

# 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 4<sup>th</sup> 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 centers (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 -
  - Lovaas Discrete Trial
  - Pivotal Response Training
  - Incidental Teaching

- Verbal Behavior
- Fluency Based Instruction
- TEACCH - Schopler
- Floor Time – Greenspan
- Relationship Development Intervention (RDI)
- General Special Education

## 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”

## Pivotal Behaviors

- 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?

- 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!