

Autism Controversies in Your Office: Vaccines, Alternative Therapies, Neurodiversity, and Beyond

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Some scenarios

- Very educated mother of 4 month old wonders if her 2 month old, slow to smile, has autism
- A different family, African-American or Latino, has just received a clear-cut diagnosis of autism— but is skeptical
- Parents of a newly diagnosed 3 yo with autism bring you multiple articles on supplements
- Another family with an older child with autism, declines vaccines for their infant



“What kind of a story have we fallen into?”

You need to understand a little about autism’s history to understand your families

Autism's “Discovery”



Dr Leo Kanner, Head of
Child Psychiatry, Johns
Hopkins



Donald Triplett: brought to see Kanner in
1938, who could recite all the American
Presidents by age 3 but could not ask or
answer a question...

The 1943 Case Report

To understand and measure emotional qualities is very difficult. Psychologists and educators have been struggling with that problem for years but we are still unable to measure emotional and personality traits with the exactness with which we can measure intelligence.

—ROSE ZELIGS in *Glimpses into Child Life**

AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT

By LEO KANNER

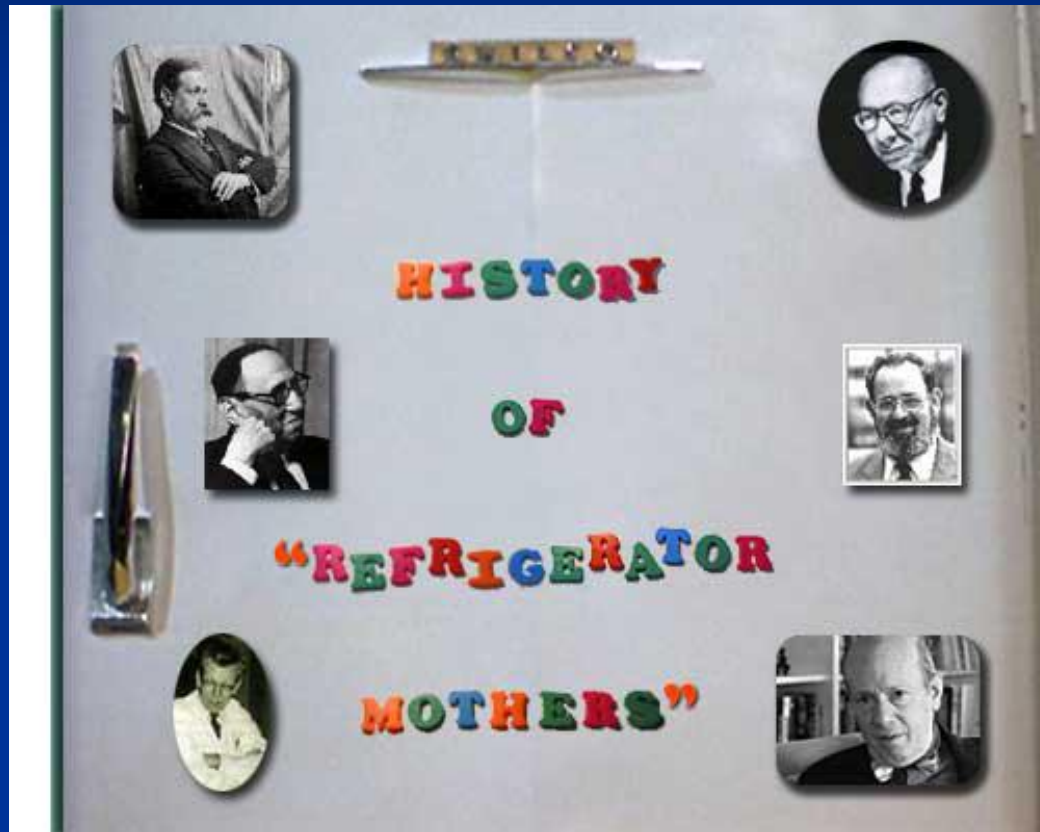
SINCE 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits—and, I hope, will eventually receive—a detailed consideration of its fascinating peculiarities. In this place, the limitations necessarily imposed by space call for a condensed presentation of the case material. For the same reason, photographs have also been omitted. Since none of the children of this group has as yet attained an age beyond 11 years, this must be considered a preliminary report, to be enlarged upon as the patients grow older and further observation of their development is made.

Case report of 11 children united by a “profound inability to relate to others” and an “anxiously obsessive desire for the maintenance of sameness”

Kanner's Autism vs Autism Today

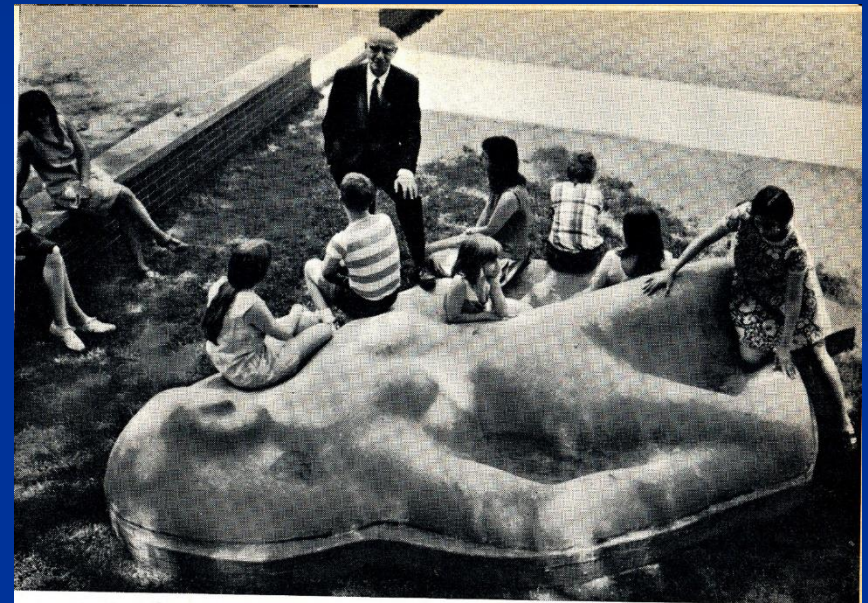
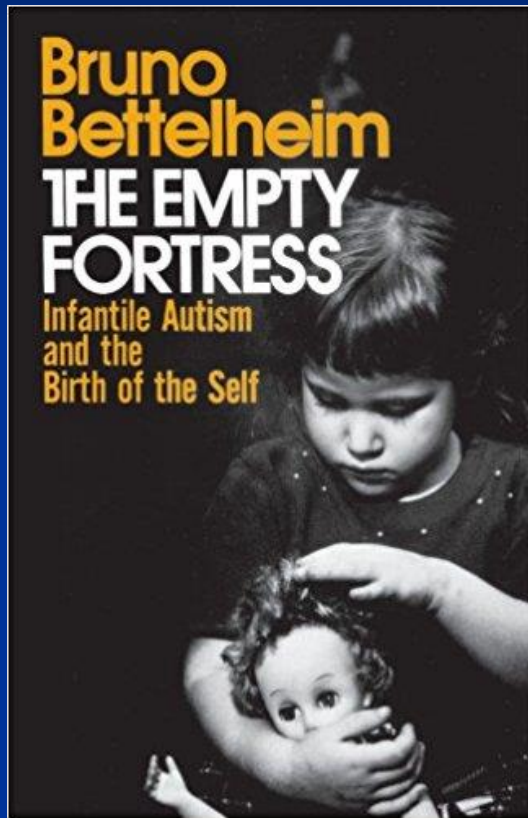
- Wrote numerous case reports 1943-60s that eventually convinced his colleagues that autism was a distinct syndrome
- But also made sweeping assertions that would no longer be accepted today:
 - No overlap between autism and intellectual disability
 - Parents were as “distinct” as the children— typically white, professional, highly educated, and emotionally distant

The “Refrigerator Mother” Era



From the 1940s through the mid-1960s, autism was widely portrayed as the withdrawal of an infant into an internal “fantasy world,” in response to a cold and emotionally frigid mother

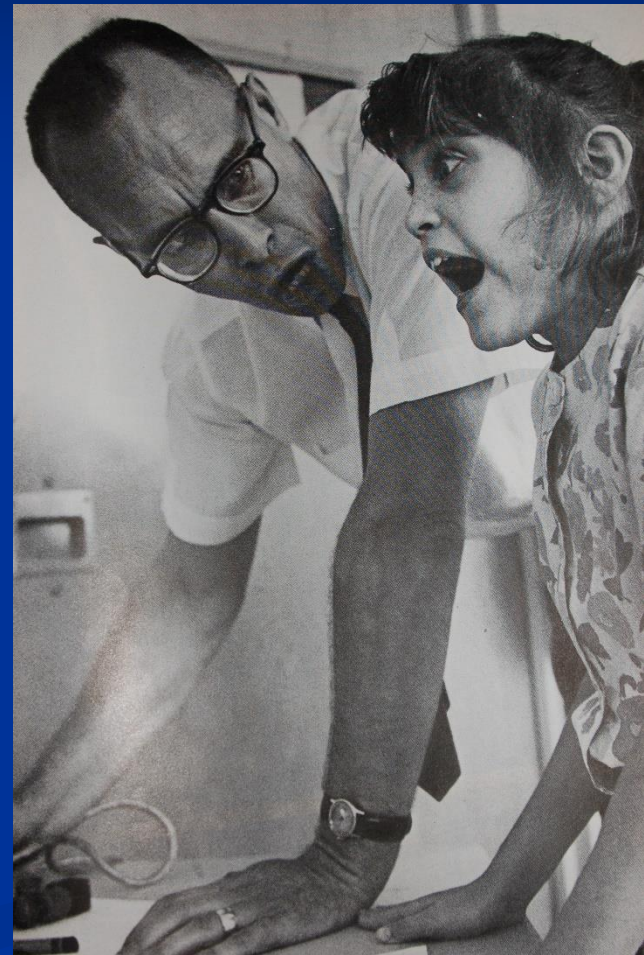
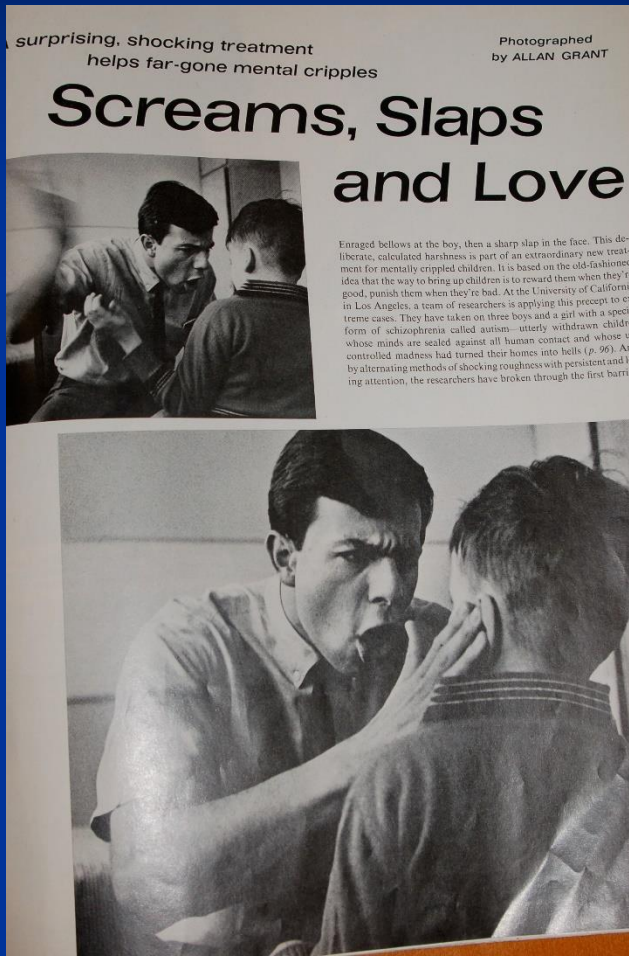
The Infamous Dr Bruno Bettelheim



BETTELHEIM WITH PATIENTS & SUPERMOTHER
A kick hurts them more than the sculpture.

Chicago Psychoanalyst, Director of Orthogenic School for Children,
Public Intellectual and Author of Acclaimed 1967 book

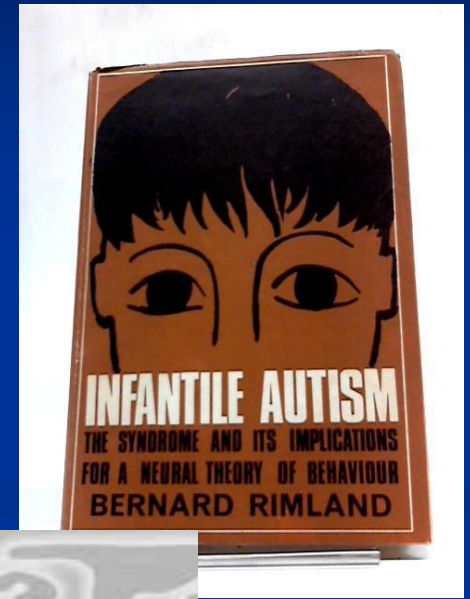
What were the alternatives?



Life Magazine Article on early behavioral therapy, published
May 7, 1965

The Great Parent Revolt

- Began with psychologist/father of autistic child: Bernard Rimland (1964 book)
- Parents wrote back!
- Formed what would become the Autism Society of America—first of the powerful parent advocacy groups for autism

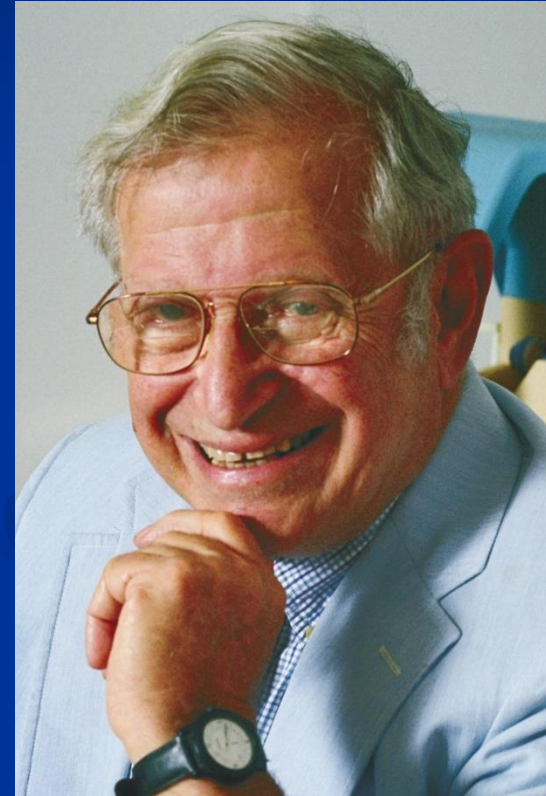


Autism Transformed: 1965-80

- Reconstructed as a neurobiological rather than emotional disorder
- Diagnosis became codified in DSM-3 as checklist of symptoms in three domains: social interaction, communication, and rigid/repetitive behaviors
- But the question of how biology explained autism would fracture the autism world into two warring factions...

“Mainstream” Autism Paradigm

- Viewed autism rooted in brain development— with strong genetic component
- With a “spectrum” of manifestations from mild “Asperger’s” to severe
- Therapy promoted early detection and aggressive services (TEACCH, ABA, language, OT)

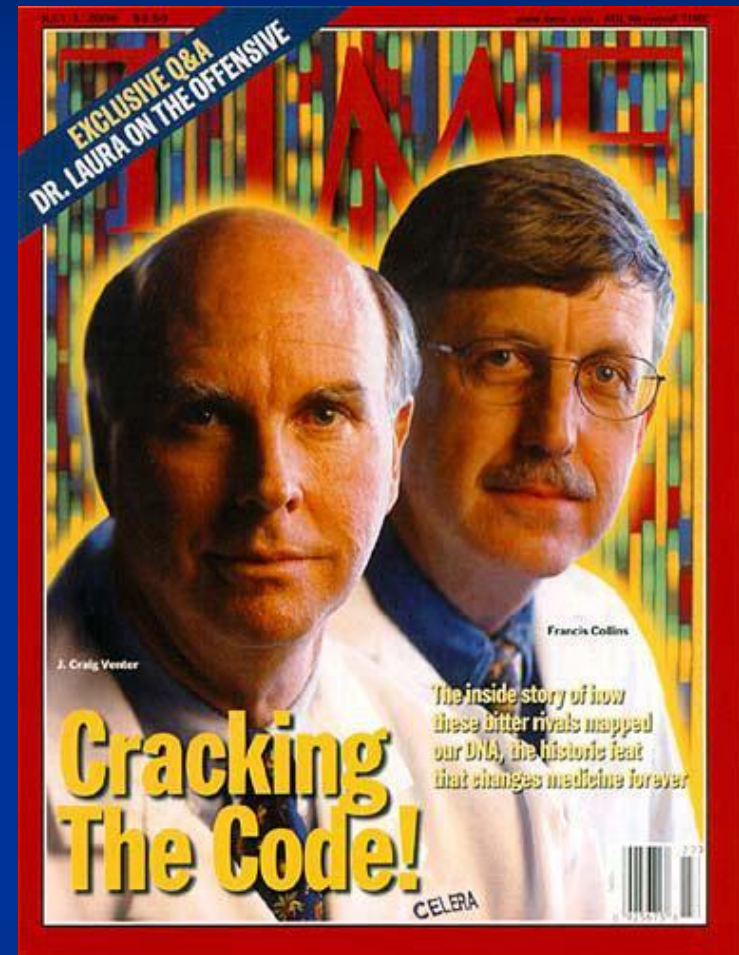


UNC’s Eric Schopler, founder of TEACCH program

Mainstream Autism since 2000:

The (Unfulfilled) Promise of Genomics

- Hopes that autism might be explained by a relatively small number of genetic variations were dashed
- We have instead identified 100s of variations, none exclusive to autism, and collectively explaining only a minority of autism cases
- Work is now exploring epigenetics, the introns, and neurodevelopmental pathways



The “Alternative” Autism Paradigm

- Promoted by parents and “dissident” professionals
- Bernard Rimland’s Autism Research Center 1967
 - Agreed autism was rooted in biology- but argued it included many disorders, some treatable with diet or supplements (like PKU)
- Launched DAN! Project 1995-2011



Bernard Rimland PhD and son Mark; the first psychologist to openly challenge the psychogenic paradigm (*Infantile Autism*, 1964)

The Defeat Autism Now! (DAN!) Project,

1995-2011

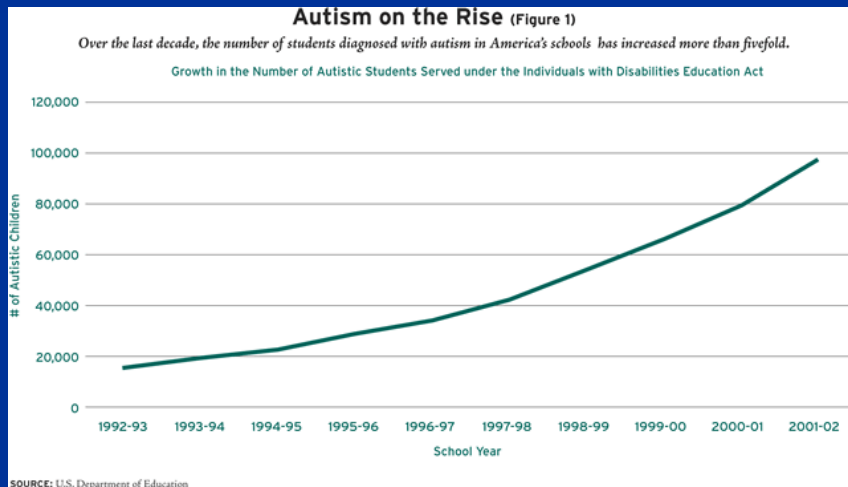
- Became a powerful network promoted via web, conferences, and books
- Disseminated by a network of practitioners (less than half physicians)



Promoted some 33 modalities for “curing” autism, including but not limited to:

- Gluten and casein free diet
- Vitamins, esp B6, Vitamin C
- Secretin
- Digestive enzymes
- Anti-inflammatory
- Anti-yeast
- Chelation meds

The Autism “Epidemic”- and the Autism Vaccine Controversies



Dr Andrew Wakefield, promoter of MMR/Autism linkage

The Vaccine Controversies Refuted

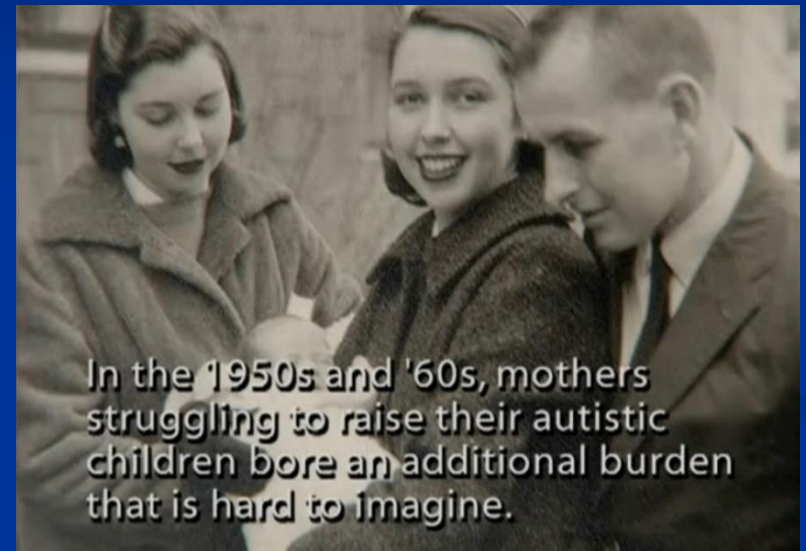
- Numerous studies have examined both the MMR and thimerosal controversies— and failed to support any role for vaccines
- “Vaccine Omnibus” cases dismissed in courts in 2009



Andrew Wakefield exposed in media for research irregularities, barred from practice in UK in 2010

Why “Alternative Autism” persists

- Persistent skepticism towards medical expertise in autism community
- The (understandable) need “to do something”
- Parents need hope more than a microarray....and a clinical partner rather than a scientist



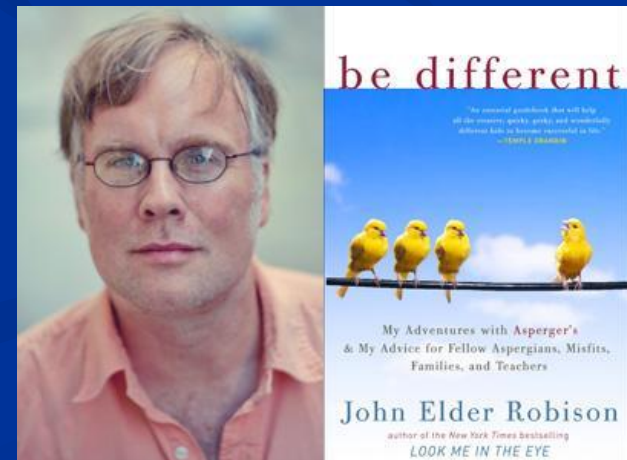
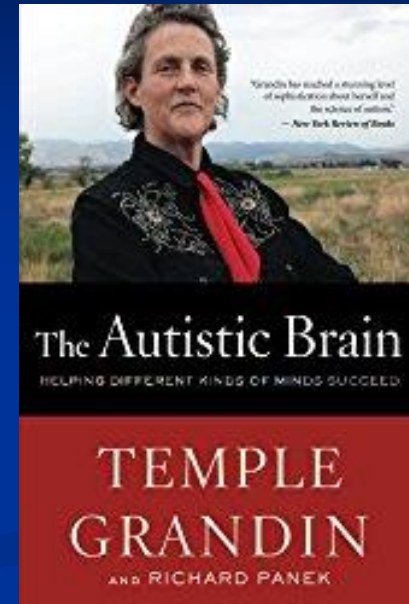
Clip from 2003 documentary
“Refrigerator Mothers”

The Newest Autism Controversy? Neurodiversity



Autism: Disability or Identity?

- High functioning people with autism have attacked both of the earlier autism paradigms
 - Assert that autism is not a pathology to be “cured”– or to be prevented through prenatal screening



How does this history play out in your office?

Recognition

Discussions with Parents

Listening to Parents

- Despite the rising prevalence of autism, the average age of diagnosis is still around age 4
- Limited diagnostic facilities are an important part of the problem
- But many parents report that their primary care practitioners played down their concerns
- Caveat: Parental anxiety over autism is still more common among the educated (reflecting composition of autism parent advocacy groups)

Red Flags in Toddlers

- Language regression or delay associated with:
- No pointing to make requests by 15 months
 - May instead pull caregiver by the hand
- No pointing to share interests by 18 months
- Not checking parents' facial expression in novel situations (contrast with separation anxiety)

Red Flags: Age 24- 36 months

- Language: may emerge, but not to communicate
 - Delayed echolalia: repeating lines from TV/video
- Stereotypical play and behaviors:
 - Rigid, repetitive rather than pretend play
 - Might just push toy car back and forth, spin wheels for long time periods, lick or smell it
 - Often love to flip light switches, run in circles, spin
 - Tantrums triggered by unexpected changes in plan

Screening: the M-CHAT

- 23-Question Screen form administered at 18 and 24 months visits (validated for 16 to 30 months)
- High Sensitivity--but high false positive rate

M-CHAT-R™

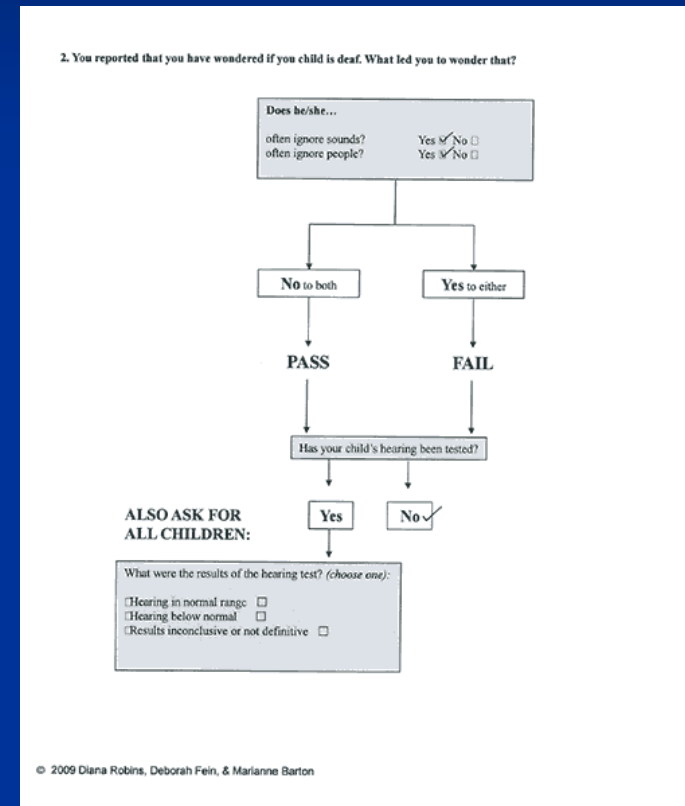
Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child might be deaf?	Yes	No
3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)	Yes	No
5. Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Yes	No
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Yes	No
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11. When you smile at your child, does he or she smile back at you?	Yes	No
12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13. Does your child walk?	Yes	No
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?)	Yes	No
18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?)	Yes	No
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)	Yes	No

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The MCHAT R/F

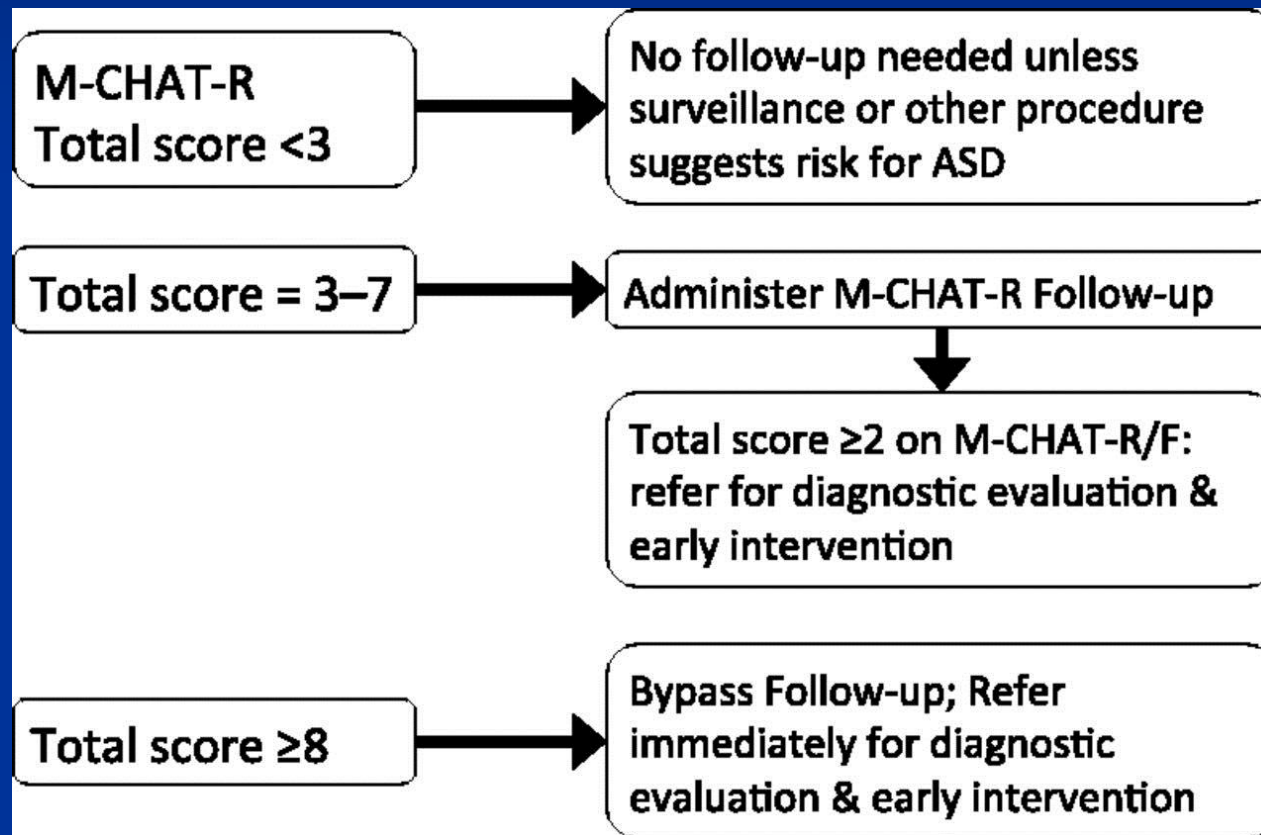
- Includes a set of follow up questions, designed to clarify any failed response
- Results in far better positive predictive value:
 - 54% of failures will have autism diagnosis
 - 94% will have some kind of developmental delay
- But takes time...



Example: Follow up for question #2

Referral after failed M-CHAT

R/F



Getting a Comprehensive Evaluation

- Ideally would include detailed interview, plus and formal developmental testing including an ADOS-2
 - Academic autism center, developmental pediatrician or neurologist, child psychologist, NC TEACCH
- In practice— it can be hard to obtain such evaluation in timely fashion
- *Always* refer to early intervention or preschool services to get services started

CDSA/Preschool Programs

- This referral will connect the child to ongoing services and periodic evaluations, often at home
- Children under 3 will receive speech and OT
- In many counties, children approaching age three and older, with suspicion of autism may well receive autism evaluation and be offered placement in an autism-specific preschool program

First Steps After the Diagnosis

What if you deliver the news?

- First ask parent what they know about autism, before offering your interpretation
- Review the child's deficits and behaviors, including special abilities (positive side of autism—memory, patterns, iphones and ipads!)
- Ask about their concerns— why this child? Is it mother's fault? What does the future hold?
- Take a generally hopeful stance and make clear you will be their partner

Talking about Autism

- Be aware of the neurodiversity perspective
- Try to distinguish the morbidities of autism from autism as an identity
- Don't talk about cure; but helping child reach full potential as a person with autism

Two Critical Resources for Parents

- Autism Speaks (leading research foundation)
 - www.autismspeaks.org
 - Great resources for parents.. A set of downloadable “toolkits” addressing common behavior problems
 - Check this yourself if you are asked a tough behavior problem related to autism
- Your state Autism Society
 - Support groups
 - Runs parent education groups, and answers questions about local resources

Medical Evaluation

- Never forget audiology if language delayed!
- Physical exam with Woods lamp as thorough as possible; specific testing and genetics referral if suggested by findings on exam or family history
- Fragile X and Microarray are recommended as basic workup— especially if significant cognitive delay or other anomalies
- Metabolic workup if Hx of regression
- MRI only for macro- or microcephaly, asymmetry on neurologic exam, significant intellectual disability
- EEG if suggestions of seizure activity

More on the Microarray

- Parents should be informed that this is recommended for all children with autism by American College of Genetics (2009)
- But proceed with caution if doing yourself:
 - Yield is low for phenotypically normal and higher (cognitively) functioning children
 - Significant chance of incidental variations
 - Cost is around \$2000 for both Fragile X and microarray; can be issue for high deductible plans

Four “Standard” Therapeutic Strategies

- Speech and Language: need to address visual communication
- Occupational Therapy: helpful in addressing (but not curing!) sensorimotor challenges associated with autism
- Structured Education (TEACCH): focuses on making home and routines “autism friendly”
- Behavioral: Applied Behavioral Analysis (ABA) and its variations

More on ABA

- The most evidence-supported therapy for improving communication and behavior in autism
- In earlier years, was often very rigid reward/punishment (Discrete Trial Conditioning); “aversives” dropped long ago
- Has evolved into more naturalistic approaches (ie, early start Denver model, pivotal response training)— take advantage of child’s natural inclinations to promote communication

What if parents ask you about CAM approaches?

- Don't judge too quickly— think about being in their shoes!
- Help parents be informed consumers— look at anecdotal claims with suspicion
- Identify possible risks and costs— avoid potentially dangerous interventions (chelation)
- And if they do wish to try a safe intervention, have a concrete plan to assess target symptoms

CAM in Autism: Evidence Grades

Levy SE, Hyman SL *Child Adol Psych Clin N Amer* 2015; 24: 117-143

- Grade A: No positive trials
 - Strong NEGATIVE evidence for secretin
- Grade B: Melatonin, Vitamin C, Music Therapy, GFCF Diet
- Grade C+: Oxytocin
- Grade C: Vitamin D, Omega-3 FA
- Grade D: Chelation Agents (DMSA; one death reported); Vitamin B6/Magnesium

The GFCF Diet

- Used by 15-16% of children per Interactive Autism Network
- Based on “leaky gut” hypothesis: allowing entry of gluten- and casein-based peptides into circulation and then binding to opioid receptors in CNS
- Early studies reported abnormal levels of gluten and casein in urine of children with autism; but studies were not replicated
- Still, diet was aggressively promoted in 1990s

GFCF Diet: Best studies

- Four published experimental studies prior to 2015 had conflicting results
 - Compromised by reliance on nonblinded parent reports, and no effort to control concomitant therapies
- Hymen et al (2015) small but well designed double blind challenge trial addressed both shortcomings— and showed no benefit. N-14.
 - Hyman SL (2015). *J Autism Dev Disord* 46:205-220.

GCFC Diet: What you can tell parents

- If it works at all, can only be on a small subset of patients with ASD
- Anecdotal reports have likely failed to mention concomitant therapies
- Difficult to implement— especially in feeding-averse children
- Involve a nutritionist, and have a clear assessment plan

And What About Vaccines?

Talking Points

- You can tell parents that while the rising prevalence of autism is not fully understood, expanded recognition explains most of it, and numerous studies have examined, and exonerated, any role for vaccines
- Can talk about problems of anecdotal reports: selective memory and omitted details
- And the fate of Dr Wakefield...

And maybe try sharing a little history

- If they still worry that vaccines explain the rise of autism, ask:
 - Why was there no autism epidemic in 1970s, when US introduced MMR?
 - Why did autism rates fail to decrease after thimerosal withdrawn from vaccines after 2003?
- In the end, much comes down to building a relationship of trust

Tomorrow: Autism Co-Morbidities

- Sleep
- Diet
- Behavior