

Pediatrics TeleECHO

Setting the Stage: Overview of Autism in the US



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AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT

By LEO KANNER

Infantile autism

“...inability to relate themselves in the ordinary way to people and situations...”

“...anxiously obsessive desire for the maintenance of sameness.”



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Autism Spectrum Disorder

Persistent deficits in social communication and social interaction across multiple contexts

Restricted, repetitive patterns of behavior, interests, or activities

Autism Spectrum Disorder

Social communication and social interaction

Deficits in social-emotional reciprocity

Deficits in nonverbal communication

Deficits in developing and maintaining relationships

Restricted, repetitive behaviors

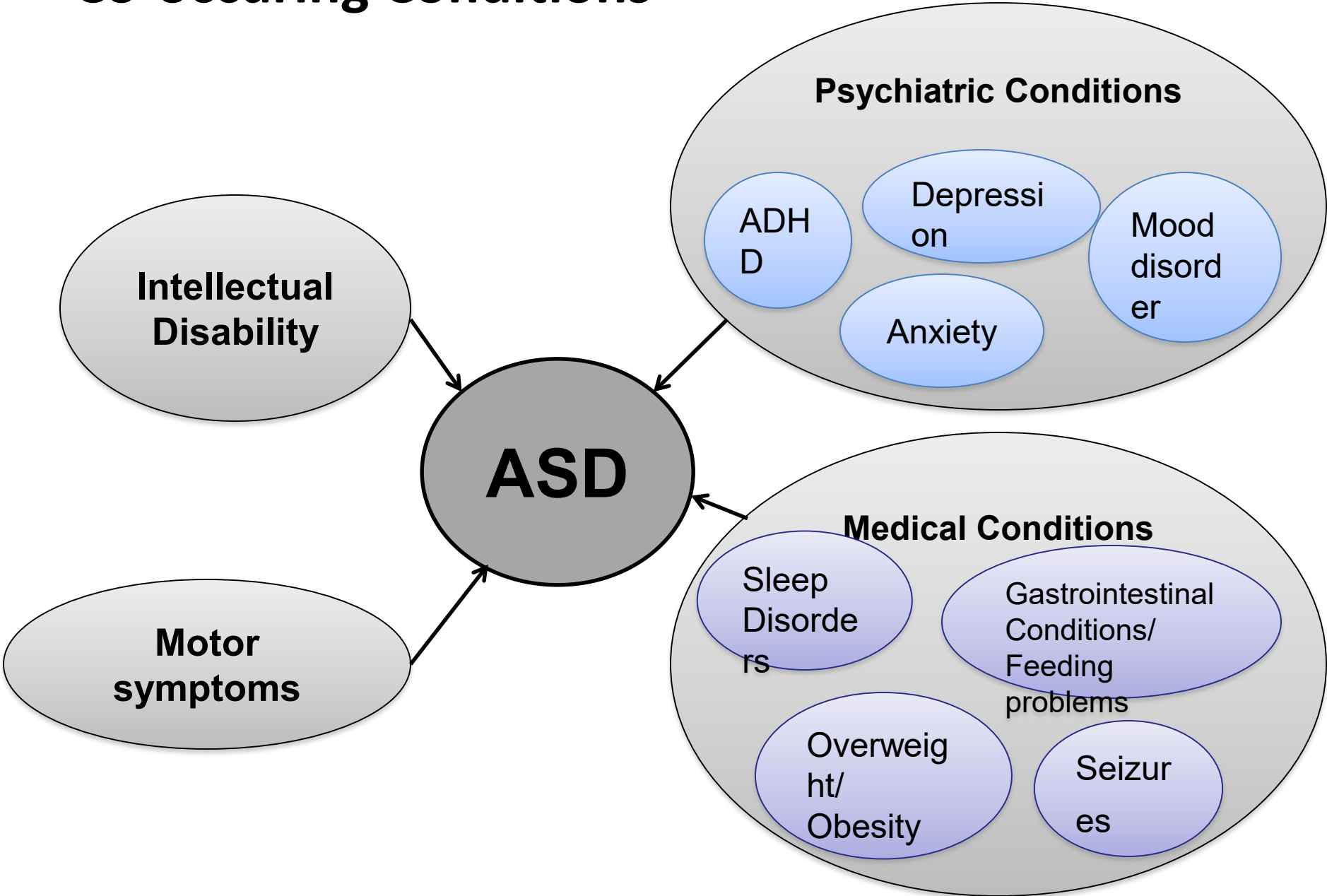
Stereotyped or repetitive behaviors

Insistence on sameness; rituals

Restricted interests

Sensory aberrations

Co-occurring Conditions



1 in 59

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., et al. (2018). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveill Summ*, 67(6), 1-23, doi:10.15585/mmwr.ss6706a1.

Prevalence of Autism in a United States Population: The Brick Township, New Jersey, Investigation

Jacquelyn Bertrand, PhD*; Audrey Mars, MD‡; Coleen Boyle, PhD*; Frank Bove, ScD§;
Marshalyn Yeargin-Allsopp, MD*; and Pierre Decoufle, ScD*

Bertrand J, Mars A, Boyle C, Bove F, Yeargin-Allsopp M, Decoufle P. Prevalence of autism in a United States population: the Brick Township, New Jersey, investigation. *Pediatrics*. 2001;108(5):1155-1161.

Identified Prevalence of Autism Spectrum Disorder

ADDM Network 2000 – 2012
Combing Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5–9.9)	1 in 150
2002	1994	14	6.6 (3.3–10.6)	1 in 150
2004	1996	8	8.0 (4.6–9.8)	1 in 125
2006	1998	11	9.0 (4.2–12.1)	1 in 110
2008	2000	14	11.3 (4.8–21.2)	1 in 88
2010	2002	11	14.7 (5.7–21.9)	1 in 68
2012	2004	11	14.6 (8.2–24.6)	1 in 68

Most recent estimated ASD Prevalence



Why the increase in prevalence?

Changes in diagnostic criteria

Diagnostic substitution

Greater case finding incentive due to treatment availability

Improved awareness of parents, health care providers and school evaluators

Increased recognition among high functioning individuals

?? Other factors

What is the average age of ASD diagnosis in the US?

4 ½ years old

At what age is therapy for ASD most effective?

Before 4 ½ years old

The benefits of early identification for young children with ASD

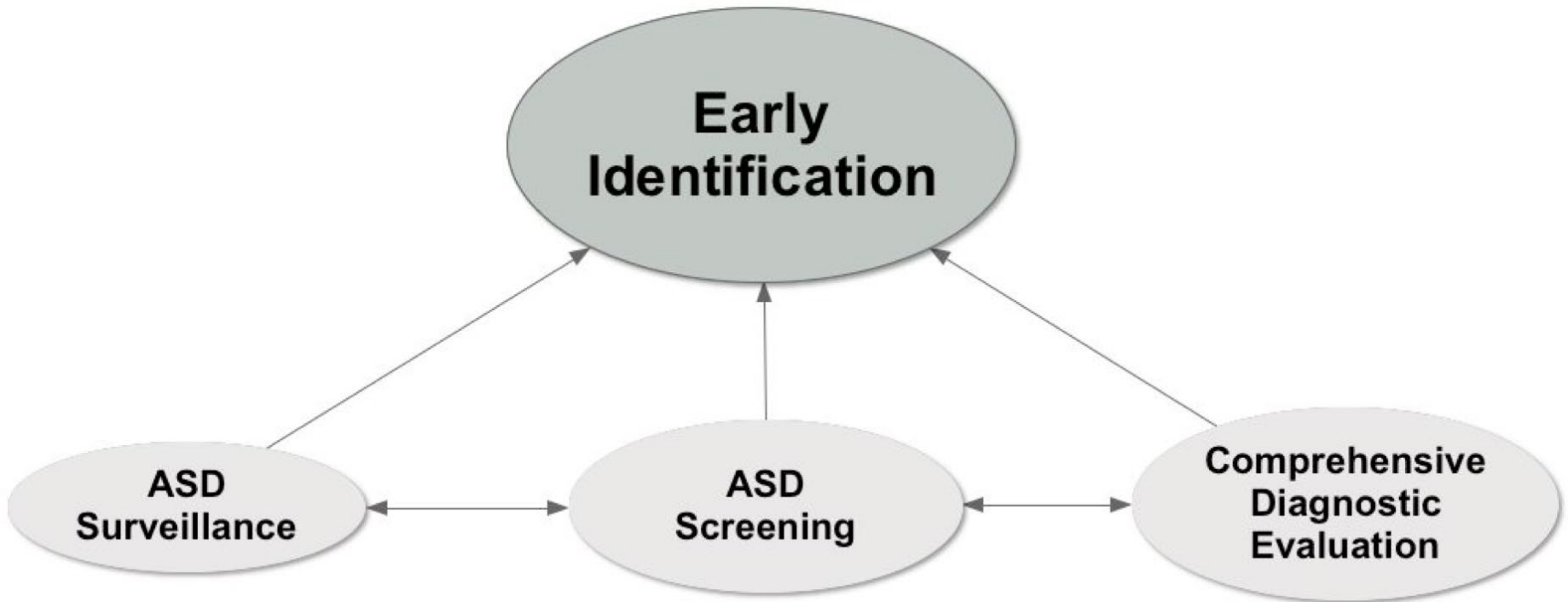
Early intensive developmental/behavioral interventions result in significant improvement in cognition, language, adaptive behavior in children as young as 18 months. (Lovaas, 1987; Dawson, 2010)

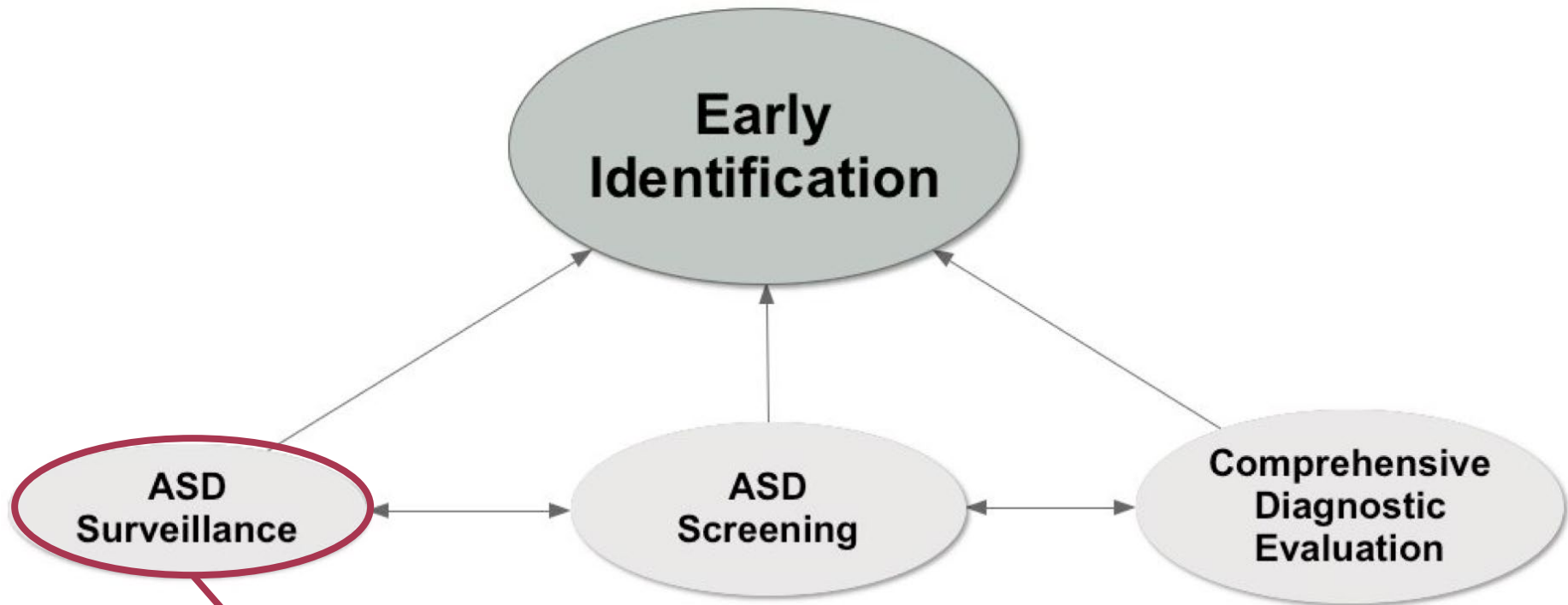
How early can autism be diagnosed?

- Signs of autism emerge over the first 18-24 months and are not present at birth
- Difficult because of different patterns of symptom emergence (heterogeneity!)

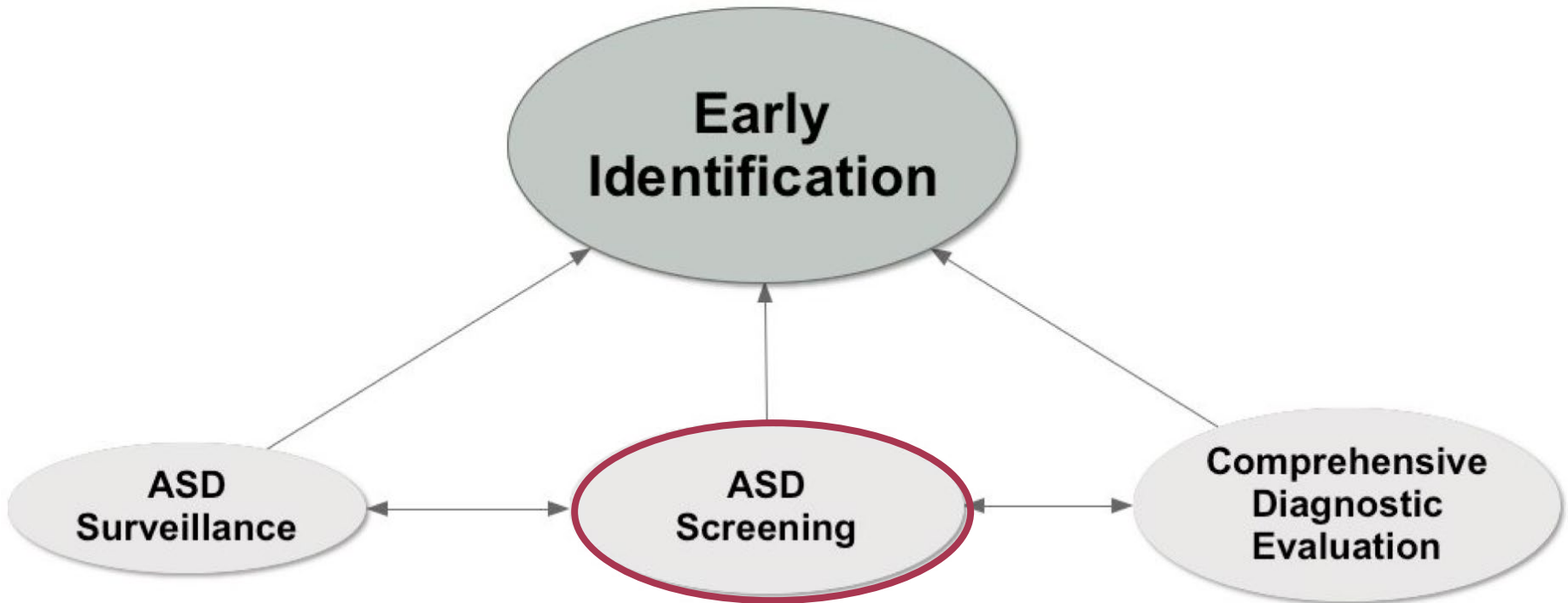
How do we recognize the earliest signs of autism?

- Family history
- Listen to parents
- Look for the early signs:
 - Early social skill deficits
 - Language delay or odd use of language
 - Restricted interests, repetitive behaviors or movements





→ Ask about concerns regarding behavior and development and family history
Observe for early signs
(all well visits)

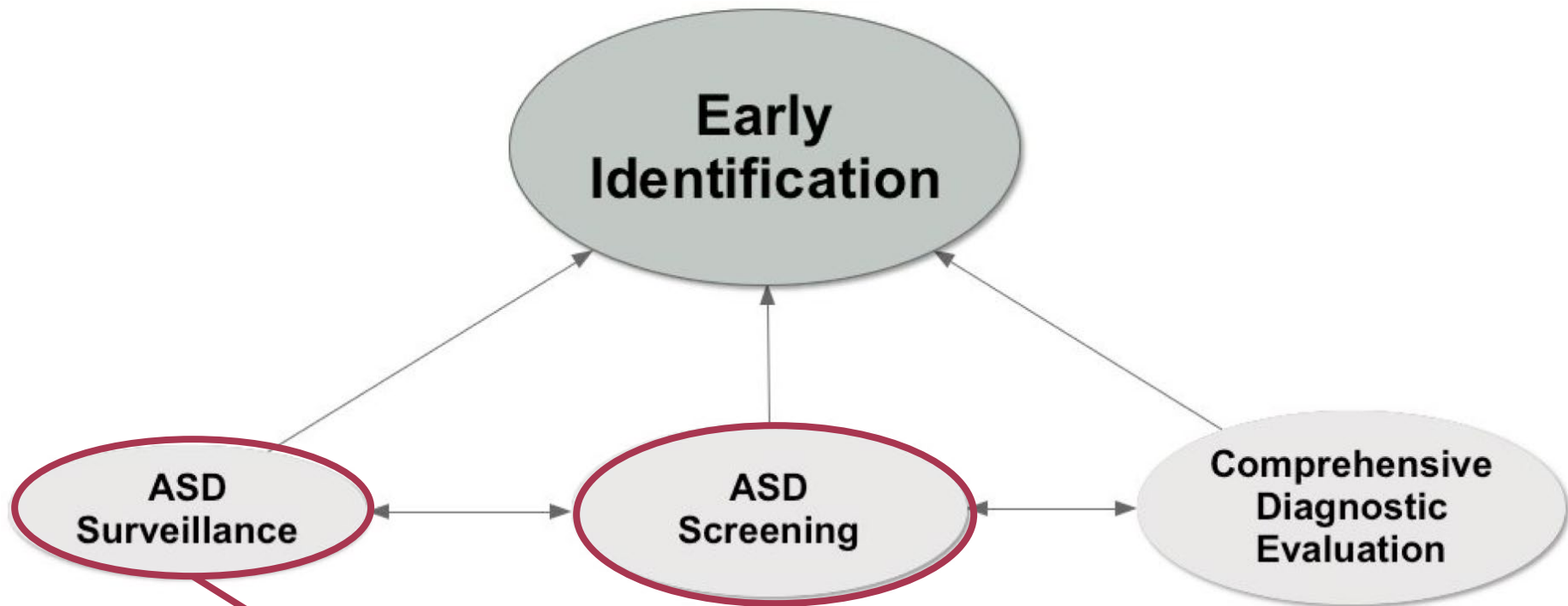


Brief standardized tool that aids the identification of children at-risk (**18, 24 month visits**)

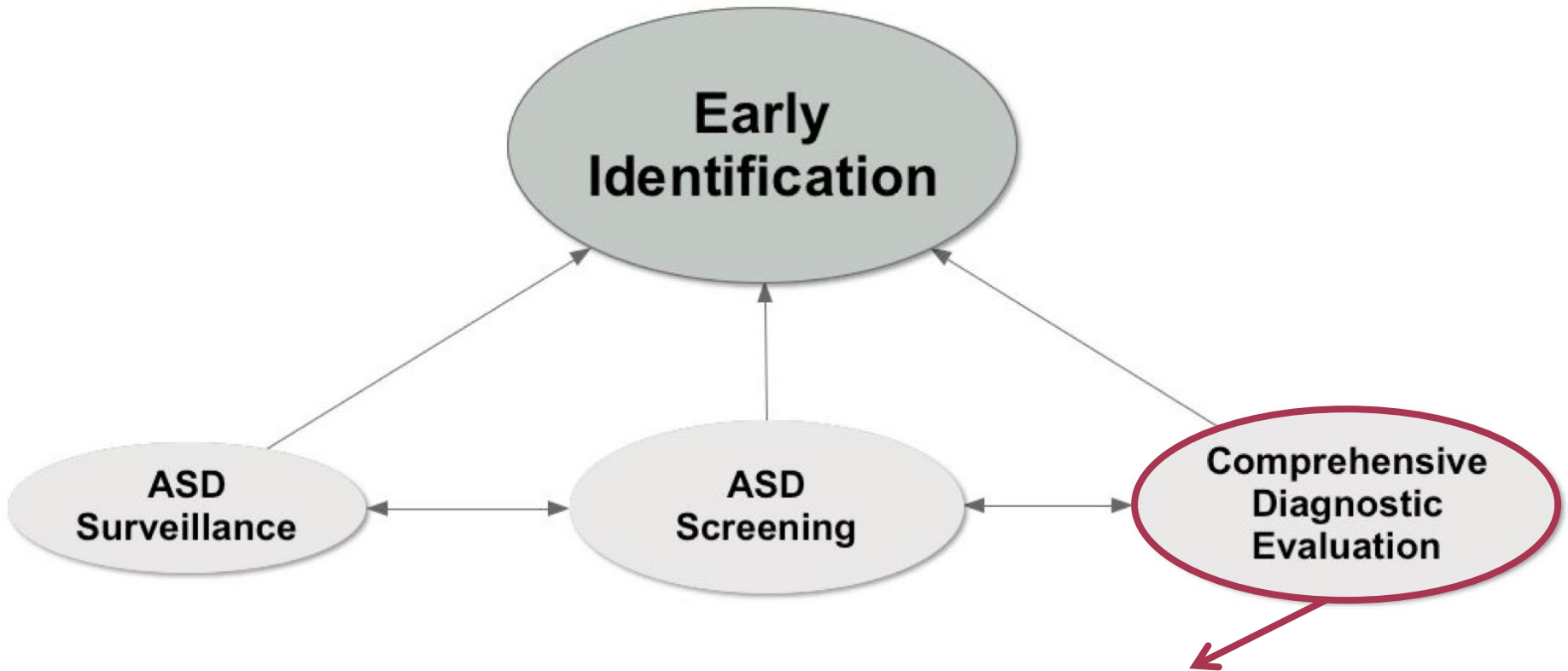
M-CHAT-R™

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 <u>unusual</u> 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



Identify children at-risk for ASD, do not provide a diagnosis



The definitive diagnosis of ASD is made by a specialist or team of specialists with expertise in ASD.

Comprehensive Diagnostic Evaluation

- Developmental history
- Physical exam
- Observation
- Autism specific diagnostic tests
- Cognitive testing
- Ideally interdisciplinary
- Etiologic workup

Long-term management

- Goals: maximize functional potential, minimize maladaptive behaviors and support individuals and their families
 - Behavioral/developmental interventions
 - Educational interventions
 - Speech, occupational, physical therapy
 - Medical management
 - Treat co-occurring medical and psychiatric conditions
 - Address complementary and alternative therapy questions
 - Refer to community based services

Transition to adulthood

- Housing
- Employment
- Social participation
- Sexuality/gender issues
- Guardianship
- Medical issues

The health status of adults on the autism spectrum

Lisa A Croen¹, Ousseny Zerbo¹, Yinge Qian¹, Maria L Massolo¹, Steve Rich², Stephen Sidney¹ and Clarissa Kripke³

Medical conditions

Epilepsy

Constipation

Insomnia

Dyslipidemia

Diabetes

Hypertension

Obesity

Stroke

Psychiatric conditions

Anxiety

Depression

Bipolar Disorder

Dementia

Suicide attempts

Premature mortality in autism spectrum disorder

Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein and Sven Bölte

Table 3 Risk for all-cause mortality for the entire autism spectrum disorder (ASD) group, as well as separately for females and males, and low-functioning ASD and high-functioning ASD groups

	Controls Number of deaths (%)	ASD OR (95% CI) Number of deaths (%)	Low-functioning ASD OR (95% CI) Number of deaths (%)	High-functioning ASD OR (95% CI) Number of deaths (%)
Total	24 358 (0.91)	2.56 (2.38–2.76) 706 (2.60)	5.78** (4.94–6.75) 169 (2.71)	2.18 (2.00–2.38) 537 (2.57)
Females	11 693 (1.39)	2.24 (1.99–2.51) 296 (3.51)	8.52 (6.55–11.08) 61 (3.00)	1.88 (1.65–2.14) 235 (3.67)
Males	12 665 (0.69)	2.87* (2.60–3.16) 410 (2.19)	4.88 (4.02–5.93) 108 (2.57)	2.49 (2.22–2.80) 302 (2.08)

ASD, autism spectrum disorder; OR, odds ratio; CI, confidence interval.
*Partial likelihood ratio test for interaction effect ASD × gender, $P=0.001$.
**Partial likelihood ratio test for model selection (low-functioning ASD/high-functioning ASD), $P<0.001$.

Individuals in the control group died at a mean age of 70 compared with 54 in the ASD group (40 for the low-functioning ASD, 58 for high functioning ASD)



My favorite books with autism as a theme

Non-fiction

- Neurotribes: The Legacy of Autism and the Future of Neurodiversity
- Asperger's Children: The Origin of Autism in Nazi Vienna
- The Reason I Jump

Fiction

- The Curious Incident of the Dog in the Night-time
- The Rosie Project
- Eleanor Oliphant is Completely Fine
- A Man Called Ove

What is Applied Behavioral Analysis (ABA)?

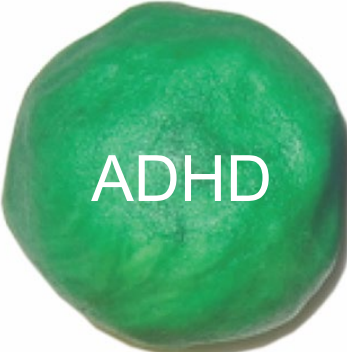
Method: build functionally useful behaviors and reduce problematic ones

Focus: small, measurable units of behavior are taught systematically

Goal: build on simple responses into complex and fluid combinations of age-appropriate responses



Co-occurring behavioral/psychiatric conditions



ADHD



Depressio
n



Anxiety



Mood
Disorder