Fact and Fiction: Sorting through the Information on Autism to Guide Best Practice

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Fact:
• There are many more young children with ASD than we originally thought
• ASD is the 4th most common disability after learning, behavioral/emotional, and cognitive disabilities
• The majority of direct service providers have had scant if any training in autism

Incidence
• From 1990 to 2003, the incidence of autism has increased by nearly 726.25%
• This Data does not include all forms of autism, only those with primary diagnosis
• We can now diagnose Autism Spectrum Disorders confidently at age 2 and are working hard on the characteristics of autism between age 1 and 2.

Current best estimate of prevalence of ASD = 4 to 7 in 1,000 children
It is plausible that children with ASD could represent 1% of school age children

VA Department of Education Incidence Data

What is driving the increase?
• Better Diagnosis
  – More Awareness
• Widening the Spectrum
– Added Asperger’s Syndrome in 1994

**Diagnostic Substitution**
– People are now dx’ed with ASD were previously dx’ed with other disabilities

**More Autism?**

**Number of Students by Age**
for 1997 to 2003 (Data for Birth to 2 not available before 2002)

**Challenges of Early Diagnosis of Autism in Virginia**

- The Number of 3 years olds diagnosed with Autism on December 1, 1999 was 19.5% of the number of 5 year olds diagnosed with autism on December 1, 2001
- The number of 3 year olds diagnosed with autism on December 1, 1997 was 5% of the number of 7 year olds diagnosed with autism on December 1, 2001
- Both of these figures indicate that, in Virginia, we routinely miss between 80 to 95% of children with ASD in the early childhood age range
- This does not take the ‘Developmental Disability’ Label into account.

**Just How Many Children with ASD should we expect?**

- Number of school children in Virginia, 2002 - 1,445,585
- Incidence of autism - 4 to 7 in 1,000
- 5,782 to 10,119
- Actual number of individuals with Autism in 2002 - 3350 (primary dx only!)
- 43% to 63% under diagnosed in Virginia

**Challenges of Autism in Virginia**

- Autism is emerging as the 5th disability when considering those who have cognitive, learning, behavioral, or sensory motor disabilities
- The state workforce of service providers receive scant (if any) training in the unique profile and support needs of persons with Autism

**Fiction**
• Autism is more prevalent than all other developmental Disabilities
• Autism is the most common developmental disability
• There is an over diagnosis of autism because it is ‘posh’ to have autism
• Parents want their kids to have autism

**Fact**

• Autism research is in its infancy
• We do not know autism well
• We have not identified subtypes of autism
• Autism is not a ‘one-size-fits-all’ disability when it comes to treatment

**Wide Range of Presentation**

• Autism is multidimensional
• Communication continuum
• Social continuum
• Executive function continuum
• Intellectual ability continuum
• Level of family and community support continuum

**The State of the Research on Autism in 2005**

• We are just beginning to get to the real questions in Autism research:
• Much more funding for all kinds of research to help us describe ASD
• Many more multi-site center (e.g.: RUPP-Autism, Centers for Excellence in Autism, and STAART centers)
• The beginning of longitudinal research
• Combining of threads of research to follow to macro findings

**Still Learning . . .**

• Still don’t fully understand structure brain findings
• Still don’t have finely defined characteristics
  – Asperger’s Disorder
  – Biomedical Findings in Autism
  – Subtypes of Autism
• Still don’t have strong data for specific treatment protocols
• Individuals and families still need excellent services today!
**Fiction**

- If you have seen one person with autism, you have seen them all
- There is such a thing as an ‘autism expert’
- We know what causes autism
- There will be a singular cure for autism

**Fact**

- We are just getting to the real questions about intervention
- There is more that we do not know than we know
- Lovaas’ landmark 1987 article was impressive, but flawed and not replicated since

**Fact**

- There is nothing magic about 40 hours of intervention
- Intensity and engagement are the key to ‘treating’ autism in the early childhood period
- What works for 4 year olds, does not necessarily work for 2 year olds

**The Three Pillars for Success**

- Communication
  - Both Form and Function

- Attending
  - Alerting and Calming

- Social Skills
  - Getting along with others

**National Research Council Findings on Educational Interventions for Children with Autism**

- Charge
  - Integrate scientific, theoretical, and policy literature
  - Create framework for evaluating scientific evidence of educational interventions for young children with autism
National Research Council Findings on Educational Interventions for Children with Autism

• Findings
  – Diagnosis Assessment and Prevalence
    • Children with ASD be eligible for special education within the category of autism
    • Diagnosis can be made reliably in 2 year olds by experienced professionals
  – Role of Families
    • Parents concerns and perspectives should shape educational planning
    • Families’ participation should be supported through family training and consultation

National Research Council Findings on Educational Interventions for Children with Autism

– Goals for Educational Services
  • Ongoing measurement of treatment objectives and progress be documented to determine if child is benefiting and that intervention be adjusted accordingly
  • Objectives should be
    – observable and measurable
    – accomplished in a year
    – anticipated to affect a child’s participation in education, the community, and family life

National Research Council Findings on Educational Interventions for Children with Autism

– Characteristics of Effective Interventions
  • Begin as soon as child is suspected of having ASD
  • Minimum of 25 hours a week, 12 months a year
  • Child is engaged in systematically planned and developmentally appropriate educational activities toward identified objectives
  • Sufficient individualized attention

National Research Council Findings on Educational Interventions for Children with Autism

– Characteristics of Effective Interventions
  • Priorities of focus =
    – functional spontaneous communication
    – social instruction
    – cognitive development
    – play skills
    – proactive approaches to problem behavior
  • Young children with ASD should receive specialized instruction in a setting in which ongoing interactions occur with typically developing children

Types of Intervention Strategies

• ABA -
  – Lovaa Discrete Trial
  – Pivotal Response Training
  – Incidental Teaching
ABA - Lovaas Discrete Trial
- At least 40 hours a week
- One therapist to one child
- Discrete trial instruction on specific skills
- High degree of repetition

Myths of ABA (Anderson & Romanczyk, 1999)
- Exclusively for home based settings
- Is always one to one
- Is always teacher led, discrete trial
- Cannot be applied in socially integrated school settings
- Does not develop functional skills
- Uses aversive techniques

Three Points along a Continuum
- Direct Teaching
- Activities Embedded
- Incidental Teaching

Direct Teaching
- Usually One to One
- Highly Structured
- Teacher Directed
- Many Instructional Opportunities
- Skills acquired quickly
- Distractions Managed
- Easier to manage behavior problems
- Generalization may be restricted

Activities Embedded
- Usually small group
- Shared teacher/child control
- Some natural distractions
- Typically few instructional opportunities
- Moderate level of structure
• Challenging to find reinforcing activities
• Generalization may be enhanced

**Incidental Teaching**
• Small and large group
• Most natural
• Child directed
• Natural distractions
• Challenging to find reinforcing activities
• Typically fewer instructional opportunities
• Generalizations may be enhanced

**Pivotal Response Training, Koegel and Koegel**

• Uses ABA to teach “pivotal responses” in natural environment
• Pivotal responses are skills that result in greater learning
• Pivotal responses include attending to multiple cues, motivation, self management, and self initiation

**Pivotal Behaviors**

**Response to Multiple Cues**
– Incorporating “within stimulus prompting” and “conditional discriminations” into activities at home and in school
  • Provide colored pencils, markers, and crayons and have children ask for the color and media
  • Ask child to get “green sweatshirt”

**Motivation**
– Child choice
  • Child chosen materials, topics, or toys
– Natural reinforcement
  • Reinforcement that is naturally and directly related to the task
  • Avoid arbitrary reinforcement
– Interspersing mastered tasks and new tasks
– Incorporating turn taking into interactions

**Pivotal Behaviors**

**Self-Management**
– Identify Target Behavior
– Identify Reinforcers
– Select Self Monitoring Device
– Teach use of Self Monitoring Device

**Pivotal Behaviors**

• **Self Initiations**
  – What’s that?
    • place desired items in opaque bag
    • prompt child to say “What’s that?”
    • give child item
  – What’s happening?
    • Show pop-up book with activity tabs
    • Prompt child to say “what’s happening?”
    • Have child move tab and answer with verb+ing

**Incidental Teaching, McGee**

• Combination of home based and center based program
• Inclusive model in typical day care setting (1 child with autism to 2 children without autism)
• Children become “trainers” through environmental arrangement

**Curriculum Areas**

• Toddler Goals
  – Expressive language
  – Engagement with toys
  – Social responsiveness to adults
  – Social tolerance/imitation of peers
  – Independence in daily living

**Curriculum Areas**

• Environmental Arrangement
  – Zone based teacher schedule
  – Goals embedded in natural activities
  – Supplemental one to one instruction in natural contexts
  – Child selected teaching materials
  – Systematic display and rotation of toys

**Environmental Arrangement**

• Incidental Teaching Procedures
  – Vigorous speech shaping
  – Active social instruction
– Wait - ask - say - show - do
– Promotion of engagement
– Checklist based performance appraisals

**Verbal Behavior - Partington & Sundburg - Skinner**

- Teach verbal initiations
- Teach expressive mands
- Teach tacting - commenting (tool for gaining information from the environment; “look at that bird”)
- Intraverbals - foundations of social communication (Summoning attention, making comparative statements; “I’m going to the playground but you have to work!”)

**Fluency Based Instruction/Precision Teaching**

- Things that we have mastery of we can do quickly and accurately
- Focuses on key component skills -
  - Rapidly and accurately shift attention to various stimuli
- Building speed and accuracy of previously acquired skills -
  - Expressive labeling, sound symbol associations, math facts
- In autism, we rehearse and teach social, language, and pre-academic skills

**TEACCH - Structured Teaching**

- Clearly organized, visually instructive environment
- Visually clear expectations - visual schedules, visually structured work area
- Continuum of supports and strategies

**What should the classroom/work space look like?**

- Person should be able to answer four essential questions:
  - What work?
  - How much work?
  - When is it finished?
  - What is next?

**A TEACCH Classroom Layout**

**Common Features of Excellent ABA Programs**

- Rich ratio of adults to children
• Sophisticated knowledge of ABA
• Well-trained and well-supervised staff
• Well-developed curriculum
• Support for family involvement
• Knowledgeable administrators
• Systematic transition to new settings
• Provision for interaction with typical peers

Floor Time - Greenspan
• Teaches interaction to facilitate the mastery of developmental skills
• Addresses sensory modulation, motor planning, sequencing, and perceptual processing
• Addresses emotional development
• Child leads the session

Elements of a Comprehensive Program
• Home based developmentally appropriate interaction and practices
  – Spontaneous, follow the child’s lead floor time - 20 to 30 minutes, 8 to 10 times daily
  – Semistructured problem solving (15 minutes, 5 to 8 times a day
  – Spatial, motor, and sensory activities (15 minutes, 4 times a day)

Elements of a Comprehensive Program
• Speech Therapy, typically three or more times a week
• Sensory Integration, typically two or more times a week
• Educational Program - Daily
• Biomedical interventions

Relationship Development Intervention (RDI)
• Focuses on Social Interaction using a developmental model
• Parent based clinical treatment
• Focuses on changing neurology by changing the activities that children and parents engage in
• Uses parent feedback through videotaping

Fiction
• You must choose one approach and stay with it
• If you pick ABA (or floortime etc.) You are against any other approach
• ABA has been proven to cure autism
**Fiction**
- TEACCH lets kids be ‘autistic’ while ABA teaches them to be normal
- You should not use pictures (or sign, or verbal language)
- You have to be certified in an intervention before you can do it
- Intensive intervention for young children is against Part-C’s philosophy of natural supports and environments

**What is Essential**
- Early is essential
- Intensity - direct active interaction between child and therapist/caretakers/peers
- Engaged time - 80% of time engaged in interaction
- Most approaches use ABA as foundation
- Individualization no one approach works for everyone!
- Family education and support is critical!

**What is Not Essential**
- Specific curriculum - should address the core symptom of autism
- Spending lots of money
- Using one approach to the exclusion of others

**What do People with Autism Want?**
- Safety
- Security
- Success
- An expert in them (not autism)

**What do Parents of People with Autism Want**
- To hear their child say “I Love You”
- To have their kid’s friends show up for a pick up game of baseball
- To sleep through the night
- To trust that when their child goes to school, they won’t hurt or be hurt
- To trust that the professionals serving their child know what they need to know
- To have a place to go to get services and be heard

**What do Professionals who Serve People with Autism Want**
Want?
• To know what they need to so that they can provide excellent services
• To have good training before they begin to practice and while they are practicing
• To have someone available to help them when they encounter a “tough case”
• To be told that they know their job and are doing it well
• To have a place to go to get training and help
• To make a difference

What do we Currently Have In Virginia?
• Inadequate numbers of professionals to serve children with ASD in many areas of Virginia
• Approximately 50% of direct service providers questioned their training and qualifications to work with children with ASD
• Few professionals received adequate preservice training for ASD
• The quality of services for ASD varies greatly across the state

Factors Influencing Choices
• Child Variables
• Family Variables
• Parent’s Values

Child Variables
• Amount of independent engagement in environment
• Language skills prior to starting program
• Supportive relationships around the child

Family Variables
• Choice of intervention
• Resources available through community
• Vision of outcomes from intervention
• Expectation of intervention

Parent Values
• What should children do with their time
• What should early childhood include
• The role of professionals in the life of the family and child
The Future of Early Intervention for Children with Autism Spectrum Disorders

- Identifying the match between child characteristics and intervention specifics
- Identifying which variables are essential, desired, and unnecessary
- Making supports more widely available through current public systems
- Offering true choice

**Fact**
- We are finished with this presentation

**Fiction**
- We are finished learning about autism!