Screening and Diagnosing Autism: Early Characteristics and Early Screening Tools

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.

Number of Students by Age for 1997 to 2001

Why should we diagnose early?

- Of 1,000 children in your locality between the ages of birth to 3, how many should you expect to have autism?
  - 3 to 7
- The symptoms of autism are present from the first year of life.
- What is the average age for diagnosis in the U.S.?
  - 3 1/2 years
- Average age of diagnosis in Virginia?
  - 6 to 7 years old
- When does intervention for children with autism have the greatest impact?
  - When it begins before 3 1/2 years

Won’t we worry the parents unduly if we mention autism too early?

- Over 85% of children diagnosed by experienced professionals at 24 months of age are still on the autism spectrum at 4 years of age.
- Over 97% of children identified as having autism at age 2 still had developmental delays at age 4.
- Wetherby found that 90% of parents of children with autism were worried about their children before diagnosis.
- Schall found parents know something is wrong, they just want to know what it is.

What about our model of intervention versus the autism intensity model?

- What intense means
- Many hours of intervention by all who know the child
- Developmentally appropriate practice
- Getting into the child’s world

- What intense does not mean
  - ABA only
  - Floortime only
  - Adult Directed only
  - Developmentally Unusual

**Behavioral Syndrome Vs. Absolute Diagnosis**
- String of behavioral symptoms
- Various causes
- The average family in Richmond sees 5 practitioners before getting a diagnosis (Central Virginia Autism Society of America, 1996)
- A wide spectrum disorder that describes many different individuals
- We may be trying to fit several pieces into the same puzzle when in fact we actually have different puzzles

**Communication Development in Typical Children**

**Back of handout**
- Babies learn to talk at an amazing rate
- What parents tell us about their children’s communication

**Screening for Autism**
**When do the ‘Salient’ characteristics of ASD show up?**
- Social impairments
  - 24 months
- Communication impairments
  - 24 months
- Restricted repertoire of activities and interests
  - 36 months

**Physicians Office Surveillance**

**Step-wise process**
- General Observation and Developmental milestones
Routine Developmental Screening
Referral to Early Intervention
Lead Screening (if pica or environmental concerns)
Audiological Assessment
Autism Screening
Formal Diagnostic

General and Pediatric Tools for Prescreening
PEDS -- good first step to identify parental concerns about development
Follow-up with Ages and Stages

Autism Screening
If other screenings are negative, or if significant concerns exist

Recommended Screening for Autism in Young Children
(Filapec, et al. 2000)
Absolute indications for immediate evaluation:
  - No babbling, pointing, or gesturing by 12 months
  - No single words by 16 months
  - No 2 word spontaneous phrases by 24 months
  - Any loss of any language or social skills at any age

These recommendations are based on . . .
Clinician impression
Expert observation

Gold Standard Tools
Observational Tools
  - Autism Diagnostic Observation Schedule (ADOS)
  - Gilliam Autism Rating Scale (GARS)
  - Childhood Autism Rating Scale (CARS)
Checklists
  - Autism Diagnostic Interview (ADI)
Markers based on M-CHAT at 18 months

- No or rare proto-declaritive pointing - showing (versus proto-imparitive pointing-asking)
- Poor gaze-monitoring
- Poor pretend play
- Sensitivity - True Positives - 35%
- Specificity - True Negatives - 98%

Despite the lack of data, use of these tools indicate that . . .

- Confident Diagnosis can be made by 2
- Some have made diagnosis earlier

Why not based on better data?

Problems with Research Prior to 1999

- No common definition or diagnostic parameters
- No multi-site findings
- Very low numbers
- Little use of controls

Problems with Research Prior to 1999

- Little reporting of “type” of asd
- No consistent definition of success or good outcome
- Heterogeneity of population
- No longitudinal studies

Result

- Inconsistent description of disorder
- Lack of the development of excellent tools
- Very confusing treatment outcome studies
- Lack of validity or reliability of treatment protocols
- Prone to whim of area
- Lots of theory, little data
Since 1999

- 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

Continuing the search to Understand Autism before age 2

Osterling and Dawson, University of Washington, Seattle
Landa, Johns Hopkins University
Wetherby, Florida State University

Osterling and Dawson

- Retrospective research
- Reviewed videotapes of first birthday for children diagnosed with autism
- Limitations based on:
  - Retrospective research
  - Lack of full observation on specific developmental profiles
  - Good observation of children in social situations

Findings of Autism from Home Videotapes at 12 Months

- Delayed or decreased pointing
- Delayed or decreased showing
- Decreased looking at others
- Significantly low responding to name call

Only the last two distinguished children with autism from children with developmental delays
Landa, 2003

Longitudinal Study
- Baby siblings of children with autism (recurrance rate of autism - 8%, occurance rate of significant communication and social impairments - 20 to 40%)
- Babies with no known risk
- Now adding (but no data yet from) baby siblings of children who were late talkers
- Tested babies at 3 mos. (just a baseline review), 6 mos., 14 mos., 18 mos., 24 mos., 36 mos.,

Findings
- By 14 mos., the group of children who later have autism test and look different than control group, but not in “autistic” way
- Red flags include
  - not responding to name at 1 yo
  - problems understanding words out of context at 2 yo
  - fine motor delays at 6 mos. old

Patterns at 14 mos.
- Visual reception is average or above
- Gross and fine motor is delayed from peers
- Expressive and receptive language is delayed from peers
- Integration of gaze, smile, and communication is off
- Poor use of eye contact and social smile to regulate behavior, but not to show interest
- Poor three point gaze

Findings
- Cannot rule out autism just because child displays appropriate infant affect, imitation, and isolated functional play
- Look at whole package of infant social relatedness
- Children identified as having autism at 2 who later do not have autism, still do have developmental challenges

All Sibling of Children with Autism
Should Be Routinely Screened!

Wetherby, 2003

- Prospective Longitudinal study to
- Develop screening tool for children with early communication problems, including autism
- Differentiate autism from language delay, and general developmental delay

Mass Screening to develop tool

- Physicians Well Childcare Visits
- Childcare Centers
- Public Places where Families Go
  - Health Fairs
  - Church
  - Booths at the Mall

Screening Process

- Step One - Brief Parent Report
  - Communication and Symbolic Behavior Scales- Developmental Profile (CSBS-DP) Infant/Toddler Checklist (on line at http://firstwords.fsu.edu)
- Step Two - More Detailed Parent Report
  - CSBS-DP Caregiver Questionnaire
  - Ages and Stages Questionnaires
- Step Three: Child and Family Evaluation
  - CSBS-DP Behavior Sample

Data from Study

- 3,012 completed the CSBS-DP Infant and Toddler Checklist between 12 and 24 months
- 350 Were videotaped during the Behavior Sample

Prospective Study - Three Groups of Children

- ASD Group - children were later diagnosed with ASD
- DD Group - Children with DD but not ASD
- TD Group - Children with typical development
18 subjects in each group

Classification Results from Communication and Symbolic Behavior Scales - Developmental Profile (CSBS-DP)

Wetherby and Wood’s (2002) Red Flags for ASD

- Difficulty with Social Interaction
- Unconventional Sounds and Words
- Unconventional Gestures
- Repetitive Behaviors and Restricted Interests
- Difficulty with Emotional Regulation

9 Strongest Red Flag Behaviors for Autism between 12 and 24 months

- Lack of Showing
- Lack of coordination of non-verbal communication
- Lack of sharing interest or enjoyment
- Repetitive movements with objects
- Lack of appropriate gaze
- Lack of response to name
- Lack of warm, joyful expressions
- Unusual prosody
- Repetitive movements or posturing of body

6 Red Flag Behaviors for Autism and DD

- Lack of playing with a variety of toys
- Lack of response to contextual cues
- Lack of communicative vocalizations with consonants

- Lack of anticipatory posture or movement
- Difficulty calming when distressed
- Lack of pointing
**Alex, 2.5 years old**

- **Developmental Milestones**
  - First word - 6 months
  - First step - 20 months
  - Poor crayon/pencil grasp
  - Poor eye/hand grasp
  - Awkward gait, awkward running
  - No obvious motor disabilities

- **Communication characteristics**
  - Repeats phrases over and over again. Tantrums if you do not answer the question in the exact same words you did before
  - Does not identify happy, sad, or mad in others
  - Does not predict what will hurt others
  - Does not ask questions- makes statements
  - Does not understand idioms

**Alex, 2.5 years old**

- **Social interaction characteristics**
  - Needs excessive reassurance to try anything new
  - Easily frustrated
  - Very difficult to calm down
  - Tantrums when corrected or told he is wrong
  - Does not imitate faces or motor movements
  - Carries toys around, but does not ‘play’ with toys

- **Patterns of behavior**
  - Must have every day events happen exactly alike -- breakfast, bath, etc.
  - Watches the same show on television at the same time -- Discovery Channel
  - Talks about maps, death, weather, and roads
  - Does not play with or near others
  - Wants what ever others have
  - Cannot be coached through sharing

**Alex, 2.5 years old**

- **Cognitive patterns**
  - Beginning to show sound symbol relationships
  - Identifies written name and family members names
  - Reads simple words -- stop, don’t walk, favorite book titles, video titles
  - Excellent memory
  - Odd sense of humor

- **Other behavioral/ medical characteristics**
  - Sleep irregularities
  - Chronic ear infections
  - Very oppositional, even for a 2 year old
  - Very, very active

**Alex**
What are the characteristics that indicate the possible presence of ASD?
What are ‘2 year old’ characteristics?
Would he be eligible for services?
What would services would be appropriate?

Matt 2 years old

Developmental Milestones
- Walked at 14 months
- Ran at 18 months
- No words yet
- Tested for deafness, but hears
- No interest in crayons or paper tasks

Communication characteristics
- Does not point or show
- Does not look for mom in new situation
- Cries frequently, little soothes him
- Smiles infrequently
- Looks at people near him

Matt, 2 years old

Social Characteristics
- Grab others by hand and takes them to areas
- Only apparent toy is piece of rope or red Po character from Teletubbies, carries and flicks them
- Very difficult to calm
- Tantrums when new people are in home
- Pulls mom's hair when hurt, hungry, wet, tired, and unknown reasons

Patterns of Behavior
- Not comforted by being held
- Arches back when touched
- Does not respond to loud noises
- Cries in bright light
- Has a few (but not excessive) odd hand movements
- Bangs head on floor

Matt, 2 years old

Cognitive Patterns
- Watches same section of video over and over again
- Studies moving things -- hinges on doors
- Successfully uses mouse on computer
- Points at words, not pictures in board books
- Appears to do interlocking puzzles?

Other Medical/Behavioral Characteristics
- Eats only baby food, has not started on solid food, despite many attempts by parents
- Chronic Diarrhea
Sleeps 4 or less hours per night -- sitting up
Does not nap
Constantly moving around the house
Darts away from caretakers

Matt
What are the characteristics that indicate the possible presence of ASD?
What are ‘2 year old’ characteristics?
Would he be eligible for services?
What would services would be appropriate?

Once we Screen for Autism . . . Then What?
It is an error to assume that tested treatment for an older age group applies to a younger age group
We don’t have studies published showing what to do with this age group yet

We do have general treatment recommendations though!
The earlier the better
Active engagement in intensive instruction for at least 25 hours a week year round
Repeated planned teaching opportunities
Developmentally appropriate
Intensive family participation
Low child to adult ratio
Mechanisms for ongoing program evaluation
With typically developing children
Six kinds of intervention areas

Six Intervention Areas
Functional spontaneous communication
Social instruction in various settings
Teaching play skills with peers
Instruction leading to generalization
Positive approaches to address problem behaviors
Functional academic skills

*Intervention Programs must address the core challenges of Autism*

- Joint Attention
- Symbol Use
- Teaching Speech and Language
- Teaching Communication
- Teaching Social Skills

**Continuum from Behavioral to Developmental**

**Traditional Behavioral/ Discrete Trial**

- ABA
- Lovaas Therapy
- Verbal Behavior Therapy
- PECS (early stages)

**Contemporary Behavioral/ Naturalistic**

- Pivotal Response Training
- Incidental Teaching
- PECS (later stages)
- Visual Strategies
- Structured Teaching
- Positive Behavior Support

**Developmental/ Social-Pragmatic**

- Floortime
- Social Communication Emotional Regulation Transactional Support

**Commonalties from All Approaches**

- Supportive and Structured Learning Environments
- Family Involvement
- Early Intervention
- Specialized curricula focusing on communication and social interaction
- Integration with typical peers

**Commonalties from All Approaches**
- Predictability and routine
- Functional approach to problem behaviors
- Planned transition between home/preschool/kindergarten/first grade
- Individualization of supports and services
- Intensity of engagement
- Developmentally appropriate practices