

# Best Practices for Autism Screening and Diagnosis in Community Settings

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9/8/2022



College of Health Sciences  
Wyoming Institute  
for Disabilities



Mountain Plains (HHS Region 8)

MHTTC

Mental Health Technology Transfer Center Network  
Funded by Substance Abuse and Mental Health Services Administration

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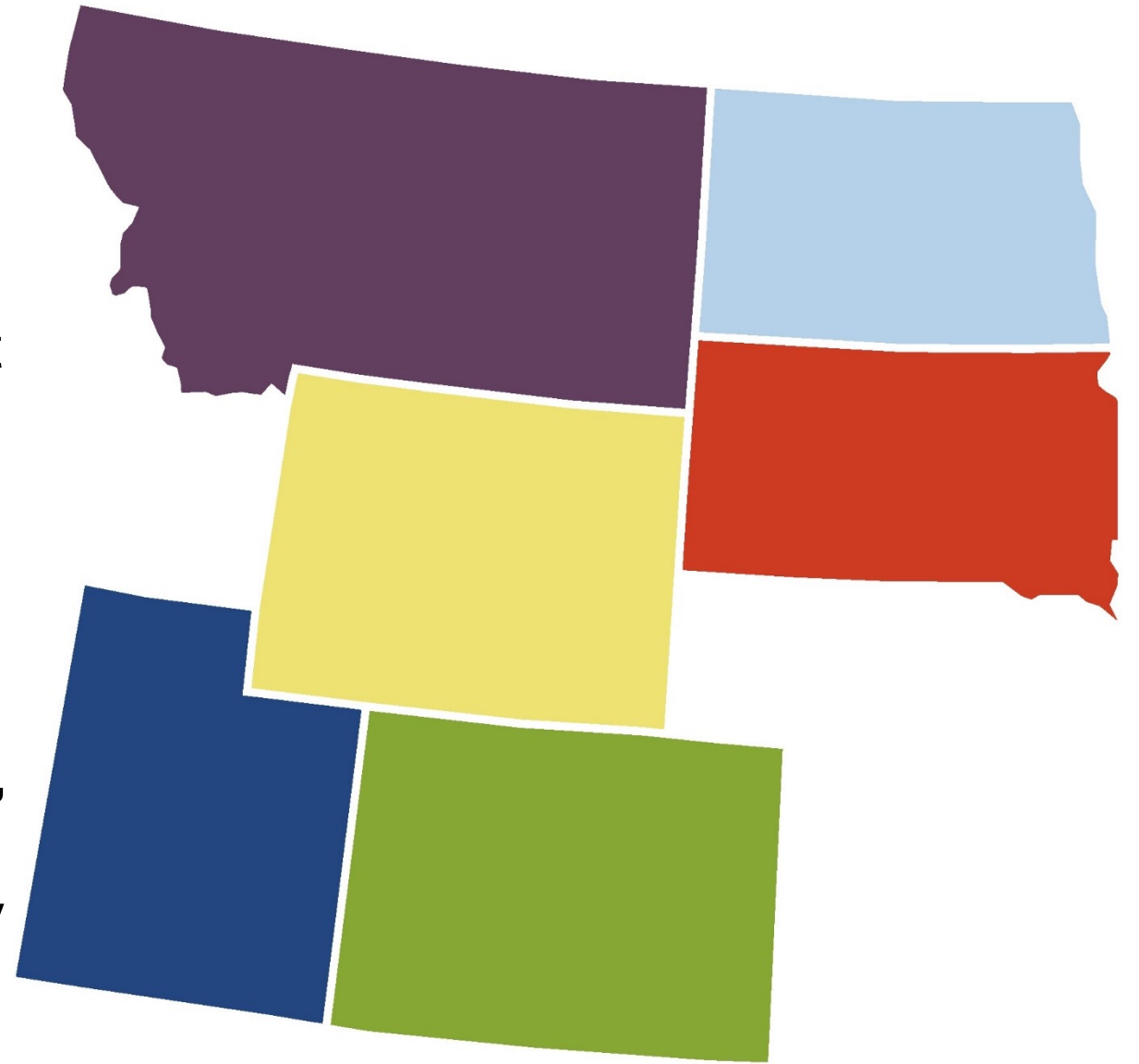
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# The Mountain Plains Mental Health Technology Transfer Center

The Mountain Plains Mental Health Technology Transfer Center (Mountain Plains MHTTC) provides training and technical assistance to individuals who serve persons with mental health concerns throughout Region 8 (Colorado, Montana, North Dakota, South Dakota, Utah and Wyoming).

We belong to the Technology Transfer Center (TTC) Network, a national network of training and technical assistance centers serving the needs of mental health, substance use and prevention providers. The work of the TTC Network is under a cooperative agreement by the Substance Abuse and Mental Health Service Administration (SAMHSA).





# Land Acknowledgement Statement

Today, the University of North Dakota rests on the ancestral lands of the Pembina and Red Lake Bands of Ojibwe and the Dakota Oyate - presently existing as composite parts of the Red Lake, Turtle Mountain, White Earth Bands, and the Dakota Tribes of Minnesota and North Dakota. We acknowledge the people who resided here for generations and recognize that the spirit of the Ojibwe and Oyate people permeates this land. As a university community, we will continue to build upon our relations with the First Nations of the State of North Dakota - the Mandan, Hidatsa, and Arikara Nation, Sisseton-Wahpeton Oyate Nation, Spirit Lake Nation, Standing Rock Sioux Tribe, and Turtle Mountain Band of Chippewa Indians.



The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

STRENGTHS-BASED  
AND HOPEFUL

INCLUSIVE AND  
ACCEPTING OF  
DIVERSE CULTURES,  
GENDERS,  
PERSPECTIVES,  
AND EXPERIENCES

HEALING-CENTERED AND  
TRAUMA-RESPONSIVE

INVITING TO INDIVIDUALS  
PARTICIPATING IN THEIR  
OWN JOURNEYS

PERSON-FIRST AND  
FREE OF LABELS

NON-JUDGMENTAL AND  
AVOIDING ASSUMPTIONS

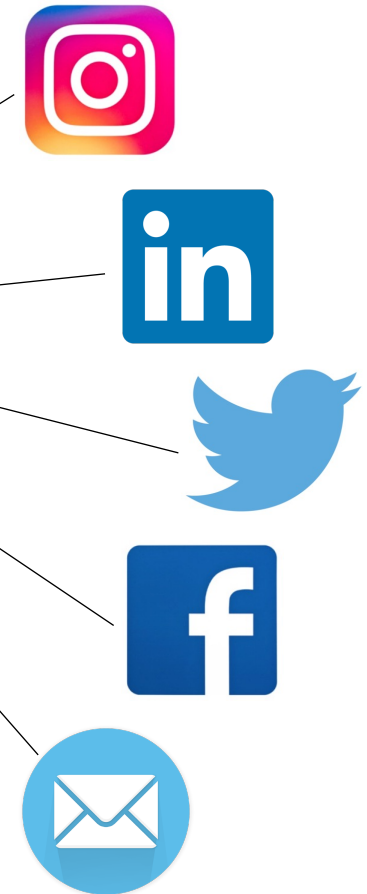
RESPECTFUL, CLEAR  
AND UNDERSTANDABLE

CONSISTENT WITH  
OUR ACTIONS,  
POLICIES, AND PRODUCTS

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# Best Practices for Autism Screening and Diagnosis in Community Settings

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# Autism features

- DSM –IV

- Autism
- Asperger's Syndrome
- Pervasive Developmental Disorder-Not Other Specified (PDD-NOS)

- DSM-V

- A spectrum, not subgroups
- Deficits in Social Communication
- Restricted and Repetitive Behaviors
- Severity Levels



# Unique features of Autism

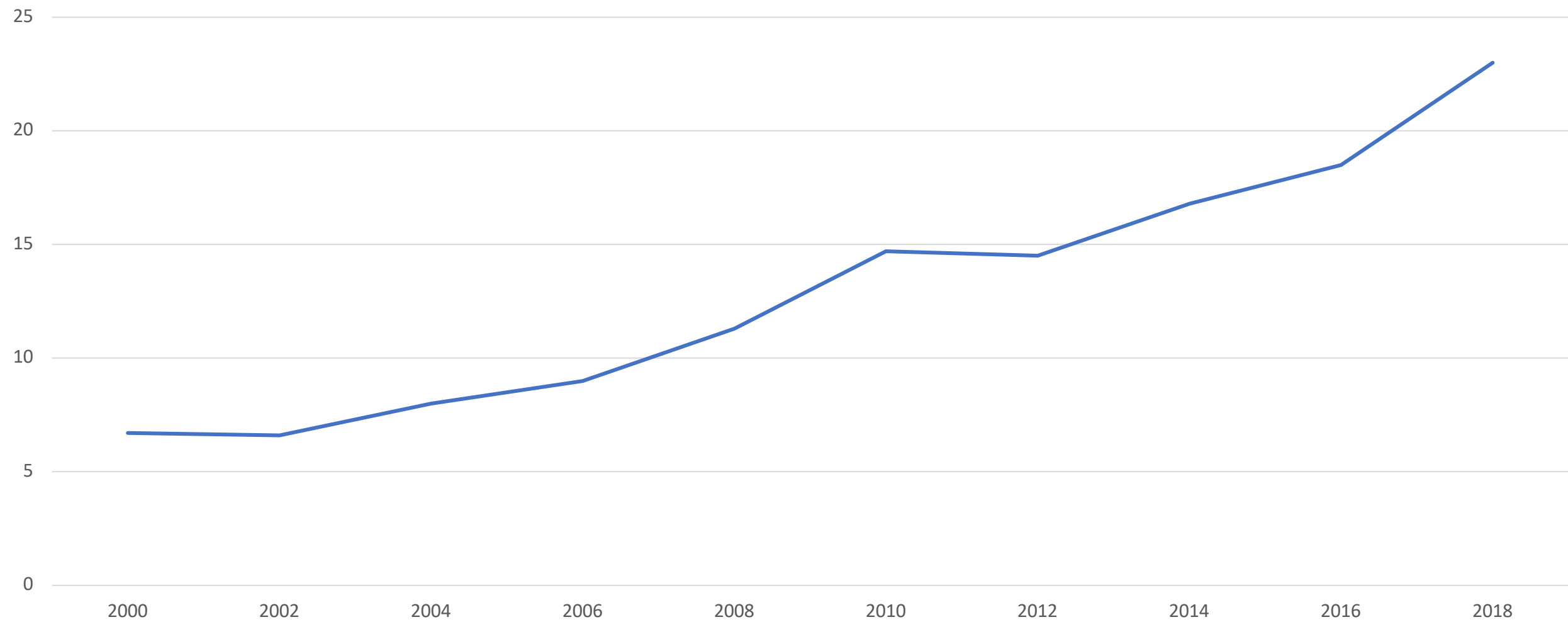
- Behaviorally defined
  - “Invisible”
  - Inconsistent pattern of development
  - Spectrum
  - comorbidities and overshadowing
- Behaviorally treated
  - Multiple disciplines
  - Medical, schools, community
- Lifetime condition
  - Multiple social systems
  - \$2.4 million (Buescher, et al, 2014)
  - \$40,000-\$60,000 per year behavioral treatments
  - Annual medical costs 6X no ASD
- Minimal effectiveness data / treatment individualization (Mattron, 2017)

# Public Health Impact

- 1 in 44 nationally (8 yr olds)
- Average age of Dx ~ 4 yrs
- Increased family stress

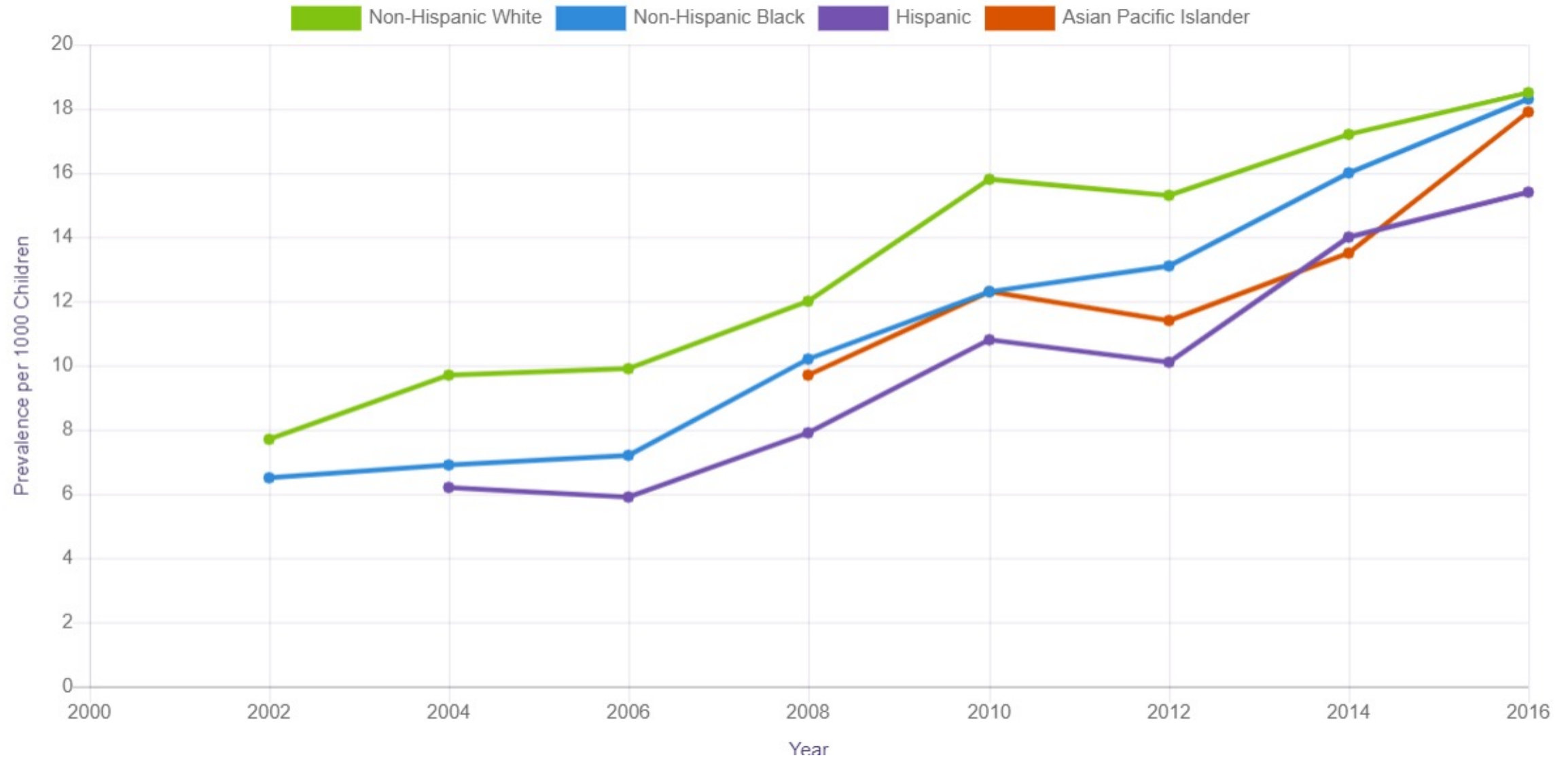
# Autism prevalence

Combined Prevalence per 1,000 children (All ADDM sites)



### Prevalence Estimates by Race/Ethnicity

Show ADDM prevalence estimates\* by race/ethnicity for:



Overall economic impact: Cakir, et al. (2020)

## 2019-2020 costs:

- \$7 trillion

## Projected:

- \$15 trillion over next decade





# How it is supposed to work



# but there is a lot more to it

False neg/pos?

Cost of treatment

Pediatrician hesitancy

Parental concern

Lack of providers/waitlists

IEPs and 504 plans



What cut off to use?

Level 1 vs 2 screeners

Educational ID vs Medical Dx

Lack of providers

Lack of access to providers

Parental concern 20-25 hrs of ABA?

# Screenener purpose & types

- Quick, minimal effort
- Part of routine monitoring
  - (but not just a kid thing)
- Level 1 vs Level 2
  - ASD specific or DD general
- Observational or parent report
- NOT diagnostic; know your next steps

# Level 1 screeners

- M-CHAT-R/F ([mchatscreen.com](http://mchatscreen.com))
  - 20 items
  - Free
  - 16-30 months
  - >50 languages
  - Low, medium, high risk
  - Sensitivity/specificity
    - w/o follow up, cut off = 3: 73% / 89%
    - w/ follow up, cut off of 2, sensitivity = 2: 94%

## 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

# Other Level 1 Screeners

## Parent's Observations of Social Interactions (POSI)

- Format: 7-items
- Age range: 16-35 months and 31 days.
- The
- Languages: English, Spanish, Khmer, Burmese, Nepali, Portuguese, Haitian-Creole, and Arabic
- Scoring:  $\geq 3$  indicates increased risk
- Sensitivity=83% and specificity=74%
- Free

## Communication and Symbolic Behavior Scales Developmental Profile (CSBS-DP) Infant-Toddler Checklist (CSBS-ITC)

- Format: 24-item,
- Age range: Functional communication age between 6 months and 24 months
- Languages: English
- Sensitivity=89% and specificity=89% for ASD or other developmental delays;
- PPV = 20% for ASD alone when used as a stand-alone screener.
- Sens 0.78, Spec 0.84 for communication delay including autism.
- Free
- Does not reliably discriminate between autism and another communication delay or disorder.



# Level 2 Screeners

## SCQ Social Communication Questionnaire

- 4+ years
- 40-item parent completed checklist; children must have a mental age of at least 2 years
- 5 to 10 minutes to complete; 5 minutes to score; scoring must be done by a developmental professional
- Available in multiple languages
- Sens 0.85, Spec 0.75

## CARS-2 – Childhood Autism Rating Scale 2

- 15-items
  - The Standard Version (CARS 2-ST) is used with children younger than 6 years.
  - The High-Functioning Version (CARS 2-HF) is used for verbally fluent individuals 6 years and older with average or above intellectual ability.
- Clinician completed
- Interpreted relative to the level of autism-related behaviors.
- 15 mins
- Administered by practitioner, includes an unscored parent survey

# Level 2 Screeners

## **SRS – Social Responsiveness Scale**

- 4-18 years
- 15-20 mins
- 65-item
- severity of autism symptoms as they occur in natural social settings.
- Social motivation, Social cognition, Social awareness, Social communication, & RRIB.
  - quantitative score for autistic social impairment.

## **RITA-T – Rapid Interactive Screening Test for Autism in Toddlers**

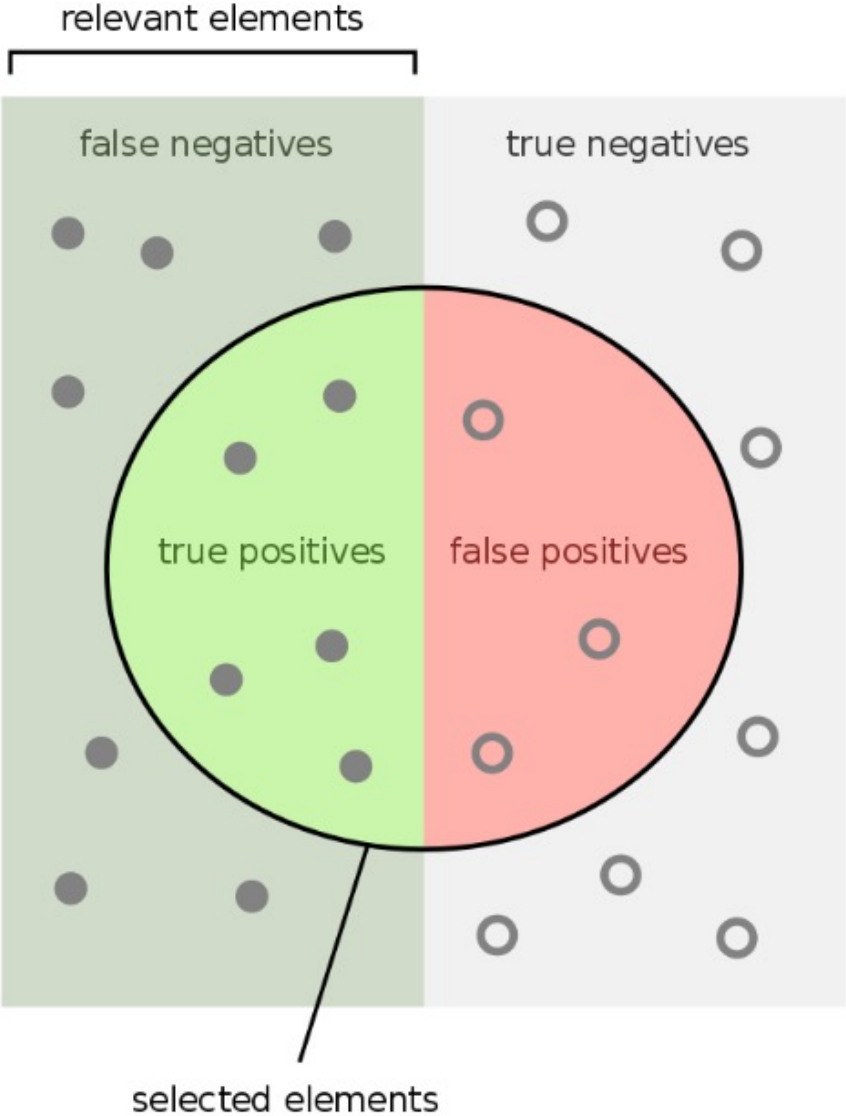
- 18-36 months
- 9-item provider-completed interactive/observational measure;
  - requires training and special kit to properly administer
- 5 to 10 minutes to administer and score;
- Requires training
- English, Spanish, Portuguese
- Sens 1, Spec 0.84, PPV 0.88, NPV 0.94

# Problems with screeners

- But.....



# Sensitivity and specificity



How many relevant items are selected?  
e.g. How many sick people are correctly identified as having the condition.

Sensitivity =  $\frac{\text{true positives}}{\text{true positives} + \text{false negatives}}$

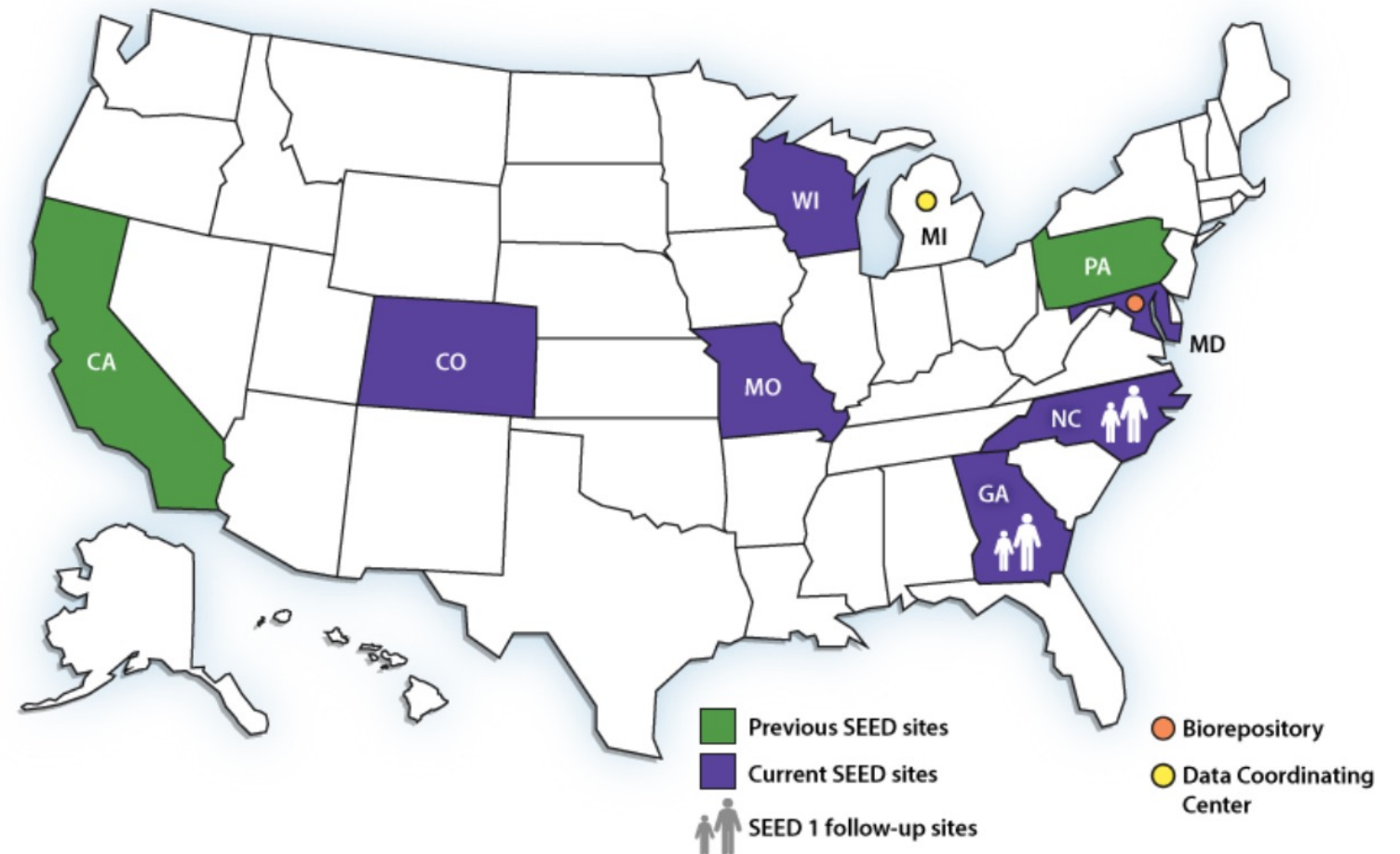
How many negative selected elements are truly negative?  
e.g. How many healthy people are identified as not having the condition.

Specificity =  $\frac{\text{true negatives}}{\text{true negatives} + \text{false positives}}$

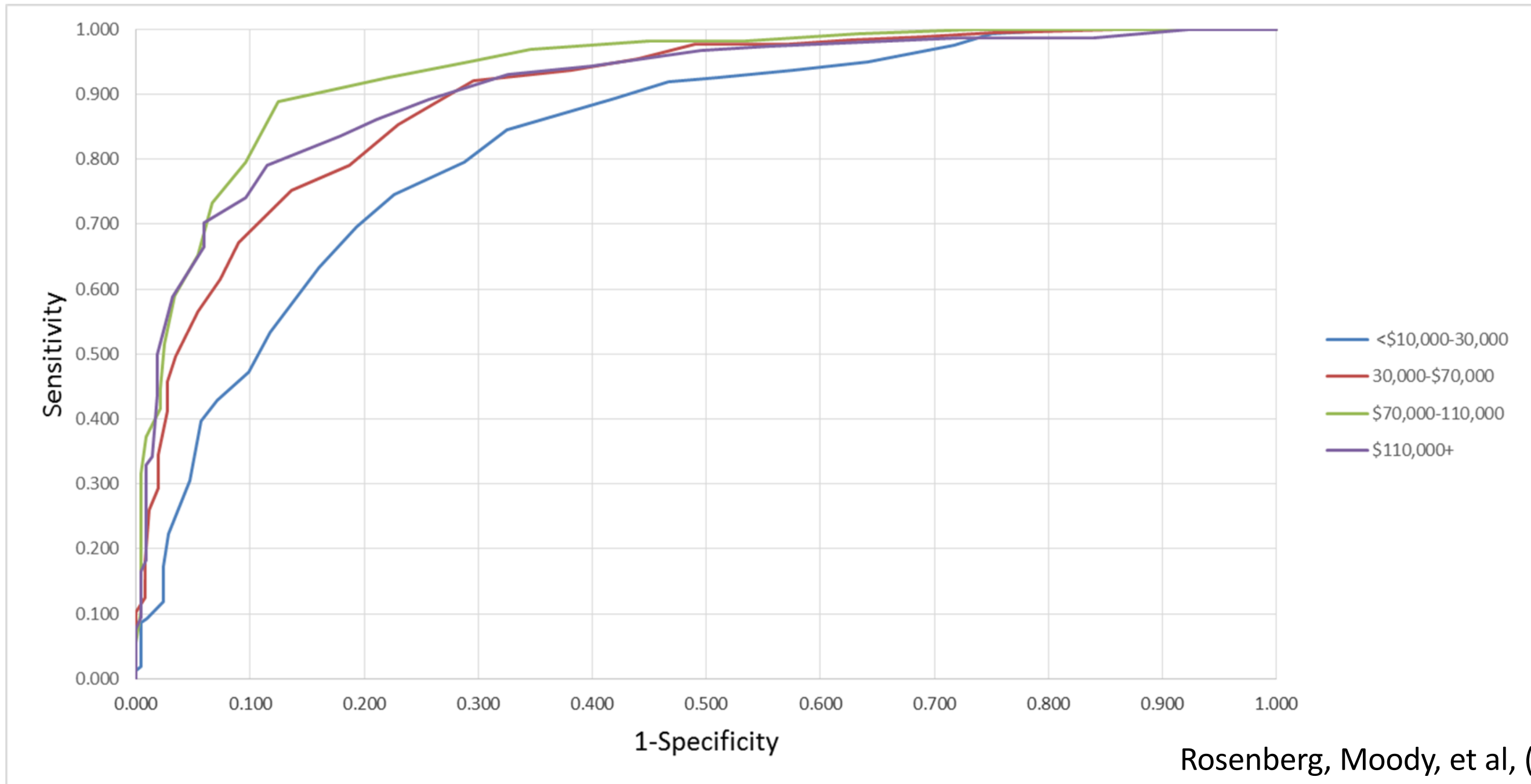
## Study to explore early development (SEED)

- Case-control
  - Risk factors for ASD
- 30-68.9 month
- Phase 1 & 2 completed
  - >4000 children
- Phase 3 wrapping up

### Study to Explore Early Development (SEED): Phases 1, 2, and 3







Rosenberg, Moody, et al, (2018)

# screening

- SRS and SCQ don't work well in all groups

	Sensitivity	Specificity
Overall: SRS	85	77
African American	89 (+4)	59 (-18)
White	84 (-1)	82 (+5)
Other	84 (-1)	79 (+3)
Hispanic	86 (+1)	69 (-8)
Overall: SCQ	87	81
African American	90 (+3)	55 (-26)
White	85 (-2)	87 (+6)
Other	88 (+1)	84 (+3)
Hispanic	92 (+5)	74 (-7)

Moody, et al. (2018)

# SCQ

• With cut off of 11

	Sensitivity	Specificity
<b>Overall</b>	<b>87</b>	<b>81</b>
<= High school	96 (+9)	59 (-22)
Some college	87 (0)	71 (-10)
Bachelor's degree	86 (-1)	88 (+7)
Post graduate	87 (0)	93 (+12)
	Sensitivity	Specificity
<b>Overall</b>	<b>87</b>	<b>81</b>
<=\$10K	95 (+8)	52 (-29)
\$10-\$30K	92 (+5)	59 (-22)
\$13-\$50K	88 (+1)	76 (-5)
\$50-\$70K	88 (+1)	81 (0)
\$70-\$90K	88 (+1)	89 (+8)
\$900-\$110K	89 (+2)	90 (+9)
>\$110K	75 (-12)	91 (+10)

Moody, et al. (2018)

# SCQ

• With cut off of 11

Mullen	Sensitivity	Specificity
<b>Overall</b>	<b>87</b>	<b>81</b>
Verbal	94 (+7)	55 (-26)
Fine motor	91 (+4)	61 (-20)
Receptive language	92 (+5)	54 (-27)
Expressive language	92 (+5)	58 (-23)
CBCL	Sensitivity	Specificity
<b>Overall</b>	<b>87</b>	<b>81</b>
Attention probs	96 (+9)	36 (-45)
Anxious/depressed	96 (+9)	36 (-45)
Emotionally reactive	95 (+8)	46 (-35)
Somatic complaints	93 (+6)	50 (-31)
Withdrawn	94 (+7)	34 (-47)
Sleep probs	92 (+5)	38 (-43)
Aggressive	97 (+10)	26 (-55)

Moody, et al. (2018)

Learn the Signs. Act Early.

## Screening

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- American Academy of Pediatrics standard
  - Universal screening: 18 & 24 months
  - Benefit of early and intensive intervention



# Screening

- US Preventive Services Taskforce (2016)
  - Does NOT recommend universal screening
  - Insufficient evidence of benefit
  - Potential for harms
  - Ongoing monitoring, screening as appropriate
    - Not universal
  - Recommendations being updated

Special Communication | **USPSTF RECOMMENDATION STATEMENT**

## Screening for Autism Spectrum Disorder in Young Children US Preventive Services Task Force Recommendation Statement

Albert L. Siu, MD, MSPH; and the US Preventive Services Task Force (USPSTF)

**DESCRIPTION** New US Preventive Services Task Force (USPSTF) recommendation on screening for autism spectrum disorder (ASD) in young children.

**METHODS** The USPSTF reviewed the evidence on the accuracy, benefits, and potential harms of brief, formal screening instruments for ASD administered during routine primary care visits and the benefits and potential harms of early behavioral treatment for young children identified with ASD through screening.

**POPULATION** This recommendation applies to children aged 18 to 30 months who have not been diagnosed with ASD or developmental delay and for whom no concerns of ASD have been raised by parents, other caregivers, or health care professionals.

**RECOMMENDATION** The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for ASD in young children for whom no concerns of ASD have been raised by their parents or a clinician. (I statement)

*JAMA*. 2016;315(7):691-696. doi:10.1001/jama.2016.0018

← Editorial page 661

+ Author Audio Interview at jama.com

← JAMA Patient Page page 718

+ CME Quiz at jamanetworkcme.com and CME Questions page 701

+ Related articles at jamapediatrics.com, jamaneurology.com, and jamapsychiatry.com

**Author Affiliations:** Author affiliations are listed at the end of this article.

**Authors/Group Information:** The USPSTF members are listed at the end of this article.

**Corresponding Author:** Albert L. Siu, MD, MSPH (chair@uspstf.net).



# But wait! There's more

- American Academy of Family Physicians
  - Follows USPSTF recommendations (2020)
- American Academy of Neurology and the Child Neurology Society
  - routine developmental surveillance with ASD specific follow up
- The American Academy of Child and Adolescent Psychiatry
  - Developmental assessment should include ASD specific questions

# Other “screeners”

- Parents are pretty darn good at knowing something is wrong
  - Early concerns predict Dx by 3 yrs
- **So...listen to parents!**
  - (monitoring)

**Researchers find parent concerns at 6-12 months commonly predict autism diagnosis by age 3; urge doctors to address concerns earlier**

April 24, 2015



Left to right, study participants Leanne Bilodeau and her son Jack with researchers Lonnie Zwaigenbaum and Lori Sacrey

# Diagnosing Autism

- ***Often*** requires in depth testing
  - Behavioral and developmental history
- Psychologist, DBP, Allied Health
  - Trained in recognizing ASD
- Multidisciplinary team ideal
- Anyone with proper credentials can diagnose
  - Clinical judgement is key

# Diagnosing Autism

- Gold standard: Autism Diagnostic Observation Schedule (ADOS)
- Clinical observation
- Play based
- ~40-60 mins
- Requires intensive training and clinical licensure
- ADOS 2: Social Behavior and Restricted/repetitive behaviors
- Calibrated severity score: 1-10

# Diagnosis Best Practices

- Multi-disciplinary teams, Dodd et al, 2014

Areas of Assessment	Responsible Person
Autism Spectrum Disorder Assessment	Psychologist, SLP
Cognitive Functioning	Psychologist
Executive Functioning	Psychologist
Visual-Spatial Processing*	Psychologist, OT
Memory*	Psychologist
Language Functioning (syntax, morphology, semantics)	SLP
Narrative Language Skills*	SLP
Social Communicative Functioning	SLP, Psychologist, Teacher
Speech Sound Production Skills	SLP
Developmental/Pre-Academics/Academics	Psychologist, Teacher, Parent
Adaptive Functioning	Psychologist, Teacher, Parent
Behavior/Self-Regulation/Emotion Functioning	Psychologist, Teacher, Parent, SLP
Sensory Processing	OT
Motor Skills	OT, PT, Adaptive PE Specialist
Other (vision, hearing, auditory processing, assistive technology, functional behavior assessment)	

# AAP recommendations

<https://publications.aap.org/pediatrics/article/145/1/e20193447/36917/Identification-Evaluation-and-Management-of#sec-8>

- For diagnostic evaluation: developmental-behavioral or neurodevelopmental pediatrician, psychologist, neurologist, or psychiatrist
- Language testing: Speech or language pathologist
- Adaptive functioning testing
- Motor assessment: Occupational or physical therapist
- Sensory assessment: Hearing
- Sensory assessment: Vision
- Sensory assessment: Sensory processing
- Genetic testing (Etiologic investigation begins with a careful medical, developmental-behavioral, and family history and a thorough physical and neurologic examination)
  - If there is a cooccurring genetic syndrome suspected, a referral should be made to a pediatric geneticist/neurologist



# Common co-morbidities

- Anxiety
- Depression
- Suicidal ideation
- Gender dysphoria
- Tic disorders
- GI complaints
- Dental concerns
- Intellectual disabilities
- Self-injurious behavior

# Another model

- Limited resources
- Need to reduce time from first concern to Dx
- STAT
- ECHO model




## **STAT-Screening Test for Autism in Toddlers and Young Children**

- 24 to 36 months
- 12-item provider-completed interactive/observational measure; requires training and special kit to properly administer
- 20 to 30 minutes to complete; 5 to 10 minutes to score; must be administered and scored by someone trained on the test
- English
- Sens 0.83, Spec 0.86, PPV 0.77, NPV 0.90 for ASD among children >24 months
- \$500 for kit with required provider training required

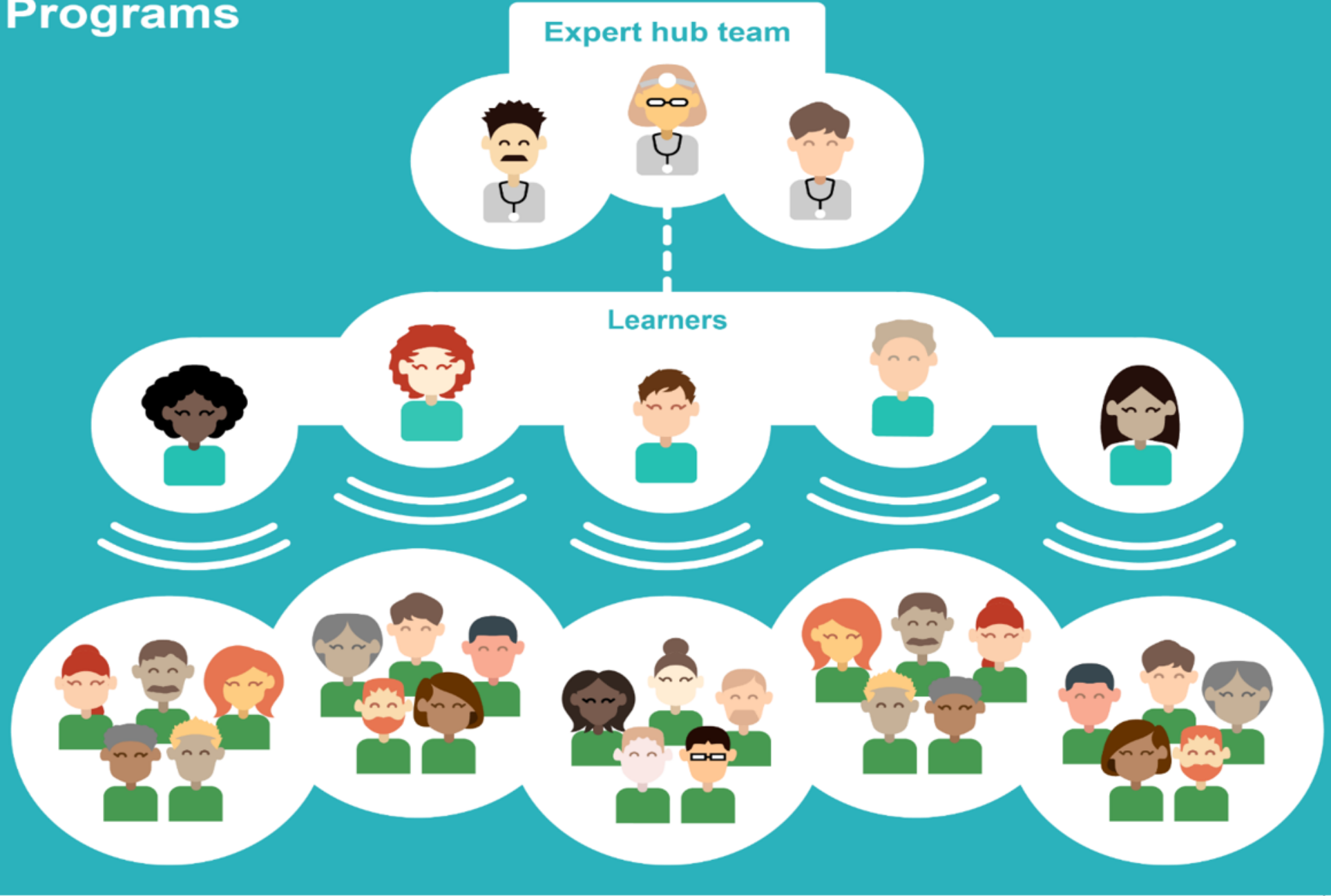
## Professional development: ECHO

- 30 minute didactic
- Case presentation
- Expert advice
- Co-learning
- Ongoing case consultation



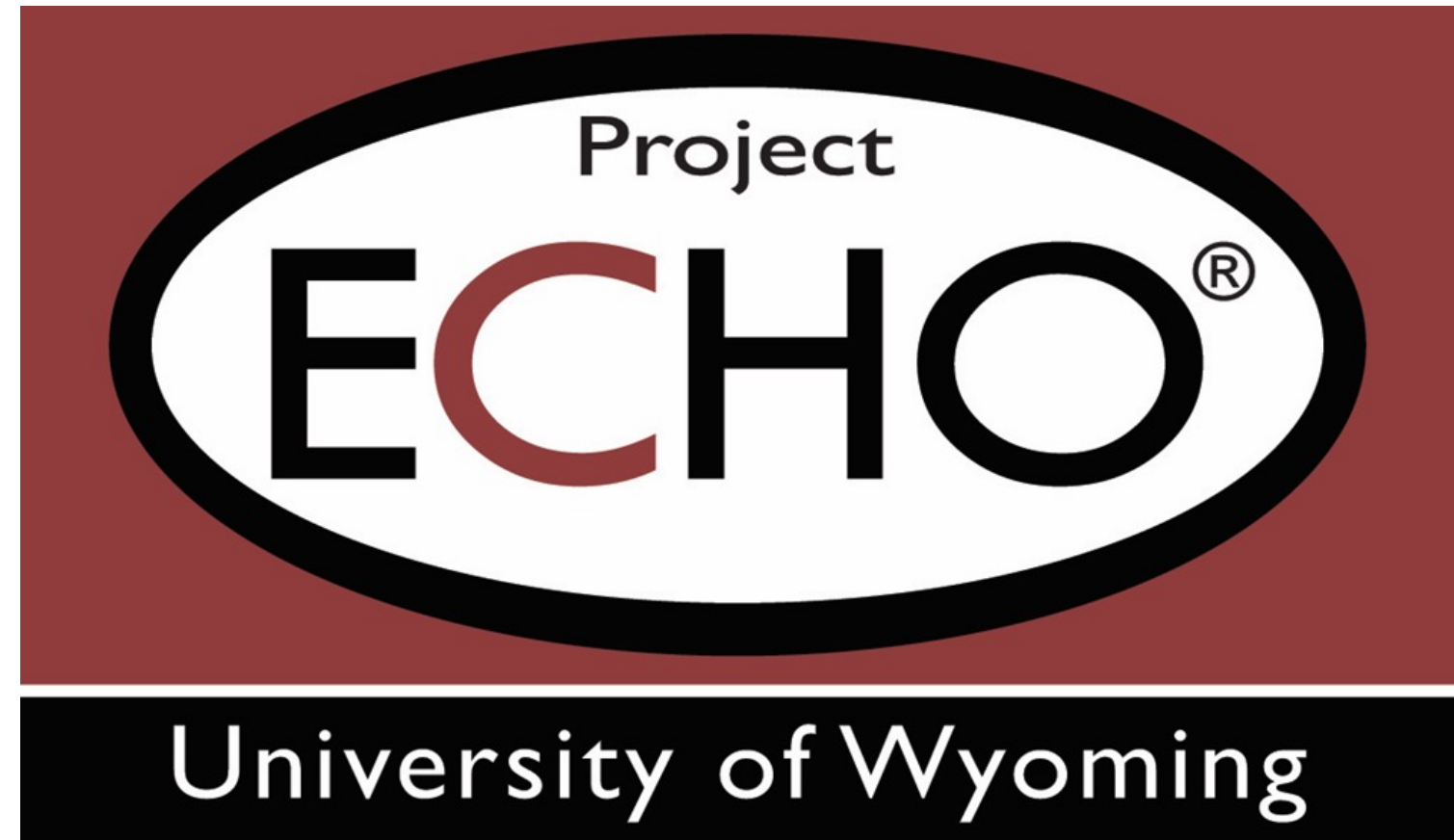
- 
- Develops expertise over time
    - Health Affairs 2011
  - As safe/effective as specialist
    - NEJM 2011
  - Demonopolizes knowledge
    - Academic Medicine 2014
- ECHO trains primary care clinicians to provide specialty care services. This means more people can get the care they need.

# TeleECHO™ Programs



# The ECHO model™

- Schools will provide most direct services
  - SLP, OT, SPED, School psych
    - but usually not ABA or ESDM
  - **professional development** centered on ASD





# Other ECHOs for Autism

## UW PROJECT ECHO NETWORKS



### EDUCATION

- Act Early ECHO
- UW ECHO in Assistive Technology
- UW ECHO in Autism and Positive Behavior Supports
- UW ECHO in Early Childhood
- UW ECHO in Student Health

[Learn more about UW ECHO in Education](#)



### HEALTH

- Act Early ECHO
- ECHO in Autism for Rural Healthcare Providers
- UW ECHO in Geriatrics
- UW ECHO in Integrative Care
- UW ECHO in Student Health

[Learn more about UW ECHO in Health](#)



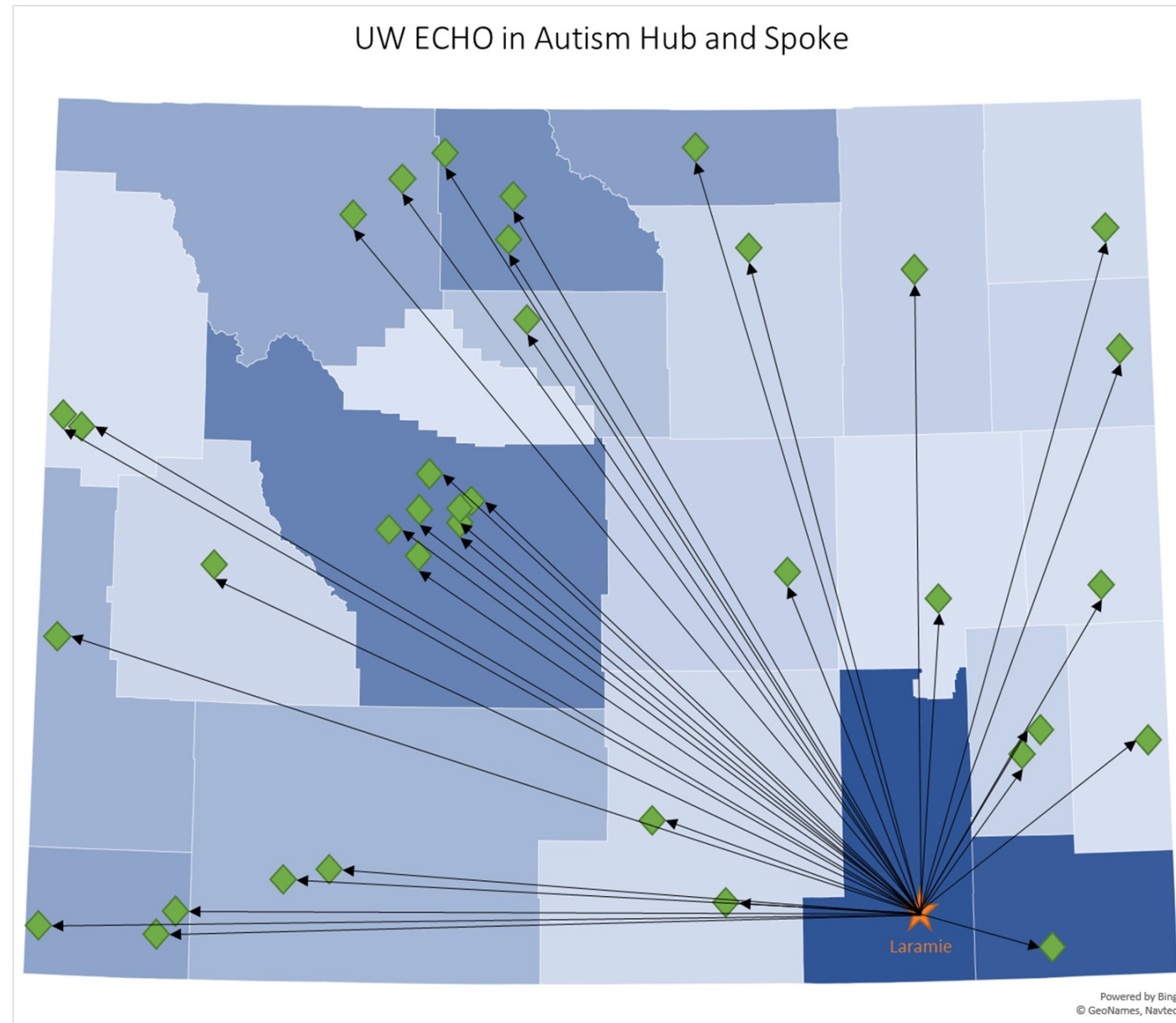
### FAMILIES

- UW ECHO for Families

[Learn more about Wyoming Family to Family Health Information Center](#)



# Reach



- Reach even most remote communities
- Easy to connect
- No travel time
- Weather no problem
- Model for teacher change (Guskey, 2002)
  - Content
  - Active learning (hands on)
  - Implementable
  - Follow-up

# Treatment Best Practices

- **Autism Speaks/Autism Treatment Network**
- [Applied Behavior Analysis \(ABA\)](#)
- [Early Start Denver Model \(ESDM\)](#)
- [Floortime](#)
- [Occupational Therapy \(OT\)](#)
- [Pivotal Response Treatment \(PRT\)](#)
- [Relationship Development Intervention \(RDI\)](#)
- [Speech Therapy](#)
- [TEACCH](#)
- [Verbal Behavior](#)

# Early Intensive Behavioral Intervention

- Best practice
- BUT
  - Cochrane review: mixed findings, weak evidence
    - Improves adaptive behaviors
    - No evidence on ASD Sx
    - Improves IQ and verbal behavior
  - Need to manage other concerns
  - Family may need a break

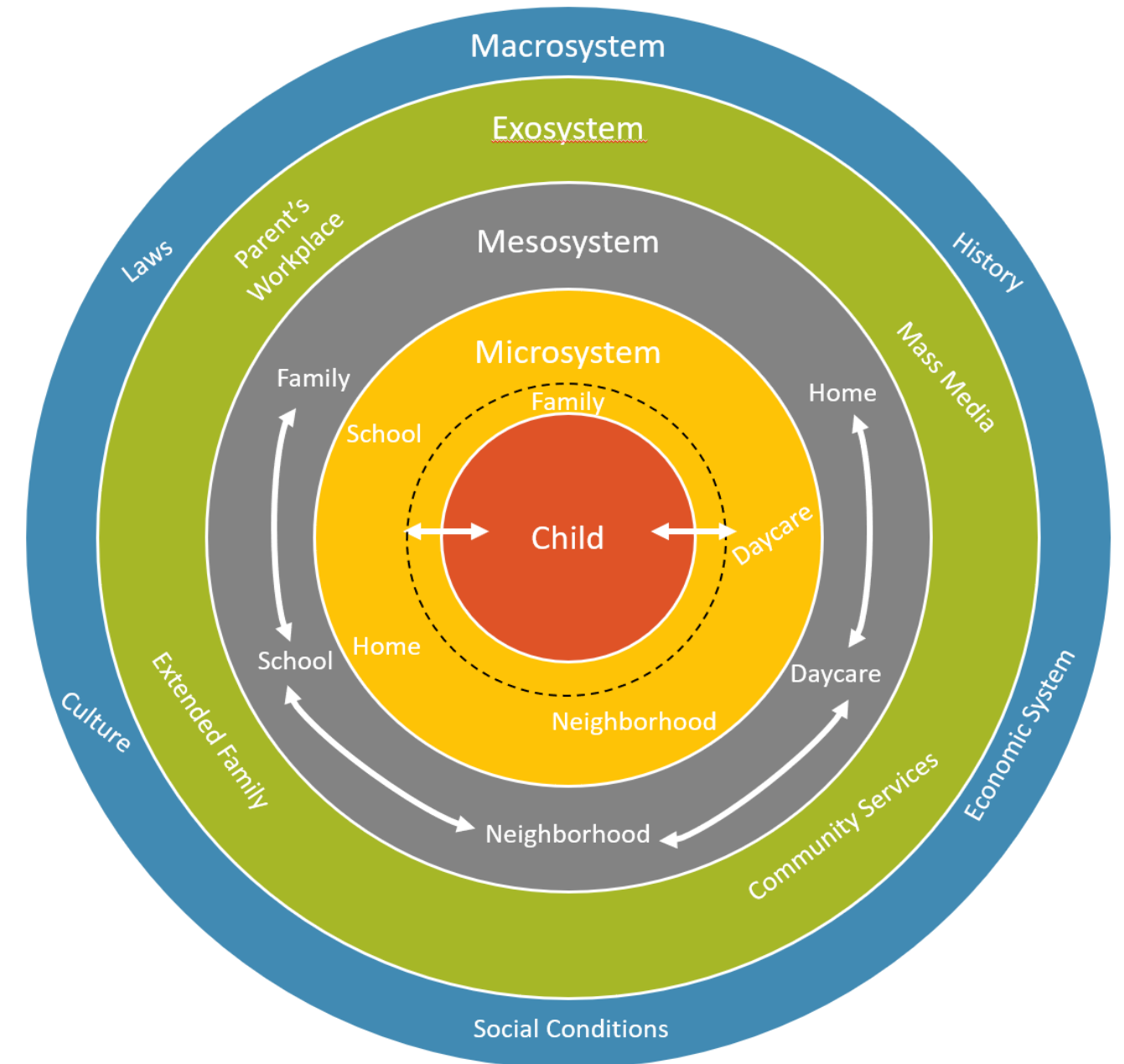
# **Components of Effective Intervention**

**The National Academy of Sciences, *Educating Children with Autism***

- ◎ **Young kids need lots of learning opportunities (active engagement in intensive instructional program)**
- ◎ **Active plan for generalization**
- ◎ **Time with typically developing peers**
- ◎ **Emphasis on communication, imitation and play**
- ◎ **Require direct, active instruction**
- ◎ **Intervention should be systematic, goal focused and playful**
- ◎ **Needs family involvement, parent training**

Social context matters

Family burnout common



**Moody, E.J., et al. (2020).** A Public Health Approach to Family Supports: Empowering Families of Children with Autism Through the ECHO Model, *International Review of Research in Developmental Disabilities: Family-Focused Interventions*, 59.



**MAKE A SENSORY BIN OUT OF BEANS,  
THEY SAID. IT'LL BE FUN, THEY SAID.**





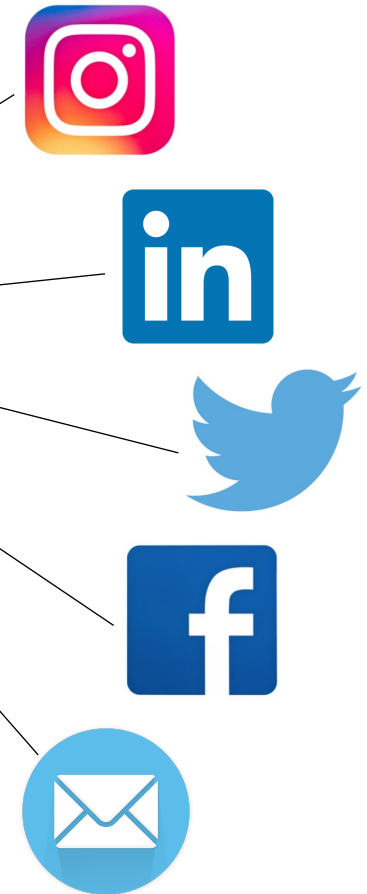
“If you meet one person with autism, you  
have met one person with autism!”

~~Anonymous

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# Best Practices for Autism Screening and Diagnosis in Community Settings

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Thank You!

