EARLY DIAGNOSIS & INTERVENTION IN AUTISM SPECTRUM DISORDERS

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WHAT IS…

- Autism is a neurodevelopmental disorder, affecting development in social interactions, communication with problem behaviors that are restrictive, repetitive & stereotypic.
- Highly genetic disorder of undetermined inheritance with no definite gene culprit, probably polygenetic with some environmental interaction.
WHAT IS THE AUTISM SPECTRUM?

- A continuum of disorders that share the 3 common characteristics
- Impression that the “spectrum” is from severe (autism) to mild (Asperger) with PDD-NOS in between
- Asperger individuals can be severely impaired psychiatrically, autism can be high functioning
- Spectrum extends to borderline normal with concept of BAP (broad autism phenotype)
SUBTYPES OF AUTISM SPECTRUM DISORDERS

- Autistic Disorder/Classic Autism
- Asperger Syndrome/Asperger’s disorder
- Pervasive Developmental Disorder, not otherwise specified (PDD-NOS)
- Childhood Disintegrative Disorder (CDD)
- Rett Syndrome/Rett’s disorder
A. A total of 6 (or more) items from (1), (2), & (3), at least 2 from (1), and 1 from (2) & (3):

(1) qualitative impairment in social interaction:
   (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   (b) failure to develop peer relationships appropriate to developmental level
   (c) a lack of spontaneous seeking to share interests, enjoyment, or achievements with other people (e.g., by a lack of showing, bringing or pointing out objects of interest)
   (d) lack of social or emotional reciprocity
DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER

(2) qualitative impairments in communication as manifested by at least one of the following:
   (a) delay in, or total lack of, the development of spoken language (not accompanied by attempt to compensate through alternative modes of communication gesture or mime)
   (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   (c) stereotyped and repetitive use of language or idiosyncratic language
   (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
(3) restricted **repetitive** and **stereotyped** patterns of behavior, interests, and activities:
   (a) encompassing preoccupation with one or more stereotyped, restricted patterns of interest abnormal either in intensity or focus
   (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
   (c) stereotyped and repetitive motor mannerisms (hand or finger flapping, or complex whole-body movements)
   (d) persistent preoccupation w/parts of objects
DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER

- Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.
A WORD ABOUT THE OTHER ASDs

- CDD: Very rare, rapidly regressive pattern, usually between 3-5 years age in multiple areas: fine motor, language, cognitive, usually seen with seizures

- PDD-NOS: many of autistic features, but not meeting all 6 criteria of autism
  Critical to have social deficits however to qualify as PDD-NOS. Not a “waste-basket” diagnosis if applied correctly
ASPERGER SYNDROME

- Not a diagnosis typically made in 0-3 age group
- Improvement in communication in an autistic child does not mean AS diagnosis is warranted
- Autism diagnosis takes precedence
- “Fashionable” diagnosis due to connotations of “mild” form with supposed better prognosis
RETT SYNDROME…
An Unique Model for PDD

- X linked (Xq28.2)
- MeCP-2 gene
- Acts by gene regulation of silencing protein synthesis
- More than 50 mutations involved
- Still clinical diagnosis, genetics only 75-80% sensitive
- 99% sporadic cases, <1% familial
RETT SYNDROME

- Affects predominantly girls, theorized to be lethal in males
- However, some males have mutation and phenotype of seizures, profound cognitive impairment, encephalopathy, shortened life-span
- Early phases of Rett can mimic autism till typical hand-wringing stereotypies present

Estimates translate to ~425,000 < 18 years, and 114,000 < 5 years age. (Fombonne 2003)

Media portrayal of “epidemic”

Pitfalls of using educational data for estimating prevalence criteria that are neither rigorous nor consistent and are inconsistent from region to region. (Laidler 2005)
Number of Cases
[ U.S. School Years 1992 - 2003 ]

Graph Source: www.fightingautism.org
Data Source: www.ideaadata.org and www.cdc.gov/nchs/
WHY SO MANY...

Possible reasons for increased prevalence:
- Changes in diagnostic criteria
- Methodology for case ascertainment
- Increasing awareness among parents & professionals
- Awareness of comorbidity of autism with MR and other conditions
- Availability of specialized services
- Possible true increase
WHY YOUNGER CHILDREN..

- Changes in diagnostic patterns
- Previously mean age at first diagnosis was 6-7 years (Fombonne 2004, Mandell 2002)
- Evolution of screening and evaluation tools for younger children
- Impetus to diagnose between 12-24 months of age
- Use of M-CHAT, CHAT, PDDST-II for stage 1 and STAT for stage 2 screening standardizes observations (Goin et al, 2004)
- Infancy diagnosis is emerging (use of family videotapes) but still unreliable
WHY EARLY INTERVENTION..

- Intensive early intervention outcomes substantially better (Rogers 1998)
- Significant cost-benefit for early intervention (Jacobson et al 2000)
- 90% of children who don’t receive effective EI require custodial care costing US ~ $ 13 billion annually (FEAT 1996)
- Cost to school system per year for autistic student programming ~ $ 40,000-60,000 per student (NAS 2001)
## KY SCHOOL 2004 DATA

### Statewide Total

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WHAT’S MISSING?

- Kentucky Population: 4.15 million (2004 est)
- Persons under 5 years age: 6.6% (2000 census)
- Estimated children = 274,000
- Expected autism prevalence 60/10,000
- Expected autistic children KY = 1650 under the age of 5!

No actual prevalence study in KY, this is estimate based on current data available
EARLY IDENTIFICATION

- Pediatricians/Family Practitioners often first professional to encounter the child (in course of well child visit)
- Numerous encounters between 15 months and 3 years age (min. 4)
- Opportunity to explore development, parent concerns and observe behavior
- Concerns regarding adequate awareness/skill in primary physicians to alert to signs of autism
NEEDS FOR EARLY IDENTIFICATION

- Improve awareness of “red flags” for autism
  - parents and primary care providers
  - Service coordinators and providers through First Steps
- Improve screening of established clients in First Steps (esp. w/language delays)
- Use of standardized tools: M-CHAT, STAT, PDDST-II for screening children > 15 months
- Prominently displayed information on autism in form of wall charts, parent handouts etc in physician offices, therapist locations, libraries, daycare centers
FIRST SIGNS

- National non-profit organization dedicated to educating parents and pediatric professionals about the early warning signs of autism and other developmental disorders.
- **First Signs Screening Kit** for professionals, including educational video, screening guidelines, screening tools, wall chart of developmental milestones, and Early Intervention referral guide.
- Check out website [http://www.firstsigns.org/](http://www.firstsigns.org/)
- Excellent references on website including:
  - Books and Literature
  - Web Sites
  - Videos and DVDs
  - Products and Services
HOW EARLY TO IDENTIFY?

- Although some use of infant videotapes, not reliable diagnostic tool
- Some regression (25%) children after normal development till ~ 18 months
- Current mean age of diagnosis = 34 months
- Mandate to diagnose under 2 years of age, in light of reliable early screening tools
- Stability of diagnosis from 2 to 4 years age
SUSPICIOUS SIGNS OF AUTISM

If the child shows any of these signs, have practitioner immediately evaluate:

- No babbling by 12 months
- No pointing, showing, reaching by 12 months
- No words by 16 months
- No two-word meaningful phrases (without imitating or repeating) by 24 months
- Any loss of speech or babbling or social skills at any age
USING THE m-CHAT

- M-CHAT is modified (Fein, Robins et al) Checklist for autism in Toddlers (Baron-Cohen)
- Used as parent report at 18-24 months age
- Yes/no responses over 23 items
- Sensitivity & specificity 85-95%
- Free to obtain, easy to use and score
- Fail 2 “critical” or any 3 items warrants concern and referral for diagnosis
DIAGNOSTIC PROCESS

- Identification of referral sources
- Prompt referral to specialists for diagnosis
- Multidisciplinary approach helpful for planning interventions, not necessary for diagnosis
- Mechanism for sharing of information esp. of naturalistic observations
- Review of diagnosis after age 3 (“movement” along the spectrum)
INTERVENTION & DIAGNOSIS..

- Referral to First Steps must not be delayed till confirmatory diagnosis
- Identify Point of Entry and initiate referral through parent/primary provider
- Once diagnosis obtained, return to table to review modification of therapies
- Autism is considered “high probability” and automatic eligibility in several states
Inability to effectively translate research into practice:
- Inability to stay abreast of research literature: cost, access, “technical divide”
- System resistance to change
- Ineffective training of service providers and staff
- Lack of resources
- Clinicians’ impression that research situations don’t apply to practice
MYTHICAL BARRIERS

- Accessibility to scientific literature through partnership with higher educational institutions
- Systematic, repeated training of staff, supported by supervisors and the system
- Pooling of resources, non-traditional areas of funding (grants, private sector foundations)
- Other barriers to generalization (Adkins, 2002)
  - Readability of behavior plans by BCBA specialists at college level hampers implementation by direct care staff
  - But modifying the readability level of these plans resulted in enhanced treatment outcomes
- With the possible exception of the magnitude of the treatment effect, research outcomes quite generalizable to day to day practice. (Chambless & Ollendick, 2001).
SERVICES FOR CHILDREN WITH ASDs: VOICES OF PARENTS & PROVIDERS

- **Areas of Convergence: Parents and Providers**
  - **Family Support**: family-centered services, parent-to-parent support and respite.
  - **Early Identification**
  - **Finance**: provide resources to meet the financial responsibilities that accompany raising, educating, and providing services
  - **Training**: ongoing preservice, in-service, technical assistance and education for parents and providers
  - **Collaboration**: between parents and professionals and among professionals from different agencies
SERVICES FOR CHILDREN WITH ASDs: VOICES OF PARENTS & PROVIDERS

- **Areas of Convergence: Parents and Providers**
  - **Advocacy**: to foster a sense of empowerment so parents and providers can advocate effectively for children with ASD
  - **Inclusion**: not only the physical presence in an inclusive setting, but also the quality of those experiences within those settings
  - **Equity**: family-centered locus of control over decisions that impacted their children and themselves.

- Emergent themes analyzed from focus groups conducted at NECTAS-sponsored national meetings.

Sperry et al Infants & Young Children (1999)
PARENT CONCERNS IN KY

Themes of concerns:
- Lack of evidence based practices
- Lack of awareness of service providers
- Lack of early diagnosis through physicians

Forum for concerns:
- Online Chat rooms Autism KY
- Public forums on ASDAC website
- Direct contact with families
- Autism support group meetings
EVIDENCE BASED PRACTICES


- Emphasized education is primary form of treatment
- Reviewed existing scientific, policy and theoretical literature and create framework for evaluating scientific evidence concerning effects and features of educational interventions for young children with autism.
- Focus on Early Intervention, preschool and school age up to age 8.
EFFECTIVE INTERVENTION PROGRAMS

- Early entry into intervention programs
- Active engagement in intensive instructional programming 25 hours a week, 12 months a year
- Use of planned teaching opportunities that are developmentally appropriate
- Sufficient amounts of adult attention to meet individualized goals (1:1 and small group)
- Services to begin as soon as a child is suspected of having an ASD
TYPES OF INTERVENTION PROGRAMS

Excellent overview with detail in book by Handleman & Harris (2000)

Some examples are

❖ Behavioral programs:
  ➢ UCLA YAP (Lovaas)
  ➢ Pivotal Response Training (Koegel)
  ➢ LEAP preschool (Strain)

❖ Educational programs
  ➢ TEACCH (Marcus, Schopler)

❖ Developmental programs
  ➢ Developmental Intervention Model (Greenspan)
CONVERGENCE OF MODEL PROGRAMS

- Intervention begins early
- Intervention is intensive in hours of “active engagement”
- Families are actively involved
- Staff are highly trained and specialized in autism
- Ongoing objective assessment of child’s progress
- Curricula provide systematic teaching
“BEST” PRACTICES IN AUTISM

- States with literature reviews:
  - CA  http://www.ddhealthinfo.org/asd.asp
    http://www.feat.org/docs/cabestpr.pdf/
  - NY  http://www.health.state.ny.us/nysdoh/eip/
  - NJ  http://www.state.nj.us/health/fhs/eiphome.htm
  - ME  http://www.madsec.org/docs/atf.htm
Staff Requirements

It is recommended that intervention staff working with children who have ASD have the following knowledge and skills to best meet their students’ needs:

- Are familiar with a variety of assessment methods.
- Use assessment information to design interventions.
- Apply positive behavioral management techniques during assessment and instruction.
- Have knowledge of strategies to improve communication skills.
STAFF REQUIREMENTS

- Intervention staff knowledge and skills requirements (cont’d)
  - Have knowledge of techniques to improve social interaction.
  - Have knowledge of accommodations and interventions related to sensory differences.
  - Are aware of current legal issues affecting services to children with ASD.
  - Understand differences in the learning profile of children with ASD.
TRAINING COMPONENTS

- Ensuring that administrators, teachers, parents, direct-service providers, and support staff are prepared with the knowledge and skills necessary to deliver services.
- This preparation may include initial and ongoing training and support for staff and families.
- Individuals who plan and provide training should disseminate information on training opportunities to parents, professionals, and agencies.
- Training needs can be met in a variety of ways, including, but not limited to, professional consultation; demonstration teaching; planned presentations and trainings at in-service sessions, workshops, and professional conferences; and attendance at university classes.
“BEST” PRACTICES- NJ EIP

- Eligibility guidelines for children with and without diagnoses
  (ASD is presumptive eligibility and eligible for EI services)
- Referral and intake procedures
- Assessment procedures
- IFSP Development
- Service Providers/Approved Services
- Transition
- Services
IFSP DEVELOPMENT

- Writing Outcomes
- Engagement: 15-20 hrs “active”
- Direct Instruction/Professional Contact
  1-20 hours (versus 25 hrs NAS rec.)
- Procedures to justify > 20 hours (appendix B)
- Methodology choice
- Implications for Mixed methodologies
SERVICES & PROVIDERS

- Supports providers and interventions with developed curricula and instructional strategies supported by professional literature
- Criteria for providers based on NAS guidelines (previously outlined)
- Family’s choice honored when more than one available
- Paraprofessional have good experience and clinical skill but not meeting personnel standards
SERVICES & PROVIDERS

- Treatments NOT supported by NJEIS
  - Auditory integration
  - Craniosacral therapy
  - Diets
  - Dietary supplements/vitamins
  - Vision therapy
  - Facilitated communication
  - Medications
  - “Biomedical” treatments
MAINE MADSEC AUTISM TASK FORCE

- Reviewed 8 popular interventions with stratification based on scientific validity, using scientific and lay literature review, and expert review by Task Force members
  - Objectively substantiated: Applied behavior analysis
  - Anecdotally promising: TEACCH, Sensory Integration, Auditory Integration*, Miller Method
  - Ineffective, perhaps harmful: Facilitated Communication
  - No scientific evaluation: Floor Time, Son-Rise
RECOMMENDATIONS OF MADSEC AUTISM TASK FORCE

- Develop aggressive plan for screening autism in routine pediatric care
- Ensure services for children with autism are based on scientific validity
- Ensure services include systematic instruction focusing on acquisition of skills and decrease in interfering behaviors
- Ongoing evaluation of interventions
- Identify and recruit qualified behavior analysts to meet current service needs
Diagnostic Guidelines
- Recommends only licensed psychologists and physicians experienced in autism make diagnosis, based on DSM-IV
- Confirms autism diagnosable in 1st 3 years
- Developmental surveillance in 1st 3 years
- Emphasis on evidence behind screening and assessment measures
- Provides framework for assessing cognition, communication, social interactions and behavior under 3 years of age
Emphasis on medical/health evaluation

- Diagnosis made on history and observation
- Clinical “clues” to suspicion of autism and their evidence bases
- Comorbid medical conditions
- Recommends Fragile X, hearing & seizure evaluation only
- No evidence for immunological, heavy metal, brain scans, allergy and diet assessment
NYS EIP CLINICAL PRACTICE GUIDELINE FOR AUTISM/PDD

- Intervention Guidelines:
  - Recommends linking assessments to interventions (determine strengths & needs)
  - Monitoring and periodic reassessment with guidelines for modifying intervention
  - Collaboration/ coordination of multiple interventions that are compatible
  - Scientifically valid interventions ONLY
  - Pay attention to comorbid medical conditions
NYS EIP CLINICAL PRACTICE INTERVENTION GUIDELINE

- Parent Guide: Questions to ask providers
  - Validates caregiver active role in intervention
    - What services do you provide?
    - What experience do the therapists have?
    - What ongoing training does staff undergo?
    - Do you provide parent training?
    - What techniques for difficult behavior?
    - How do you evaluate progress? How often?
Evidence based review of individual interventions: sensory, music, FC, ABA, Intensive behavioral intervention (IBI), DIR, AIT, Diet, Medication, “Biomedical”

Nicely outlines limitations and advantages for each intervention

Only behavioral interventions: IBI & ABA meet criteria for evidence of efficacy
GOALS OF FIRST STEPS

- Early recognition of signs of autism and referral for formal diagnoses
- Interventions focus on the Core Deficits in Autism
- Support and advance education of families of individuals with autism
- Collaborate and cooperate with medical and other community professionals
INTERVENTION SHOULD FOCUS ON CORE DEFICITS

- Functional communication
- Joint attention and non-verbal communication
- Play skills, imitation skills and peer-related activities
- Removal of problem behaviors interfering with functioning
- Enhance cognitive development with acquisition & generalization of skills
HOW TO ACHIEVE THESE GOALS

- Recognition of evidence based interventions
- Appropriate personnel training in recognition of autism and evidence based interventions
- Collaboration with other professionals and experts to continue education, supervision and planning interventions
- Administrative and financial support for interventions
PERSONNEL TRAINING

- Working with existing personnel (PSCs, service providers, supervisors, consultants):
  - requirements for being identified as “autism specialist” DI
  - mandatory credits for autism training/awareness
  - system-wide policy for all providers/PSCs to ensure consistency

- Pooling of resources with other systems: eg. LEAs, mental health systems etc. for joint training of staff
PERSONNEL TRAINING

- Recruiting of new personnel:
  - emphasis on exposure to ASDs in training
  - special certification (BCBA, AAC etc)
  - incentives for graduate students and trainees to enter field of intensive behavioral therapy, speech-language therapy
  - Collaboration with regional universities to provide students with “real-life” exposure
PERSONNEL TRAINING

- Utilizing local and regional experts in training personnel
- Establish minimal standards for personnel
- Models of training:
  - continuing credits
  - Conferences, workshops
  - Web-based/distance learning
- None of these substitute specialized training/certification in specific interventions
- Personnel training is the weakest link and the most important piece of the intervention process!
COLLABORATION ACROSS DISCIPLINES

- Identify local/regional “experts” in various fields: medical, mental health, education, policy, advocacy
- Provide mechanisms for sharing of information with specialists via consultation (consent, HIPPA guided)
- Access scientific information via literature, conferences etc through university settings
- Open communication lines are critical!
FIRST STEPS AND FAMILIES OF INDIVIDUALS WITH AUTISM

In step with First Steps mission: Family Centered
- Provide support: direct to respite, support groups, parent information centers
- Provide initial/ongoing training: for behavioral strategies, maintaining consistency of therapies, recognition of “warning signs”
- Increase awareness: disseminate information regarding autism to ALL families enrolled in FS
- Provide information: regarding validity and scientific basis on interventions use; disclose any experimental or non-validated therapies
FIRST STEPS AND FAMILIES OF INDIVIDUALS WITH AUTISM

In step with First Steps mission: Family Centered

- **Empower families**: to take active role in preparation of IFSP, seek options for transition
- **Encourage families**: to share information with medical providers and vice-versa (avoids HIPPA restrictions)
- **Be aware**: of families frustration, despair, shock, disbelief related to the diagnosis; cultural issues related to disabilities
- **Be prepared**: to present the information over and over and over
GOALS FOR INTERVENTIONS

- Educational interventions are the mainstay of autism treatment to address cognitive, social, communicative, sensorimotor and adaptive domains.
- Creation of goals on IFSP emphasizing functional skills in real-life contexts.
- Utilizing positive behavior supports and applied behavior strategies for problem behaviors.
GOALS FOR INTERVENTIONS

- Provide supervised opportunities for interactions with typical children
- Emphasize continuation of treatments to generalize to naturalistic environments
- Periodic assessment to re-evaluate intensity, curricula, instructional method, etc.
A HODGE-PODGE OF TERMS

- ABA = applied behavior analysis
- IBI = intensive behavioral intervention
- DTT = discrete trial training
- VB = verbal behavior
- PRT = pivotal response training
- NET = natural environment training
ABA is discipline devoted to improvement of human behavior through the methods of science.

It is the practical application of behavioristic principles to behaviors of social significance.

Modified from BF Skinner “behaviorism” on principles that behavior has antecedents and consequences and manipulation of these can affect behavior.

Famous “ABCs” of behavior Antecedent, Behavior & Consequence.

Remember reward and punishment schedules, operant conditioning and “shaping” of behavior with successive approximations.
VARIATIONS ON ABA

- While ABA is a discipline, it is realized through strategies like:
  - Discrete Trial Teaching
  - Natural Environment Teaching
  - Incidental Teaching
  - Pivotal Response Training

DTT has become synonymous with ABA even though they are very different.
DISCRETE TRIAL TRAINING

- Based on original Lovaas work at UCLA YAP: detailed in *Teaching Developmentally Disabled Children: The Me Book* (1981)

- DTT in autism can target
  - **Attention** -- In DTT, tasks are broken down into short, simple trials. As the child's attention span increases, the length of the interactions increases accordingly.
  - **Motivation** -- DTT attempts to build motivation by rewarding performance of desired behaviors with tangible reinforcement (food, toys, etc.) paired with social praise
  - **Stimulus control** -- In DTT, the presented stimuli (instructions from a teacher) are clear and consistent. The child is given rewards only for behaviors in response to those stimuli
DISCRETE TRIAL TRAINING

- A discrete trial is a single cycle of a behaviorally-based instruction routine, repeated several times in succession, until the skill is mastered.
- The instruction or environmental cue to which the teacher would like the child to respond; -- a prompt or cue from the teacher to help the child respond correctly *(optional)*;--- skill or behavior that is the target of the instruction; ---reward
- Originally, punishment with verbal and some physical aversives for negative; now modified to only a sharp “no” if dangerous behavior exhibited
- Extensive data of efficacy, however labor-intensive and needs well trained DTT therapist to administer and teach other providers
PIVOTAL RESPONSE TRAINING

- Developed by Drs. Bob and Lynn Koegel at UCSB
- Detailed in their book “Teaching Children with Autism: Strategies for Initiating Positive Interactions and Improving Learning Opportunities”.
- Premise that there are some skills which are "pivotal" for an individual to function. Addressing a pivotal area of deficit hypothetically produces “large collateral improvements in other areas” not directly targeted
- Several pivotal areas for intervention include responsivity to multiple cues, motivation to initiate and respond appropriately to social and environmental stimuli and self-direction of behavior including self-management and self-initiations of behavior.
PIVOTAL RESPONSE TRAINING

- Designing interventions around materials/topics for which the child expresses a preference and incorporating child-choice into routine activities (i.e., selecting which shirt to wear)
- Natural Reinforcers: planned reward flows naturally from the child’s actions or verbalization; in contrast with arbitrary reinforcers (i.e., M&Ms), in Lovaas DTT
- Reinforcement of Attempts: whenever the child makes any unambiguous attempt to produce the desired behavior versus success in trial for DTT
- Child initiation: techniques to increase self-initiations include “Wh” questions and learning to ask for help.
- A criticism is the lack of randomized trials with adequate longitudinal follow-up data.
CHOOSING AN ABA THERAPIST

- For lead therapist or therapy supervisor: prefer Board certification (BCABA) + experience/training with a mentor on Editorial Board of major ABA scientific journals
- Specific experience in teaching children with autism, and creating programs for systems to maintain therapy
- Flexibility in understanding complementary roles of ABA and other interventions
- Merely attending a workshop or taking a few courses in behavioral approaches not enough.
- Request references (both professional & parents)
- Awareness of progress in the field and ability to apply evidence based methods, individualized to the child
Most significant deficit in preschool children with autism is communication

- Upto 50% of all autistics are non-verbal
- Critical to begin even in prelinguistic children
- Emphasis on functional, total communication, not just “speech”
- Use of multimodal strategies: verbal, sign, pictures, augmentative
- Functional outcomes better in verbal, communicative children before 5 years
PICTURE EXCHANGE COMMUNICATION SYSTEM (PECS)

- Defined by Bondy & Frost (“A Picture’s Worth”)
- Modified ABA program designed for early nonverbal symbolic communication training. It is not designed to teach speech, although the latter is encouraged indirectly and some children begin to spontaneously use speech while enrolled in the PECS program.
- Professional training a two-day workshop is required in order to implement the program as designed. Training family & child in PECS is essential.
- Child who is aware of the need to communicate and has some personal preferences, is ideal candidate; picture discrimination ability is not a pre-requisite.
- Some individuals, who can discriminate pictured material and know to use pictures to communicate preferably should begin traditional augmentative (AAC) programming.
PICTURE EXCHANGE COMMUNICATION SYSTEM (PECS)

- Pictures used with PECS may be photographs, colored or B&W line drawings, or even tangible symbols. Selection of picture representation type and size is dependent on individual’s functional needs.
- It is necessary to follow the total PECS protocol as published; only adaptation permitted is following the protocol for the 1st 3 stages and then shifting to a more traditional AAC intervention program.
- Can be used complementary to ABA based behavioral programs.
- Recent data (Magiati & Howlin) suggest children’s acquisition of PECS is rapid and has good acceptance by families and therapists; but broader communication improvement much slower suggesting specific and not global impact.
AUGMENTATIVE & ALTERNATIVE COMMUNICATION

- AAC used to supplement or act as primary mode of communication (non-verbal)
  - Unaided: signs, gestures
  - Aided: devices: communication books, voice-output communication aids (VOCA)
- Total communication (speech + aided) results in faster and more complete language acquisition than speech alone, but mainly targets labeling (exp + rec)
- Manual signing=particularly difficult in autistic children with poor FM skills
AIDED AAC – BOARDS, VOCAs

- Teaches more functional communication, easy to use
- Can be used even if child has poor imitation and FM skills
- VOCAs digitized or synthetic speech output, graphic symbols and computer displays w/communication software
- Supported through IDEA 97 via AT program; but requires trained personnel, AAC evaluation and provision of device at home for generalization
VERBAL BEHAVIOR

- Term for ABA focusing on teaching verbal behavior
- Based on Skinner’s *Verbal Behavior*, which detailed group of functional units of language:
  - Echoic: vocal imitation; the teacher says, "Cookie" and the child says, "Cookie"
  - Tact: label. Child sees a cookie and says "Cookie," but just had dinner means "Hey, there's a cookie." Reinforce with praise or confirmation
  - Intraverbal: conversational language in response to another person. You say to the child "I'm baking..." and child finishes with "Cookies," intraverbal fill-in. Or "What's something you bake?" and the child says, "Cookies," intraverbal (wh- question). Reinforced with praise, or continuation of the conversational exchange
OTHER INTERVENTIONS

- Occupational therapy:
  - Particularly helpful in children with sensory dysfunction
  - Main emphasis for adaptive skill training: feeding, toileting
  - Not considered “primary” therapy in autism

- Physical therapy:
  - Usually not necessary in ASDs unless motor planning issues or comorbid neurological disorder
  - Sometimes useful to address safe negotiation of environment in some impulsive children
Often used as an euphemism for ASDs, not a legitimate DSM disorder.

SI is NOT a primary symptom in autism, but seen in up to 70%.

SI therapies do NOT improve socialization or communication.

Need OT evaluation with appropriate tools (SSP-Dunn etc).

Helpful to have sensory interventions, but not in isolation.
SENSORY PROBLEMS IN AUTISM

- Sensory processing issues in autism may involve any or all of 5 common senses:
  - Hearing
  - Sight
  - Touch
  - Smell
  - Taste
- Additionally, Proprioception (body awareness & movement in space) & Vestibular (balance/equilibrium)
- Difficulty in processing information entering the brain affects ability to form appropriate motor responses
- Problems with Registration, Modulation & Integration
- May be expressed in over- or under-sensitivity to sensory input from one or more of the senses
- These deficits appear in other areas such as:
  - Visual-perceptual skills
  - Auditory processing
  - Emotional regulation
BEHAVIORS SEEN IN ASDs

- Self-stimulatory, Repetitive “Stims”
- Self-injurious behaviors (SIB)
- Aggressive behaviors
- Difficulty transitioning, “stuck” on task/activity
- Distractible, inattentive
- Hyperactive, Impulsive
- Withdrawn, not engaging
CONTEXTS FOR PROBLEM BEHAVIORS

- Times of transition, new situations
- Non-preferred activities
- Attempting to redirect from stims
- Proximity of personnel
- Sensory stimuli: sounds, touch, light
- Medical issues: illness, pain
- Medication side-effects
PROBLEM BEHAVIORS

- Targeted by Applied Behavior Analysis techniques
- Critical to follow ABCs of behavior
- Use of functional behavioral assessment and positive behavioral supports
  - Identify “setting events” in environment: personnel, sensory stimuli, peers, transition
- Be aware of medical issues in non-verbal children
- Rarely, use of adjunctive medication for neurobiological conditions
FINAL THOUGHTS

- Early identification is critical
- Training of personnel in screening, disseminating information and evidence-based practices
- Partnership with professionals in medical, educational, mental health and advocacy communities
- Use of evidence-based intensive early interventions correlates with positive outcomes
- Focus on core deficits in autism with functional and generalizable goals
- Involvement of families in training, sharing information regarding resources, support, literature
- Monitoring and documentation of outcomes
THE TIME IS NOW

- 3/05  KY legislature bill HB296 signed
- 7/05  Appointment of Governor’s Commission on Autism Spectrum Disorders to develop a comprehensive state plan for integrated system of training, treatments, and services for individuals of all ages with ASD.
- 8/05  Subcommittee on Identification/Early intervention formed with parents, educators, First Steps, physician on subcommittee