

# EARLY SCREENING, IDENTIFICATION & INITIATION OF SERVICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDER

BARBARA BENNETT, MD

KALMANOVITZ CHILD DEVELOPMENT CENTER  
CLINICAL PROFESSOR OF PEDIATRICS, UCSF  
PRIVATE PRACTICE MARIN

DISCLOSURES  
NONE

**A**lways

**U**nique

**T**otally

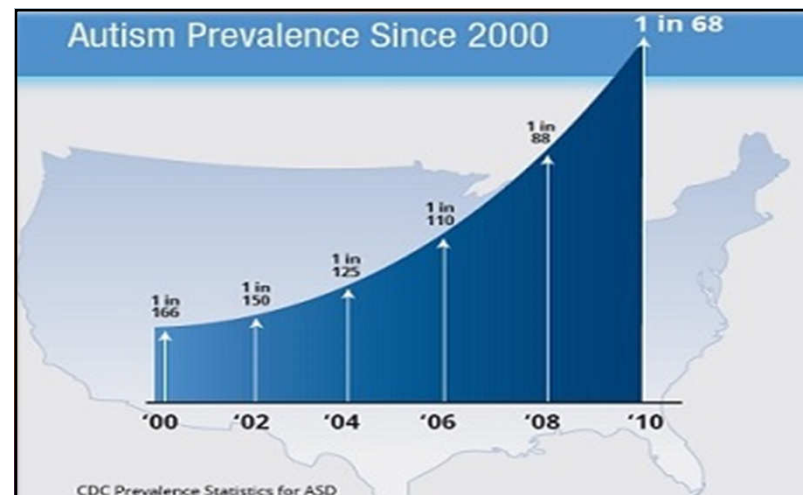
**I**nteresting

**S**OMETIMES

**M**YSTERIOUS

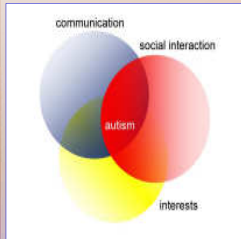


## Autism Prevalence Since 2000



**1/42 IN BOYS AND 1/189 IN GIRLS**

## WHAT IS ASD/AUTISM/S ?



**Heterogenetic neurodevelopmental disorder with varying phenotypes with a triad of issues in communication, social interaction and repetitive or restrictive interests with atypical sensory reactivity that causes some functional impairment. Autism does not have a single cause, but is instead a complex disorder with a set of core aspects.**

## GENETICS/BRAIN

- Hundreds of contributing CNV, hundreds to thousands of pieces of genes contributing to risk
- ASD and other disorders-DS, NF, TSC
- Evidence that genetics may give us concept of different phenotypes for autism and help clinically<sup>(1) Abrahams 2008</sup>
- In the future, there may be specific targeted treatment medically. Ex Fragile X model
- Twin studies-concordance: Identical 77%, fraternal 31%, sibs different genetically



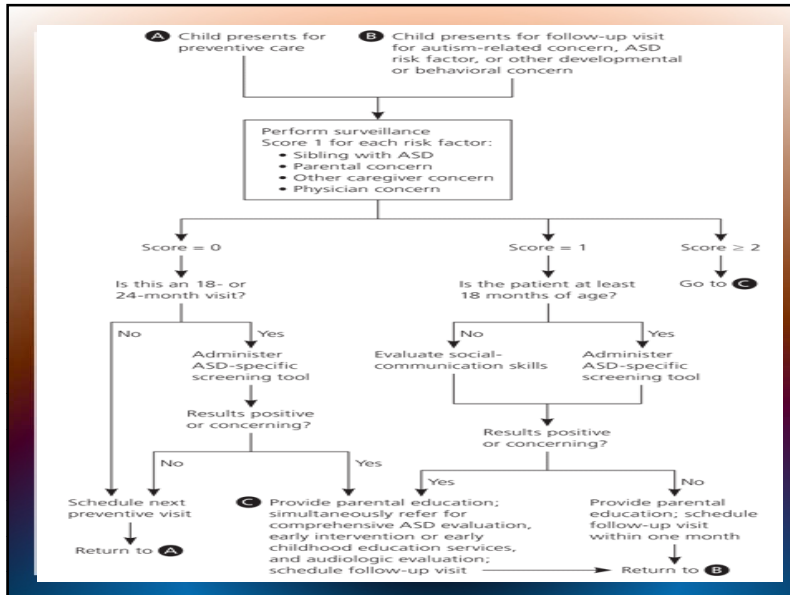
## RISK ASSOCIATIONS

- Older age in mothers and fathers as well as older (>50) paternal grandparents (2) DENOVO MUTATIONS INCREASE WITH AGE: Frans 2013
- Low folate level in mother conception/ early pregnancy, gestational diabetes, obesity.....
- Medications - Depakote (during pregnancy)...
- Extreme prematurity....
- Environmental- pollutants, fire retardants etc..

**On and on and on...**

## DEVELOPMENTAL SURVEILLANCE/SCREENING

- **AAP guidelines**-broadband screening should occur at the 9,18, 24 and 30 month visits. Examples: ASQ, CDI, ASQ-SE, PEDS etc.
- **AAP guidelines**- also indicate that autism screening should occur at the 18 month and 24 month visits. Example: MCHAT-R/F (3)Johnson 2007(4) Robins 2014
- Can screen with for language delay/ learning delay/autism at 12 months with CSBS DP-infant toddler Checklist (5)FEIN 2011
- Screening is **effective** (6)Guevara 2013 and observation is not enough to note symptoms in a well child visit (7) Danielson 2015



## AUTISM SCREENING

- In US, higher frequency of ASD in higher SES <sup>(8) MMWR 2014</sup>  
In Sweden, higher frequency in lower SES <sup>(9) Rai 2012</sup> seemingly due to access <sup>(10) Zuckerman 2013</sup>
- Updated version of M CHAT is M CHAT Revised/Follow up. Free download at [mchatscreen.com](http://mchatscreen.com).
- CSBS-DP infant toddler checklist at 1 year- free download- First Signs. Florida State
- “Widespread implementation of universal screening can lower the age of ASD diagnosis by 2 years compared with recent surveillance findings, increasing time available for early intervention”. <sup>(5) FEIN 2011</sup>

## AUTISM SCREENS

- **M CHAT R** (revised) is scored in less than 2 minutes. Can be filled out online by parents. 20 items with yes/no response. High false positive rate. If non pass, guidelines give choices of using M CHAT-F, or referral for evaluation.
- **M CHAT F** (revised follow up) can be used as secondary screen as has more detailed observations regarding all questions that are non pass. Online as well. High false positive as well but decreased compared to just MCHAT R
- **CSBS DP ITC**-one component of the Communication and Symbolic Behavior Scale Developmental Profile (CSBS DP). Consists of 24 questions about typical social communication milestones and a question about parent concern. Can be used at one year of age.

## WHY SCREEN EARLY FOR ASD?

- Common disorder 1/68 children
- No lab test or pathognomonic sign
- Implications for family planning-family with child with autism-3 to 20% risk of having another child with a similar disorder
- Parent concern-18 months with usual mean age of dx-4 years

**EARLY INTERVENTION WORKS**

## EMERGENCE OF AUTISM

- Symptoms of ASD likely emerge from a complex interaction between pre-existing neurodevelopmental vulnerabilities and the child's environment, modified by compensatory skills and protective factors.
- Studies prospectively of siblings of children with autism from birth. Multiplex families with autism may not represent the phenotype of singletons. Baby Sib.
- Studies retrospectively of children diagnosed with autism. Looks at video recordings from infancy and diaries. Can have regressive type as well.
- Early signs may represent markers of the evolution of the disorder. Likely in utero (11) Stoner 2014.

## STUDIES IN PROCESS FOR MARKERS/EARLY SIGNS

- No single marker has been found that is a completely reliable predictor.
- May be a combination of factors much like the possible etiology of ASD
- Examples of some of the studies: eye gaze/tracking/movement (12) Jones 2013, genetic studies, EEG, molecular, vitamin levels, mitochondrial, immunology, fMRI patterns (13) Just 2014- neural representations of social thoughts to predict autism diagnoses with 97 percent accuracy, establishing the first biologically based diagnostic tool that measures a person's thoughts to detect the disorder.
- **On and on and on...**

## AUTISM EARLY SIGNS IN INFANTS



### 1 Unusual visual fixations

Unusually strong and persistent examination of objects



### 2 Abnormal repetitive behaviors

Spending unusually long periods of time repeating an action, such as looking at their hands or rolling an object



### 3 Lack of age-appropriate sound development

Delayed development of vowel sounds, such as "ma ma, da da, ta ta"



### 4 Delayed intentional communication

Neutral facial tones and decreased efforts to gesture and gain parent attention



### 5 Decreased interest in interaction

Greater interest in objects than people and difficult to sustain face-to-face interactions

## POSSIBLE EARLY SIGNS OF AUTISM AT 12 MONTHS

- Not babbling –
- Not pointing –
- Not showing objects to caregivers –
- Lack of other gestures
- Lack of shared enjoyment
- Repetitive actions or movements –
- Poor eye contact
- Not following an adult's pointed finger
- Paying more attention to objects than people
- Limited play with toys
- Not copying actions or sounds
- Not responding to his or her name when called

## SIB STUDY AND EARLY SIGNS

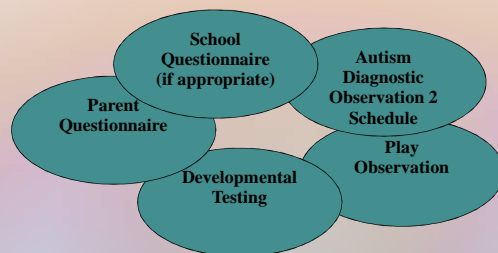
- 3 types of features at 18 months predictive of ASD vs non ASD outcome at 36 months. Accuracy 82.7% in test and 77.3% in validation. Clinical features varied as function of their 18 month symptom profile. (14)Baby Sibling Research Consortium Study 2014
- Types
- (1) poor eye contact combined with lack of communicative gestures and giving
- (2) poor eye contact combined with a lack of imaginative play
- (3) lack of giving and presence of repetitive behaviors, but with intact eye contact.
- Children with ASD who were misclassified at 18 months were higher functioning, and their autism symptoms increased between 18 and 36 months.

## WHAT DO EARLY SIGNS MEAN?

- Do not always mean a child has or will develop ASD
- May have overall developmental delay
- May have regulatory issues
- May have communication issues
- May have underlying chronic medical issues- all types including prematurity
- May be normal
- May have combination of above

## DIAGNOSIS

- Still no pathognomonic test
- Standard of care evaluation involves:



- Valid at 18 months with ADOS 2 toddler module
- Also use home video clips

## INTERVENTION FOR ASD

Time is of the essence for early intervention

- Behaviors are less likely to become firmly established if there is early intervention
- Evidence that outcome may be improved with earlier intervention.
- Parents are grieving re diagnosis and trying to access services at same time
- IT WORKS

## AUTISM INTERVENTIONS

- There is no one specific intervention that is considered the only absolutely proven method.
- Intensive clinician guided therapy- 10 to 25+ hours per week ABA (Early Start Denver Model, pivotal response, discrete trial)
- There is statistical research and there is much proof of this model's efficacy in young children (15) Weitlauf 2014.

## AUTISM INTERVENTIONS

### Programs, Agencies, Access, Logistics

- Programs- ABA(Denver Early Start, Pivotal response, discrete trial,) speech therapy (Hanan, direct, group), OT, social groups, etc.
- Agencies- Regional centers, school district, medical insurance SB 946, etc.
- Logistics- hours of therapy, parent work, family, finances, support
- Access- limited resources, many "hoops to go through"



## VERY EARLY INTERVENTION QUESTIONS

- Who should receive intervention with what diagnosis?
- What are the active ingredients of successful therapy?
- When should it start? Is there a critical period?
- Where will intervention occur? Natural setting, center?
- Why do interventions work well in some and not as well in others?
- How will the program be funded? How long?

## VERY EARLY INTERVENTION

- There is knowledge/evidence base regarding infant mental health/development and effective intervention. Can we use some of this?
- Example: Hanen More than Words (HMTW)- parent training program that provides support, education, & practical skills for enhancing communication in children with ASD. Consists of 8 weekly group sessions and 3 individual family sessions, designed to increase the frequency of playful parent-child interactions and facilitate communication. 26.Carter 2011

## VERY EARLY INTERVENTION

- The pivotal role of parents and caregivers ,the importance of starting early and the power of the “everyday”
- Empower and support parents without adding to their stress
- Take into account the variables and characteristics of a child, family, resources and access to services

## VERY EARLY INTERVENTION

- Evidence that early diagnosis and early intervention can lead to better outcome 16 Fein 2013
- Some signs may be present at 6 months, but clearer at one year.
- Studies with toddler intervention with varying models
- Studies with infant intervention with varying models
- Very promising but still more research needed

## MODELS OF EARLY INTERVENTION FOR TODDLERS

- Varying -Parent mediated, natural environment, short/long term, group or individual, center based, intense early social intervention (ESI) clinician guided (20 to 25 hours per week)
- Efficacy for toddlers with autism intervention (17) Dawson 2010 RCT with ESDM effective, (18) Dawson 2012-normalized brain activity
- Efficacy - short term (19) Landa et al 2012 Positive long-term outcomes of 2 year old with (ASD) with 6-months of early intervention.
- Efficacy parent delivered (20) Rogers 2012 12-week, low-intensity (1-hour/wk therapist), parent-delivered intervention for toddlers (P ESD)at risk for (ASD) aged 14 to 24 months and their families in 3 groups with community control. Gains- younger and more hours.

21 Parent-Implemented Social Intervention for Toddlers With Autism: An RCT. Wetherby, Guthrie, Woods, Schatschneider, Holland, Morgan, Lord. Pediatrics 2014; 134:6 1084-1093; Efficacy of individual ESI parent coaching compared with group-ESI. Showed importance of individualized parent coaching in natural environments..

## MODEL - EARLY INTERVENTION FOR INFANTS

- Early Start MIND- (22)Rogers/Dawson-2014- 7 highly symptomatic infants( 6 to 15 mos.) with high scores on the AOSI<sub>(23)Bryson</sub> & ITC received ESDM.
- Twelve one hour sessions with parent and baby ff'd by biweekly visits for 6 weeks, and follow-up assessments at 24 and 36 months.
- At the end of 9 months, the children in the treatment group (compared to controls ) had significantly more symptoms. At the end of 18 and 36 months, the children in the treatment group were significantly less symptomatic, less likely to have an autism diagnosis, and less likely to have developmental or language delays.(6 of 7 babies)

## MODEL - EARLY INTERVENTION FOR INFANTS

- Early intervention for infants at risk for ASD is feasible and effective<sup>(25) Bradshaw 2014</sup>
- BASIS study- adapted video interaction for promoting positive parenting program(iBASIS-VIPP). 54 families with infant at risk of ASD randomly assigned to program or no intervention. Six home based therapist visits using video feedback to help parents respond to babies communication style. After 5 months, families who received video therapy showed improvement in infant engagement, attention and social behavior<sup>(26)Green 2015</sup>

## PARENT SUPPORT

- Parent support is crucial-refer to Family Resource Center
- Help parents navigate the maze of systems, help each other, resources
- Parents are grieving re the diagnosis but also re possible implications for future children
- Parents very vulnerable since there is no specific test for the diagnosis, no specific intervention absolutely proven to help their child.
- May be eligible for FMLA Family medical leave for work
- Medical home

## INFORMATION FOR PARENTS AT DIAGNOSIS

- Written information for parents as part of visit with follow through for intervention/prioritization
- Include process for accessing intervention. Example: Have parents contact their mental health insurance(if applicable) SB 946 to determine if they are eligible for ABA (if indicated)
- Child is under 3 years- Contact the Regional Center for services. Can provide ABA if not covered by insurance(need denial letter from insurance)

## AUTISM RESOURCES

1. What Color Is Monday?: How Autism Changed One Family for the Better- book by Carrie Cariello
2. 10 Things Every Child with Autism Wishes You Knew-book updated 2012 by Notbohn
3. IAN site- Johns Hopkins- great reference for valid research
4. Thinking Person's Guide to Autism blog
5. Online site for interactive learning guide for ABA for parents of children with ASD. Videos and interactive learning from U Mass at [www.udiscovering.org](http://www.udiscovering.org).
6. Complementary and Alternative Medicine Use in ASD. Perrin, et al, Pediatrics NOV 2012 VOL 130, supplement 2
7. AAP toolkit , Autism, caring for children with ASD: A Resource Toolkit for Clinicians 2007
8. Autism A.L.A.R.M. handout-AAP/CDC/NCBDD.
9. ABLE Act 2014- Achieving a Better Life Experience Act. Individuals with disabilities or their families tax-sheltered savings account to pay for certain long-term expenses. Earnings on an ABLE account would not be taxed, and account funds would generally not be considered for the supplemental security income (SSI) program, Medicaid, and other federal means-tested benefits.