environment. Praxis is more than motor performance. Praxis occurs in three steps: 1) Ideation, 2) Motor planning, or sequencing and using body schema, and 3) Execution, or actually doing the action.

Assessment of praxis must occur during novel tasks in the context of both interactive play and individual play. Dr. Anzalone also emphasized that the motor system does not function separate from the sensory system. They are constantly interacting during functional activities. When we look at the sensory integrative capacity of a child, we must ask not only what skills the child exhibits, but also "in what context does this behavior happen".

Importantly, she enumerated three primary goals of intervention:

1. Educate the parents about and help them understand their child's sensory and motor profile.

2. Facilitate goodness of fit between the child and his/her various contexts, such as school, home, playgroup etc.
3. Direct remediation of sensory integrative or motor dysfunction must be the last step, not the starting point of intervention.

Assessment and Intervention with the Family

Presenter: Rebecca Shahmoon Shanok, MSW, Ph. D.

Like all children, those with autistic spectrum challenges need their parents as key interactive, developmental and relational organizers. Yet, children with autistic spectrum disorders send confusing messages to parents; it can be very hard to figure out how to respond to and support them. Thus, parents often feel inept, unsupported, and incompetent in their role as parents. Parents of children with developmental disorders may experience tremendous pain at what they perceive as rejection by their offspring. The speaker asked us to imagine what it would be like if no one at our job acknowledged us, or gave us feedback indicating that they wanted us there. That is just a hint of what it may be like for parents of children with ASD. It is necessary to work with parents to help them become interveners with their child. In our roles as professionals, it is important to recognize parents as significant partners in the intervention process. By forming real partnerships with parents, by joining together to “read” their children, we can help lessen their sense of isolated disconnection from their children.

Yet, in forming such partnerships with parents, tensions inherent between parents and professionals should be acknowledged. Parents are wary of professionals whom they think may perceive the locus of the problem as *within* the parent, rather than as parents having a child with a disability. At the same time, Dr. Shahmoon Shanok perceived that parents want professionals to acknowledge that life with a child having an autistic spectrum disorder is difficult. Parents neither want their pain dismissed nor made the defining feature of their personality.

In our roles as professionals working with small children, we help parents understand the difference between an evaluation that discovers the child’s best capacity for functioning, and establishing eligibility for early intervention, which often entails describing only the areas of functional deficit of their child. Dr. Shahmoon Shanok asked us to think how we can shift our practices so that parents can feel supported and can glimpse their child’s relative strengths even when we have to establish eligibility.

Dr. Shahmoon Shanok also delineated three aspects of parent development which emerge in relationships:

- 1) Development of person or parent within the relationship with their child.
- 2) Emergence of conscious/unconscious recollections and memories from each parent’s own past in the form of internal working models, transference, or internal representations as they emerge vis a vis the child.
- 3) Development of the parent as a person within the relationship with her or his primary professional.

It is important to continually bear in mind that the relationship between parent and professional must be nurtured no less than the relationship with the child, who may technically be the focus of our intervention. “The action is in the interaction. Read chapter 14 of the Guidelines entitled:

“The Action Is in the Interaction: Clinical Practice Guidelines for Work with Parents of Children with Developmental Disorders!”

The speaker reminded us that even if we have no training in working with parents, we know how children work; since every parent was once a child, we can use our knowledge

of child development to help us work with parents. Most parents are also adults. We also know about adults because we are all, more or less, adults. She encouraged us to let our knowledge about children and adults serve as a bridge to insight about the parents' needs and abilities. She also encouraged us to go past the borders of our disciplines through meaningful teamwork, through supervision from someone experienced in another discipline and through further study.

In progressing through an evaluation, Dr. Shahmoon Shanok spoke about gathering an array of information about the family and comparing it to a developmentally based pyramid of needs and services. The most fundamental level of the pyramid is the need for safety and basic services. The next tier is the need to be related and accepted. Perched on top of that level is the offer of developmentally appropriate interventions for the parents in their various roles, say as marital partners, as wage earners and/or as integrators with their child. The top level of the pyramid are ongoing, specific interventions for the parent geared individually to the parent's own style and to the child's profile. She highlighted the fact that the field limits the conception of our job to the child, but that limitation often misses how to reach parents, the most critical

resource on behalf of that child. In reality, when we assess what level parents are at, and meet them at their level of need then they can often much more effectively meet their child's.

Professionals need to understand the functional capacities of parents no less than of their children. Indeed, in this sense, parents of children with challenges are not a group at all, but vary as greatly as the general population. When we ask ourselves the following questions as we begin our relationships with them, our work with parents can become individualized and more meaningful. What are the strengths and vulnerabilities of this parent? What do we know about this parents' internal representations? Where are the continuities and the gaps in this parent's life "stories" that can help us understand her or him better as they work with their children? What does the parent hope for from forming an alliance with us?

We need to step back, reflect and try to see from each parent's perspective. We should not blame parents for not liking our agenda. Rather, we need to alter our agenda to meet *their* needs. "Think of yourselves as the family's team, not just the child's team." "Relationships hold the potential to help people grow and change."

Biomedical Evaluation and Interventions
Presenter: Ricki Robinson, MD

Dr. Robinson gave a wonderful presentation that outlined the medical evaluation process. She emphasized the need to use evidence based guidelines, as well as guidelines developed based on clinician experience. She stated that the physician's role involves a multi-step process.

Dr. Robinson told us that the evaluation begins with the identification and screening of children with suspected autistic spectrum disorders. She finds that the CHAT is an effective tool for screening even though it is not as sensitive as some other screening tools. The CHAT requires the physician to interact with the child, and it is a short, efficient assessment

In the diagnosis process, the physician needs to figure out the unique nature of the profile of the child in order to put a comprehensive plan together. This is a time consuming process where in order to formulate a developmental profile of the child, many questions must be asked about the child's and family's history. This type of session can take up to two hours and Dr. Robinson usually does it without the child present so that the caregivers are able to take their time and answer the questions thoughtfully. In addition to family history, medical history and developmental history she and the parents complete a Sensory questionnaire. All of this helps look for clues to begin to sort out causes of the developmental delay.

Next in the medical evaluation is to rule out treatable issues and determining what medical testing might be indicated as a result. Dr. Robinson does the following:

- Physical and neurological exam
- Look for “double syndromes” such as PKU or Fragile X
- Look for indirect factors that do not have a direct affect on the child’s behavior, but may influence another more direct factor
- Extended sleep deprived EEG’s
- Metabolic screening tests and Inborn errors of metabolism
- Genetic testing
- Structural Neuro-imaging secondary to positive EEG finding
- Allergy and immune dysfunction

Based on clinical observation and testing and results of medical tests a treatment plan must be discussed and Implemented. Dr. Robinson believes that the treatment plan implementation must start at the initial evaluation. This plan can be used diagnostically to help understand the problematic characteristics for the child. Necessary components should be: multi disciplinary in composition; family centered; and utilize service coordination and case management.

If medication trails are recommended there are general rules of pharmacologic

intervention that Dr. Robinson recommends. She believes that you must optimize functioning-that you don’t ease individual symptoms at the expense of overall functioning. For example, do not use medications to target specific individual symptomatic behaviors if overall behavior is not positively influenced. Engage in medication trials with treatment-blind observers and use titration to fine tune the dosage of any medication.

Dr. Robinson stated that it is critical for physicians to look at both biomedical issues and relational issues. As the physician embarks on implementation of a treatment plan, it is crucial to only make one change at a time so that evaluation of that change can occur and continue to inform the rest of our treatment plan. She emphasized that there is a risk profile for each child and as more and more conventional treatment strategies are shown to be ineffective, the risk profile will change. We have to support parents who want to try less conventional complimentary and alternative medical treatments.

Dr. Robinson closed by stating that the physician should always hold out hope that more searching might bring to light solutions for the medical complications affecting the child’s behavior.

<p><i>A Developmental Analysis of Intervention Research</i> <i>Presenter: Elizabeth Tsakiris, M.Ed.</i></p>

Autistic spectrum disorders involve many functional deficits, and are not one type of discreet disorder.

Although we can now screen at 15 months for ASD, early identification does not mean that we necessarily know how to treat the condition. We do not know how to intervene separate from the individual child. The biggest single issue in choosing treatment strategies is that on the basis of current literature, we don’t know how evaluate whether an intervention actually works.

First we need to define what constitutes evidence. We need to describe the disorder for each individual child. The symptoms are child driven, not disorder defined. Dr.

Tsakiris explained that clinical trial methodology does not work with ASD, because clinical trials necessitate one or more control groups. Within these control groups, no treatment options can be available. This is an untenable situation for a child with an ASD. No child should be in a control group (not) *without* getting the services that he/she needs. Single case study methods also don’t work because they can’t be generalized. Development in one domain does not predict development in other domains. Thirdly, Pre-post studies are superficial. If you only take pre and post data, you can’t know when the development occurred during the trial process. You must ask the following questions:

“How much of one intervention, for which deficit area works to what degree for which child and what is the optimum time for providing that intervention?”

“What interventions work best for what child and when should they be provided?”

We have to stop viewing autism as a singular disorder, and consider it instead multiple functional deficits. We can determine the deficit areas affected. Interventions cannot be applied in a set formula because for each child the profile of functional deficits will be slightly different.

Clinical meaningful results are different from clinically significant results. This statement means that findings must support the meaningful use of the developed skills. Equivocal results, are those that provide evidence that intervention increased the discrete skills, but show no long-term general gain in behavioral sophistication. Long-term gain is necessary. When looking at treatment strategies, we must ask if the results of the intervention generalize across the child’s behavior in different contexts.

Ms. Tsakiris explained that in her research she reviewed the literature on all the syndromes that involve the behavior patterns described in autistic spectrum disorders. By engaging in this wide-ranging review, she found she was able to get the functional deficit areas. There is medical precedence for using this approach. Diabetes, for example, is a disorder of insulin production. However, we know that diabetic individuals may be vulnerable to a host of other disorders including circulatory disorders, visual disorders, disorders of immunity to infection, and others. In the same way, a child with an autistic spectrum disorder may have a few or many other related functional deficits.

Ms. Tsakiris explained that she looked at outcome-based research. First she looked at each deficit area in autistic spectrum disorders. What she discovered is that there is amazing lack of research on play. In occupational therapy, sensory integration research demonstrated clinically meaningful data, but the least amount of clinically significant data. Finally, she explained that she looked at surface behavior studies. Surface behaviors are those behaviors that can be visually observed and quantitatively counted. Surface behavior research yielded the largest amount of studies. However, the quality of the research was low. Surface behavior studies fell into the area of multiple baseline comparisons, not clinical trials. 38 studies were in this format. Only 2 were clinical trials, and 10 were quasi-experimental. Of the 54 studies on which New York based it’s guidelines for treatment of ASD, only 3 studies had more than 20 Ss. And 51 studies had four or less Ss. This evidence points out the fact that we need to know what intervention works for what child at what point in the intervention process, and that there is no one best option for treatment of ASD.

The strongest and most definitive clinically significant and clinically meaningful research support occurred in the areas of speech language, relationship based, and motor planning.

We need to make individual recipes for individual kids.

Compelling data exists to support the DIR approach as contrasted with more circumscribed approaches. Fit the intervention to the child, not the child to the intervention.

***Assessment of subtle hearing problems in children with autistic spectrum disorders
Presenter: Jane Madell, Ph.D.***

Dr. Madell stated that auditory function is not the same as hearing loss. Audition and hearing is a complex function. Having one disability is not a protection from having another disability. We must look at everything going on with the child.

She further stated that there is no such thing as an untestable child, only an evaluator who can’t accomplish the testing. She firmly believes that hearing status can be obtained for every child. Dr. Madell stated that there are 4 types of disorders:

Hearing loss

Degree of loss

Type of hearing loss

Auditory processing disorder

Inability or reduced ability to understand speech when the signal is degraded

Auditory versus language processing disorder

Auditory processing relates to getting the message through

Auditory attention disorder

Difficulty attending to auditory information consistently

Sound sensitivities

Difficulty tolerating loud sounds

Hearing sounds at softer than normal levels—sensory overload

- Dr. Madell described that optimal audiological evaluation is one that includes: Auditory history
- Medical history for ear infections: every ear infection takes 6 weeks for normal hearing to return
- Investigation of the context of audiological deficits, auditory processing, auditory attention and sound sensitivities
- Sound thresholds
- Auditory attention—can the child attend to auditory signals. If the child won't attend visually, or tactilely, then the clinician must assume that there is an attention issue, not an auditory problem.
- History of sound sensitivity

In order to manage auditory processing difficulties in the school setting Dr. Madell suggested the following:

- Children with Auditory processing difficulties should not be in an open classroom.
- The auditory context should be modified with carpeting.
- If we know that a child has an auditory processing problem, the child should have pull out therapies rather than therapies in an included noisy setting.
- You can maximize the child's auditory functioning by giving new information in quiet and build auditory capacity in noisier contexts.

Auditory goals are set to rove auditory attention, processing, reduce sound sensitivities.

There are a number of types of intervention to address this:

- Intense auditory stimulation Tomatis, Barrard, etc.
- On-going listening
- Computerized listening therapy
- Teach the child to work through the skills

Dr. Madell explained that speech language therapy will improve the child's language, but it won't improve auditory processing.

Dr. Madell closed by stating that goals for the child with an auditory processing disability need to be created around five different contexts including normal conversation in quiet, soft conversation in quiet and three different noises.

Developmental Approach to Assessment and Intervention with Speech and Language Challenge

Presenters: Barry Prizant, Ph. D. and Sima Gerber, Ph. D.

Drs. Prizant and Gerber stated that there are parallels among their work and the work of others who have already presented, because it is derived from related research in child development over the past two decades. They then shared the guidelines for assessment and intervention in speech and language intervention as follows:

Assessment Guidelines

1. Developmental research of language and communication should provide the framework for assessment. You must address where a child is developmentally.

Major developmental stages of expressive language include:

- *Early pre-intentional communication,
- *Pre-intentional pre-linguistic language,

*Intentional pre-linguistic,
*First word stage - emerging first words and solid first words are sensory motor in nature, early multi word and two-word stage,

*Early semantic and syntactic - children make bridges between feelings and thoughts,

*Later semantic and syntactic stage - children construct meanings over many utterances emergence of discourse and conversation,

*Communicative competence, including awareness of social conventions in their use of language (e.g. whispering in a library), and socially appropriate use of language across different contexts.

2. Parents or primary caregivers should be considered expert informants about a child's communicative competence. We see significant variability in communication abilities across situations and parents can provide the best descriptions of their child's communication to capture the most valid picture. By letting parents know that they are the experts on their child, we can begin to establish collaboration with parents. Drs. Gerber & Prizant allow parents to edit their assessment reports and approve the final copy so that it is a truly collaborative effort.
3. Assessment involves gathering information over time. It is an on going process and not a one time episodic event. We must view the communicative behavior within the context of the child's capacity for emotional regulation, and the level of stress imposed by the assessment itself.
4. In order to profile communicative capacity we need to use a variety of strategies including direct assessment, naturalistic observations and interviewing significant others. Each one of these approaches provides qualitatively different information. Our goal is to paint a picture of variability over time, and over contexts. Communication abilities cannot be captured solely by numeric scores.
5. Assessment must account for conventional and unconventional communicative behavior. Unconventional communicative behavior

may include idiosyncratic, difficult to read, and/or socially undesirable means to communicate, such as echolalia, perseverative speech, or problem behavior such as aggression. When we observe conventional gestures and words, they are typically addressed in the assessment. We must also account for unconventional behavior, however, such behavior is often dismissed as problem behavior, as noncommunicative, or as interfering. Unconventional means of communication must not be dismissed, as it is part of a child's communicative repertoire. Such an understanding leads to interventions that acknowledge a child's unconventional means to communicate, and that help a child to acquire more conventional and socially desirable means.

6. Assessment should lead directly to intervention. Assessment is a form of intervention because it helps us help parents understand their child's communicative abilities, which result in parents developing supportive interactive strategies. The assessment then becomes intervention.
7. In assessment we have to recognize that children with speech, language and communication problems often have relationship socioemotional difficulties, because communication and socioemotional development are closely related. This must be addressed in assessment.
8. Assessment considers the interaction between the child and the child's communicative partners including expression of and sharing affect, and how each partner develops an internal model of how satisfying communicative interactions are.
9. There are a number of domains in assessment for children from early pre intentional stages to early multiword stages and for more verbal children. Some of these domains include:
 - Means of communication
 - Speech
 - Vocalizations
 - Communicative functions or purposes
 - Frequency of self initiated speech
 - Repair and persistence in communicative intent

- Comprehension of language
- Speech production
- Cognitive development, constructive and imaginative play
- Attentional issues
- Affective and socio emotional interactions

Intervention guidelines

1. Intervention goals should be individually based
2. Goals need to be considered developmentally and also from a child's need to communicate within the family context
3. Use visual supports for communication. (E.g., picture schedules, written language supports) even with young children.
4. When working with a child, stay at the child's physical level.
5. Embrace both child directed and clinician directed engagement. There is a continuum from more directive (adult control) to more facilitative (child centered) styles, and the right balance has to be found for a child across activities. A priority is to utilize or move to child-centered approaches, however, for some children, initial use of greater external structure may be more

organizing. Such structure can be provided through the use of predictable and consistent routines.

6. Communication is multi-modal and children should be encouraged and supported in using multiple means to communicate including gestures, vocalizations, verbalizations and non-speech communication such as signs and pictures.
7. The child needs to be an active participant in the treatment, not a passive recipient of treatment. Activity based intervention, as opposed to mass trial drills support initiation, motivation and active involvement.
8. Parents need to be included to the extent that they want to be included. Children clearly benefit from having their parents involved.
9. In routine you can provide the framework for spontaneity and engagement
10. We have to understand children's preferences, style of learning and unconventional behavior as starting points for facilitating communication.
11. Intervention designed to enhance communication abilities also supports cognitive, social and emotional development in children.

Frontiers of Biomedical Treatment in Autistic Spectrum Disorders

Richard Solomon M.D.

A Dimensional Approach to the Autistic Spectrum **Presenter: Eric Hollander, M.D.**

Dr. Hollander is a professor of psychiatry and clinical director of the Seaver Autism Research Center at the Mt. Sinai School of Medicine in New York. His presentation divided autism into three symptom domains: social impairment, communication impairment and restricted interests and repetitive behaviors. He then gave evidence for the brain systems involved and the recently studied medications that show promise of treating each dimension/brain system. Evidence for treatment efficacy was based on recent clinical trials. The medications discussed included the following:

- Venlafaxine which treats ADHD symptoms and repetitive behaviors, fluoxetine (Prozac) a serotonin re-uptake inhibitor which treats repetitive/obsessive compulsive behaviors and social anxiety symptoms.
- Olzapine (Zyprexa) which treats social/behavioral symptoms and aggression
- Divalproex (Depakote) which treats affect and aggression, and the seizures and abnormal EEG findings common in autism and

- helped improve mood and behavior problems.
- Intravenous Oxytocin which showed some evidence of helping repetitive behaviors in those treated.

The general approach involved looking at the symptom dimension and brain system, matching the treatment to the symptoms,

using one treatment at a time beginning with a low dose, following the symptoms and titrating the dose upward as tolerated until the desired effect was obtained. This symptom-based approach to the treatment of ASDs is still in its early stages of research but holds promise for future medical treatments of autism.

New Medical Treatments for Children with Autistic Spectrum Disorders (ASDs)
Presenter: Michael Chez M.D.

In this presentation, Dr. Chez, a Lake Bluff, Illinois, pediatric neurologist and Assistant Professor at Rush-Presbyterian St. Lukes Medical Center in Chicago, discussed evidence from recent clinical trials for the benefits of two new medical treatments for ASDs in children. First, he discussed Landau-Kleffner Syndrome (LKS) and its variants in which a seizure disorder mimics autism and is treatable with steroids. Dr. Chez showed evidence that pulse dose (instead of daily dosing) steroids in combination with valproic acid significantly helped a group of 44 children, with abnormal EEGs, autistic symptoms and language regression, to regain receptive language over a 13 months trial. It is important to note that most of the abnormal EEGs were discovered on 24-hour studies.

Next, he described the use of Aricept, an Alzheimer's drug, for children with ASDs. Aricept increases brain acetylcholine, a neurotransmitter that improves language in Alzheimer's patients. We have also found that it clinically effective in treating children with autism or pervasive developmental

delays. In two clinical trials, Aricept showed promise of helping children 3-13 years of age with ASDs. The first study, an open-label clinical trial, showed improvements in their CARS (Childhood Autism Rating Scale) scores and expressive language. In the second, placebo-controlled trial, patients on Aricept for twelve weeks improved their receptive language significantly more than patients on Aricept for six weeks. Receptive scores improved significantly more, in six weeks, on Aricept versus placebo. Expressive scores indicated that improvements typically resulted during the first six weeks of Aricept treatment. CARS scores, indicating an improvement in general autistic behaviors, were also statistically significant after six weeks of Aricept treatment.

For this reviewer, the significance of Dr. Chez's presentation lies in the importance of recognizing the role of abnormal EEGs obtained in 24 hour studies and the promise to improve social and language abilities with Alzheimer's medication.

Evolution, Immunity and Autism
Presenter: Andrew Zimmerman, M.D.

Dr. Zimmerman, an Associate Professor of Neurology and Psychiatry at Kennedy Krieger Institute and Johns Hopkins University, reviewed the role of human evolution in the development of both the immune system and the central nervous system. His hypothesis is that evolution provides clues to potential pathways where immune system functions interact with brain development, thus paving the way for

pathological interactions between the two systems that result in conditions like autism. For example, specific tissue types (HLA or human lymphocyte antigens), that are important to match in tissue transplantation, since a mismatch can trigger rejection), are also critical for making the correct nerve cell connections in brain networks during development. A "mismatch" reaction might occur between the tissue types a child

inherits from his parents, thereby disrupting the usual expression of the tissue types at

critical times during brain development.

PARENT PANEL

THE ROLE OF THE PARENT: FACING THE CHALLENGES OF RAISING A CHILD WITH COMMUNICATION AND LANGUAGE DIFFICULTIES

Deborah Flaschen

The Parent as Decision-Maker, Choosing an Approach

Presenter: Jane Downey

Jane Downey, a mother of eight, with one child on the autistic spectrum, spoke about the experience that she and her family have had “avoiding some paths, and running away from others.” She talked about refusing to say the “A” word because it offered her positively no hope. She was open and candid about her feelings and experience and spoke about her reluctance to turn over control of her children to others. She was introduced to Floortime through a speech and language pathologist who utilized this approach as part of her therapy session. It was play-based, interactive and relationship based which matched their family way of life and values. She then attended Dr. Greenspan’s Infancy and Early Childhood Training Course and began organizing her family around an intense “rescue mission”. Her son has done very well. He is a warm, engaged, interactive member of their family. He is fully included in school, with all therapies provided in the classroom.

While they have explored other interventions and tools Jane stated that they had never pursued any nutritional or medical options,

as she “couldn’t face another battleground.” She does plan to have her son do Samonas listening training because his verbal abilities are still lagging. Jane closed with “we are a special group of people, not by choice but by journey.”

There was then a discussion among the panelists and Deborah Flaschen explained why her family chose to pursue nutritional and medical interventions. Her son has had and continues to have gastrointestinal and food issues. She began by contacting nutritionist Kelly Dorfman, who reviewed her son’s profile and recommended a gluten-free, casein-free diet. Deborah had this confirmed by blood and urine tests and then embarked upon the diet. The results in her son are dramatic and they have been on the diet for over 6 years now adding further restrictions such as the Feingold Diet, specific food allergies, high protein, limited yeast and sugar, nutritional supplements and gastrointestinal medicines. As medical issues continue they now plan to explore immunological and endocrinological involvement.

The Parent as Coordinator: Creating a Team and Treatment Plan

Presenter: Cindy Harrison

Cindy Harrison resides in Ottawa, Canada, a region where there are no senior ‘DIR/ Floortime’ clinicians and little known or practiced about DIR intervention. Cindy explained that she found out about this

method through reading and surfing the web and became firmly committed to the ‘DIR/ Floortime’ approach. Although Cindy and her husband were confident about assuming the leadership role for their son, they

strongly believed they needed expert guidance. They found this by utilizing travel to sessions in the States one to two times a year and intermittent telephone consultation with a senior DIR clinician. Cindy believes that parents are the cornerstones of the intervention but DIR coaching and direction at regular intervals is crucial for success.

Once they had their coach in place, they began to assemble a team of “warm, empathic, high affect, multidisciplinary, creative” people to carry out their comprehensive intervention. Their plan included 8 sessions of floortime, 3 sessions of semi-structured activities, speech language therapy, OT, and peer play dates. Each week Cindy and her husband evaluated how well they performed against their plan. Cindy emphasized that communication is critical to the successful performance of the team. Cindy and her husband try to bring team members together as often as possible to celebrate successes and re evaluate goals. If in-person meetings

are not possible they utilize conference calls and use of the Internet.

In closing, Cindy encouraged every parent of a special needs child to use the web as a resource. She recommended the following sites: www.icdl.com, www.saveachild.com, and egroups for parent and professional discussion groups. Books she recommended were The Child with Special Needs, and Building Bridges Through Sensory Integration.

Sally Savelle, then spoke briefly about the value of having a local parent Floortime group as a resource. Sally chairs the Boston area Floortime Group that meets bi-monthly (and has done so for over 3 years). It is not a support group but rather a DIR/Floortime resource group. Parents share videotapes of consultations with Drs. Greenspan and Wieder, their local therapists and provide advice and feedback to one another on their floortime work with their child.

The Parent as Survivor: Holding It Together
Presenter: David Raphael

David Raphael discussed how parents must be aware of the emotional reactions to having a child with severe communications and developmental disorders. The news that one’s child has been assessed with serious development challenges can bring to the surface painful and difficult memories and experiences. The challenge, he stated is for parents confront their own fears and emotional pains in order to engage fully in their child’s treatment program. He said that we all bring our own “intergenerational angst-it can paralyze us or mobilize us. The trick is to have it mobilize us.”

He feels strongly that if the parent does not confront their own emotional issues he or she will not be able to help their child work through their challenges. The DIR method, Floortime, requires that the parent be totally present for the child and follow his or her lead. If a parent is in emotional turmoil it is very difficult to focus on their child.

Religious traditions helped David and his family provided guidance during the very

difficult times. David was able to look at biblical sources and rabbinical passages for help and strength. He spoke of the story of the Sacrifice of Isaac from the book of Genesis as one that provided particular challenges and guidance is his efforts. Through exploring this story and coming to grips with Abraham’s role and choices David realized that Abraham’s willingness to sacrifice his son was not a virtue but rather a failure. In David’s words: I will not sacrifice his child. I will work day and night on his behalf. “Someone else is going to have to build nations” because he is “too busy doing ‘Floortime’.”

David closed by encouraging each of us to follow a similar path-to explore and embrace the range of emotions within us. The goal is to help each of our children achieve as much as they can. He advised us to look to our families, our traditions and religions to work these feelings through.

Sally Savelle added to the survival topic by talking about how important it is to talk with

others about what you are going through and what you are feeling. Her husband and someone from her church counseled her to work through her feelings about her son's challenges. She told the group that she had had a very difficult time initially and needed the help of her faith and other people to work her feeling through. She closed her comments by saying stating that she has learned a great deal and that her son is my hero.

Jane added that her family survived through its commitment to a common cause and their strong faith. She said, "we were on a rescue mission. I expected everyone (there are 8 children in the family) to get on the bandwagon." Although she said she didn't focus on 'supporting the siblings' per se, she said, "I practice relationship-based therapy with all my children.

The Parent as Advocate: Working for Change
Presenter: Rick Rollens

Rick Rollins spoke about what was happening at the time his son was diagnosed with autism, He was serving as Secretary of the Senate for the California State Legislature. His son suffered an adverse reaction to his 3rd DPT shot. Rick began by reviewing the scientific literature on autism and was horrified to learn how little research had ever been done. "Up until 2 years ago, our National Institutes of Health (NIH) was spending more money on sleep disorders than on autism."

1998, DDS published the California Report that documented a 273% increase in autism over a 10 year period, and "that changed the paradigm." He then went on to co-found, with four dads, the U C Davis M.I.N.D. (Medical Investigation of Neurodevelopmental Disorders) Institute in an effort to begin a serious commitment to biological research on the causes and treatment of autism. With the help of a \$34 million appropriation from the State of California, the MIND Institute currently has \$40 million to spend on autism research.

Rick co founded FEAT, Families for Early Autism Treatment, which is a very active organization that publishes an enormously helpful, free, daily e-newsletter on all news concerning autism (see www.feat.org). Rick then encouraged the California Legislature to commission a report by the California Department of Developmental Services (DDS) to track and document the prevalence of autism cases within California. In April

Rick acknowledges that his legislative and media background uniquely qualified him to make such a large-scale impact. Nonetheless, he encouraged every family to make their own impact, whether it is through their local school district or department of social services. He also exhorted families to stay together.

Autism:
The Causes and Increase in Cases

Cecilia Breinbauer M.D.
Jo Raphael, MSW

The Epidemiology of Autistic Spectrum Disorders, California and Others
Presenter: Lisa Croen, Ph.D.

Epidemiologist, California Birth Defects Monitoring Project

Dr. Croen wonderfully explained why it is so difficult to answer today's popular question: "Is Autism increasing?" with a simple Yes or No. Although anecdotal reports from clinicians suggest an increase, Service

Agencies report an increase in caseload (DDS report: 210% increase between 1987 – 1998), and Schools show an increase in Special Education enrollment (nine-fold increase between 91/92 – 96/97),

epidemiological studies show several methodological issues that interfere with a clear answer. Early studies showing a prevalence of 4-5/10,000 are far from the latest findings (CDC) of 40/10,000. Diagnostic criteria clearly affect numbers and there are still unanswered questions like:

- Has the definition of autism expanded to include a broader spectrum?
- Is identification of children with autism improving?
- Is increase seen across the board? In all demographic groups, geographic areas, sub-types?
- What has changed over the time period of apparent increase in autism?

Dr. Croen stated the need for longitudinal, epidemiological studies in a well-defined target population. She shared also some results from a recent study done in

California, obtaining data from the Department of Developmental Services (DDS) for children born in California between 1987 and 1994.

One of many interesting findings was a change in the classical association between Autism and MR. In this study, only 35% of children with Autism also presented with MR and the percentage of Autism without MR increased to 63%. This could be associated with early diagnosis and intervention, but also with a broader spectrum. It also indicates that many autistic children who previously were given a diagnosis of MR and not autism are now classified as autistic. The main risk factor found in this study was sex, being male babies at a higher risk than female babies. The good news is that the CDC finally got funds to start a population based surveillance in the field of Autism.

Epidemiologic Studies of Autistic Spectrum Disorder

Presenter: *Marshalyn Yeargin-Allsopp, MD*
Centers for Disease Control

Dr. Yeargin-Allsopp explained that what we presently know about the clinical features of autism was described quite accurately by Dr. Leo Kanner in the 1940s and was confirmed by other early clinical studies of children with autism. Most of the information on the prevalence of autism has been learned from studies conducted outside the United States, using different methods, different case definitions, different populations, and conducted over different time periods. In order to determine the current prevalence of autism and determine whether there is an increased prevalence in recent years, we must have well-designed population based epidemiologic studies.

PREVIOUS PREVALENCE STUDIES

Dr. Lorna Wing (UK) conducted a review of 16 prevalence studies, performed between 1966 and 1991. Four early studies (Lotter, UK; Brask, Denmark; Wing & Gould, UK; Hoshino, Japan) used Kanner's criteria: a profound lack of interaction with other people; an obsessive desire for sameness; a fascination with objects; mutism, or language that is not used to communicate;

and good cognitive skills in feats of memory on performance tests. The first population-based study was performed in England in 1966 (Lotter) and reported a prevalence of 4.5 per 10,000; other early studies reported similar prevalence rates of 4-5 per 10,000. Until recently, this prevalence rate (4-5 per 10,000) was the one most often cited in the literature.

Dr. Rutter (UK) described diagnostic criteria for autism that were similar to those of Kanner. Two studies used Rutter's criteria (Bohman, Sweden; Cialdella & Mammelle, France) but the rates were markedly different (5.6 and 10.8 per 10,000).

Several studies used DSM III criteria (Matsuishi, Japan; Tanoue, Japan; Sugiyama & Abe, Japan; Burd, USA; Ritvo, USA, Gillberg, Sweden; Steffenburg & Gillberg, Sweden). DSM III first used the term Pervasive Developmental Disorders, with a subsequent broadening of the criteria, differentiated between autism and schizophrenia and described the onset as being less than 30 months. The rates varied

between a low of 3.3 (US) to a high of 15.5 per 10,000 (Japan).

DSM III-R criteria continued to broaden the criteria for autism. Two studies (Bryson, Canada; Gillberg, Sweden) had markedly similar rates (10.1 and 11.5 per 10,000). One additional Japanese study (Ishii & Takahashii) used criteria that were a combination of the others; the prevalence rate was 16 per 10,000.

Dr. Wing's review revealed that the mean prevalence of all the studies was 8.4 per 10,000 with a range of 3.3 to 16. She found no relationship between autism and factors such as size of population, age ranges, proportion of IQ groups, years of birth, social class, race and ethnicity. There appeared to be a higher prevalence in the studies that used a broader definition of autism. There was also a suggestion that the inclusion of more low functioning and more high functioning individuals may have been responsible for the higher prevalence rates seen in some studies. Dr. Wing also felt that differences in diagnostic interpretation could lead to differences in prevalence rates.

Dr. Christopher Gillberg examined these same studies and organized them according to chronological time period. Those studies performed before 1985 had a mean prevalence of 5.3 per 10,000 and with the exception of one Japanese study, all had prevalence rates between 4.0 and 6.1 per 10,000. On the other hand, all of the studies performed after 1985 had rates higher than the 4-6 per 10,000, with a mean prevalence of 11.8 per 10,000.

In order to determine if there has been an increase in the prevalence of autism over time we need to determine the prevalence in the same population, using the same methods, at difference points in time. However, there have been very few studies of autism trends. In France, the prevalence of autism was determined for two birth cohorts (1972 and 1976) and it was found that there was no change in prevalence (5.1 and 4.9 per 10,000) over that short period of time. In Sweden, the prevalence of autism was determined for two periods of time, 1962-76 and 1975-84. Over that longer

period of time the prevalence increased from 4.0 to 11.6 per 10,000. Dr. Gillberg reports a possible explanation for the increased prevalence over time. He noted that the rate of autism in children with mild mental retardation remained relatively stable over that time period, while the rates increased in children who function at the two ends of the spectrum of intelligence, children with severe MR (IQ <50) and children with normal intelligence (IQ > 70). Dr. Gillberg has also reported the prevalence of Asperger's syndrome: between 26 and 48 per 10,000 individuals. Although there is controversy about the criteria for Asperger Syndrome, it is believed that the prevalence of this disorder is several times higher than the prevalence of "classic autism."

We are aware of only three prevalence studies of autism conducted in the US prior to 1998: one in North Dakota (Burd, 1987)) reported a prevalence of 3.3 per 10,000; another conducted in Utah (Ritvo, 1989) reported a prevalence of 4 per 10,000 and a third conducted in Arkansas (Kirby, 1995) reported a prevalence of 4.0 per 10,000. The lower prevalence rates in the US may be attributed to limited access to complete health and education records for conducting epidemiologic studies.

There are several methodologic issues that affect the prevalence rate from any study. The first is the case definition. Unlike birth defects or cancer, there is no diagnostic test for autism. It relies on a description of behaviors by a professional with training and experience in autism. It appears that in the past, the prevalence of autism was greatly influenced by diagnostic criteria, criteria that have changed over time. An important epidemiologic issue that relates to prevalence is the precision of case definition, specifically, for research purposes, do we count children with "classic autism" or the broader "autism spectrum"? The method of case identification will also affect the prevalence. Studies that screened the entire population, followed by clinical assessments yield a higher prevalence than rates obtained from a review of administrative records. In addition, the prevalence does seem to be affected by our ability to identify children who function at the very low and at the high end of the range of

intelligence. The prevalence rate is also affected by migration, which is often hard to measure, e.g. families with children with autism may move into a specific area for the services; this may inflate the prevalence rate for that particular geographic area.

Anecdotal evidence from professionals seems to indicate that more children with autism are presenting for services. This may be attributed to greater public awareness due to the Americans With Disabilities Act, greater educational services under the Individuals with Disabilities Education Act (IDEA, part B) and current media attention around autism.

CDC AUTISM EPIDEMIOLOGIC ACTIVITIES

CDC conducts public health activities: surveillance: the ongoing monitoring of disease patterns; epidemiologic research: to look for risk factors and protective factors for conditions; and prevention research: putting research into effective practice. Since 1991 CDC has conducted population-based studies on four developmental disabilities: cerebral palsy, mental retardation, hearing impairment, and vision impairment in children ages 3-10 years in a geographically defined area-five counties of metropolitan Atlanta, (the Metropolitan Atlanta Developmental Disabilities Surveillance Program, MADDSP). CDC staff ascertain children for the study by review of records of service agencies, e.g., public schools, pediatric hospitals, and public and private programs and clinics for children with developmental disabilities (active surveillance). There is no clinical examination of the children. Therefore, the identification of children for the surveillance system is dependent upon a description in the record of the features that are believed to be essential for meeting the case definition. In 1998 CDC added autism spectrum disorders (autistic disorder and atypical autism, e.g., PDD-NOS and Asperger Syndrome) to the ongoing population-based surveillance for developmental disabilities in metropolitan Atlanta. For children identified with autism, in addition to the prevalence by socioeconomic factors such as race/ethnicity and gender, information will also be

available on level of functioning, presence of coexisting disabilities and underlying medical conditions.

In 1998, CDC was contacted by families in Brick Township, a middle class community in eastern New Jersey because of concerns about a perceived increased prevalence of autism and a possible environmental correlation. Another federal agency, the Agency for Toxic Substances and Disease Registry (ATSDR) was also asked to assist in the investigation because of their expertise in examining environmental factors. The Brick Township prevalence study was modeled after the CDC metropolitan Atlanta autism prevalence study in order to be able to compare the prevalence rates for the two areas. The children in Brick were 3-10 years of age (the total population of children 3-10 years old numbered 8,896) and were residents of Brick Township in 1998. There were two phases of the study: case identification and case verification (clinical examinations, which included histories, physical and neurological examinations, psychological examinations and administration of the Autism Diagnostic Observation Schedule--Generic). Children were identified through public and private schools, psychiatric and medical facilities, individual clinicians and parental referral. Medical and education records were reviewed on children that were potential cases for the study. For children residing in Brick in 1998, the prevalence of autistic disorder was 4.0 per 1,000 and the prevalence for autism spectrum disorders was 6.7 per 1,000. The prevalence of autism in Brick Township is higher than most previously published rates. However, current rates of autism in the US are not available. Yet, there are a few, very recent studies in other countries that found similar rates to Brick Township.

There has been an upward trend in the number of children receiving services for autism in the US in recent years. The characteristics of the children with autism from Brick seem to validate the methods used for the study and the study results.

CDC is conducting a case-control study to determine if there is an association between receipt of the MMR vaccine and the onset of autism. The evidence for a possible

association is based on (1) the fact that the prevalence of autism has been increasing at the same time that childhood vaccination coverage has increased and (2) the temporal association between the onset of autistic characteristics and timing of vaccination. The objectives of the study are: to estimate the exposure frequency for the MMR vaccine among school-age children with and without autism (the exposure is receipt of MMR vaccine by 36 months of age); to determine the temporal relationship, when possible, between MMR vaccine and first recognition of autism; and to describe potential confounders, such as co-existing developmental disabilities, birth certificate variables and birth defects. The cases of autism will be obtained from the CDC surveillance system, MADDSP; they will be matched with controls (3 controls per case) based on school system, age and gender. Developmental and immunization histories will be collected from education records. The strengths of the study include: it will be from a population-based sample of children with autism (available from the CDC surveillance system); immunization records of the children are available from existing files; the case-control study design provides information on children without autism from the same population; and it is a large sample: there will be information on more than 500 children with autism and more than 1500 control children. The limitations include: it is a record review of autism, hence it is difficult to pinpoint the earliest

onset of the disorder for a number of children; and information on other possible contributing factors is not always available. Results from this study are expected to be available in 2001.

Other CDC activities include funding Marshall University in West Virginia to conduct a study of secondary conditions in individuals with autism and to expand their activities to conduct surveillance of autism in 6 counties in West Virginia. In addition, CDC awarded grants to four areas to conduct population-based surveillance of autism and other developmental disabilities. Other public health activities in response to concerns about autism include an NIH/CDC Study of the Onset of Autism and Regression; an Institute of Medicine Review of Vaccine Safety Issues; an American Academy of Pediatrics Review of Autism and Childhood Immunizations; and a Case-Control Study of Reports of Inflammatory Bowel Disease from the Vaccine Safety Datalink.

CONCLUSION

Autism is an evolving field
 Epidemiology is a tool than can be used to better understand autism
 We do not know the prevalence of autism in most communities in the US
 We do not know the etiology of most cases of autism
 Recent attention to autism issues has the potential to lead to answers

Genetic and Neuroanatomical and Biochemical Pathways

Presenter: Margaret Bauman, MD.

Dr. Bauman gave an overview the research focus of neuroscientists looking at disorders of communicating and relating. She reported that we have some reasonable neurobiological information on Autism, and that we are gathering it on Asperger's, and we know more about Rett's Syndrome-especially since the discovery of a gene associated with the disorder, however, Childhood Disintegrative Disorder and PDD-NOS remain unclear.

Researchers are making a great effort to recognize children with issues early on. There is a study done by Dr. Dawson in

Seattle to look at first birthday videotapes in children who had been identified as Autistic to see if they could come up with some mechanism to identify children. They found that they were able to see lack of pointing and difficulty with joint attention. Dr. Teitelbaum looked at motor patterns in infants and found those to be atypical. This raises questions in terms of developmental milestones and as to the "why" and the "where" but not the "when". More and more research groups are looking at younger children and doing prospective studies. Researchers feel that they can pick up these children earlier if they can find the right

questions to ask. For example, it is not enough to ask “when did your child walk?”, but we must also ask, “How did your child walk?”. We need to look not only at the attainment of a developmental capacity, but also the quality of the process by which a child functioned in that developmental task.

Dr. Bauman’s lab studied 11 brains and found that the Autistic brain is bigger than they should be. This could point to a degenerative disease as the brain weight is changing. No obvious abnormalities were found. They found that the Hippocampus and the nerve size are smaller in the Autistic individuals with too many cells that are too small. This does not suggest brain damage, rather it suggests developmental delay, which leads to the hypothesis that something has slowed down the development of these neurons. Other studies have borne out the same results.

There were a number of studies done with adult monkeys looking at lesions. These monkeys had symptoms similar to Autistic children. As baby monkeys matured over time they developed, tantrums, deficits in cognitive function, stereotypic motor behavior, deficits in cognitive function, blank faces. Other studies showed adult Autistic monkey with too few, small cells. The Autistic children monkeys had larger neurons and cells. At around age 13 this reverses and the cells shrink to a more typical size.

The human children on the spectrum have intact rote habit memory, as that part of the brain is structurally normal. They are terrific at gathering data-it’s what they do with the information that becomes the problem. Representational memory involves all sensory modalities and it is in the limbic system-it is the processor of higher order information. The rote habit system is what babies use to learn from early on. The limbic system and rote habit memory kick in at 19 months give or take 3 months. If the hippocampus and the limbic system are immature you may see developmental delays. In some cases this may be what we perceive as regression in some children.

Several neuroscientists put together a consortium of about 18 labs to explore frozen brain tissue to find out what the genetics, the neurochemistry, and the neuroimmunology of these brains are and what conclusions can they reach to treat the kids. Two recent findings from these studies came out of this group: Finding one states that the brain of the autistic subject is remarkably insufficient in GABA and Finding Two states that there are major deficiencies in the acetocolene neurotransmitter system. Neurotransmitters, neuropeptides, serotonin, BDNF and BIP are all found to be involved. The scientists are getting closer but more research needs to be done.