Identifying Autism Spectrum Disorders:
Do You See What I See?

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Glenis Benson, Ph.D.

Age of diagnosis for Autism Spectrum Disorders
• 1970’s it was around 5-6 years of age
• 1980’s it was around 4-5 years of age
• presently the mean is 34-61 months, in the United States

Age of diagnosis for Aspergers is considerably later, here and abroad

Reasons for a later diagnosis:
• Need to look for both the presence and absence of behaviors; must look for the presence of atypical and the absence of typical
• Little is known about the primary characteristics of autism as by the time they are diagnosed they may have changed dramatically

Earlier identification
= Earlier intervention

The American Academy of Pediatrics (AAP) recently mandated screening for ASD in the 2nd year of life

Rationale for Early Identification
“Early intervention services are crucial for optimizing functional developmental outcomes for children and their families.”

Wendy Stone
Director of TRIAD
Rationale for Early Identification

- Access to disorder-specific interventions (e.g., visual communication system)
- Parental relief and support
- Identification of primary versus secondary characteristics
- Less harm in identifying than missing a child

Stability of a diagnosis

(Charmian et al, 1997; Cox et al, 1999; Lord, 1995; Stone et al, 1998)

Following is from Stone et al (1998):

- 21/26 retained a diagnosis of autism
- 25/26 remained on the spectrum
- 3/12 retained a diagnosis of PDD-NOS
- 4 left the spectrum
- 5 moved up to a diagnosis of autism
- Clinicians can agree on whether a child is on the spectrum
- Where on the spectrum is more difficult and dependent upon experience

Good reason to identify early and an early diagnosis is stable, so..

Methodological obstacles

- Behaviorally based - no biological or physical markers
- Diagnosed later so we don’t know what the early development looked like making it difficult to know what we are looking for
- Pattern is one of discrepancies; good at some things

Reliance upon conventional classification systems (e.g., DSM-IV) and they under-diagnose at 2 years of age

- “failure to develop peer relations appropriate to developmental level”
- “marked impairment in the ability to initiate or sustain conversation with others”

When did most parents think something was amiss?

- 18 months
What were the parents’ initial concerns? (Stone et al, 1998)

2/3 (66%) of parents initially were concerned about their child’s language.

What were the parents’ initial concerns? Cont’d

Only 12% were concerned about other developmental delays (e.g., motor delays).

Comparing parents of children with autism with parents of children with other developmental delays:

• majority of both notice before 2 years of age
• both identify speech problems primarily and developmental delays secondarily

50% of parents know something is amiss before the child is 1 year of age.

How can we identify them earlier?

• Retrospective research: home movies
• Prospective research: Sibling research

• ‘social difficulties’ and ‘unusual behaviors’ were endorsed by few parents

info@asd-doc.com
Retrospective research: home videos

Birthday videos (12 months) & ‘any’ videos prior to 12 months

Limitations of retrospective research:

• Homogeneity of comparison groups
• Biased sampling
• Less than ideal matching

Retrospective research: home movies

• Differences from typically developing and those with developmental delay are evident between 8-12 months

Retrospective findings:

• Infants, who went on to receive a diagnosis on the autism spectrum:
  • Looked at others less,
  • Oriented to their name less

How can we identify them earlier?

• Retrospective research: home movies
• Prospective research: Sibling research

Prospective Research

• $$$$
• Must include SO MANY participants
• Design what you want to watch for, not measure what you have
Sibling Research began in Canada
Zwaigenbaum, Bryson, Rogers, Roberts, Brian, Szatmari 2005

- Longitudinal study of siblings, N=150, 65 have been followed to 24 months
- Use the Autism Observation Scale for Infants, a computerized visual orienting task, standardized measures of temperament, cognitive and language development

Families with one child with autism have a 5-10% chance of a second child being dx

Initial Sibling Research
Zwaigenbaum, Bryson, Rogers, Roberts, Brian, Szatmari 2005

- Early indicators, by 6 months
  - Passive temperament
  - Decreased activity level
- As they approached 12 months
  - Extreme irritability, a tendency to fixate on objects, reduced social interaction, and a lack of facial expression
- At one year
  - Difficulties with language and communication, they used fewer gestures, understood fewer phrases and had lower scores for both expressive and receptive language

Initial Sibling Research
Zwaigenbaum, Bryson, Rogers, Roberts, Brian, Szatmari 2005

- Autism Observation Scale in Infants (AOSI) – first standardized checklist designed to measure autism-related behaviors in young infants

11/13 children who exhibit 7 or more of the 16 behavioral markers on the AOSI will have a dx of autism by age 2

Autism Observation Scale for Infants

- Variables that predict autistic disorder:
  - Atypical eye contact
  - Visual tracking
  - Disengagement of attention
  - Orienting to their name
  - Imitation
  - Social smiling
  - Reactivity and sensory interest
  - Social interest

Findings from the siblings:

- Major identifying characteristics:
  - Decreased eye contact and social smiling
  - Inconsistent respond when name is called
  - Less interest shown, less positive emotion during social interactions
  - Tendency to visually fixate on toys and other objects
  - Communication delays (use of words/gestures)

Siblings who get ASD dx

- Present at two subgroups
  - Group One
    - Early signs prior to 6 months not obvious
    - Develops signs by 12 months (language and cognitive skills level off; delays and functional impairments evident between 1-3 years)
  - Group Two
    - Signs more subtle and elude detection prior to 18 months; language and cognitive abilities appear less delayed thereby appearing more typical
A closer look at Group 2

When language and intellectual skills are in the average range at the time of the diagnosis, the early signs of autism are more difficult to detect during infancy. This group is less likely to be diagnosed before 36 months of age. It’s critical, therefore, that more is understood about earlier signs in this group.

Sibling research replications:

- Multiple sites are now doing sibling research: UCLA, Baltimore
- Expensive but can give invaluable info

Prospective findings:

- Social differences by 6 months (temperament)
- Communication differences by 12 mos
- Imitation differences by 12 mos

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- Social differences by 6 months (temperament)
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NOW WHAT?
How can we use this information?

- Screening
- Diagnostic assessment

Go to the CDC for downloadable materials:

Screening Instruments:

- STAT
- CHAT
- M-CHAT
- PDDST

Screening Instruments

- STAT (Screening Tool for Autism in Two-year-olds) (Stone & Ousley, 1997)
  - differentiates between autism and developmental disabilities
  - play, imitation and communication (12 items)
  - conducted between 24-35 months
  - <20 minutes to administer
  - conducted with child

Screening Instruments:

- CHAT (Checklist for Autism in Toddlers) (Baron-Cohen, Allen & Gillberg, 1992)
  - differentiates between autism and typical development
  - 18 items total, 9 parent report, 9 observational
  - conducted at 18 months

Screening Instruments:

- M-CHAT (Robins, Fein, Barton 1999), claim it is a work in progress
  - expands the CHAT into a 23-item checklist that the parent alone can fill out in 10 minutes
  - conducted between 18-24 months
  - failure of 3 items suggests follow-up

Screening Instrument:

- PDDST (Pervasive Developmental Disorders Screening Test) (Siegel, 1996)
  - 3 parent report subtests, each can stand alone
  - 18 items for primary care clinics, discriminates from TD
  - 17 items for developmental disabilities clinics, discriminates from other disabilities
  - 16 items for autism clinics, discriminates from PDDNOS
  - conducted between 0-36 months

Myths: Children with autism...

- Can not be diagnosed reliably until 3 years of age
- Engage in behavior problems and/or repetitive activities as their earliest indicators (e.g.,)
  - Flap their hands
  - Rock incessantly
Early identification of ASDs

- Their presentation can be subtle
- Must be looking for social difficulties, such as social relatedness, and social interaction skills.

Autism/Asperger diagnostic tools

State of the Art Diagnostic Tools

- ADI-R, Autism Diagnostic Interview-Revised (Lord et al)
  - algorithm that corresponds to the DSM-IV
    - communication score
    - social score,
    - behaviors and interests score
- ADOS-G, Autism Diagnostic Observation Scale-Generic (Lord et al)

Practical/Reliable Instruments:

- Social Responsiveness Scale - Constantino
- Social Communication Questionnaire –(SCQ, 2003; Berument, Rutter, Lord, Pickles, Bailey)

Additional Instruments:

- Childhood Asperger Rating Scale – (CAST, 2001; Scott, Baron-Cohen, Bolton, Brayne)
- Asperger Syndrome Diagnostic Scale
  - (ASDS; Myles, Bock, & Simpson)
- Asperger Syndrome Screening Questionnaire
  - (ASSQ; Ehlers, Gillberg, & Wing, 1999)
- Australian Scale for Aspergers Syndrome
  - (ASAS; Garnett & Attwood, 1995)

Know what the research says:

- Many instruments out there are less than sensitive (look at GARS/GADS) 
  ...look at the research
- SRS and SCQ are reliable and valid