

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)

- Modified Checklist for Autism in Toddlers (M-CHAT, Handout)

Markers based on M-CHAT at 18 months

- No or rare proto-declarative 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 (recurrence rate of autism - 8%, occurrence 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
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- 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 moms 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