CDC PUBLIC HEALTH GRAND ROUNDS

Autism Spectrum Disorder:
From Numbers to Know-How

Accessible Version: https://youtu.be/AIEJzXf_Qto

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U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention

Autism Etiology:
What We Know and How to Learn More

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GLOBAL PUBLIC HEALTH

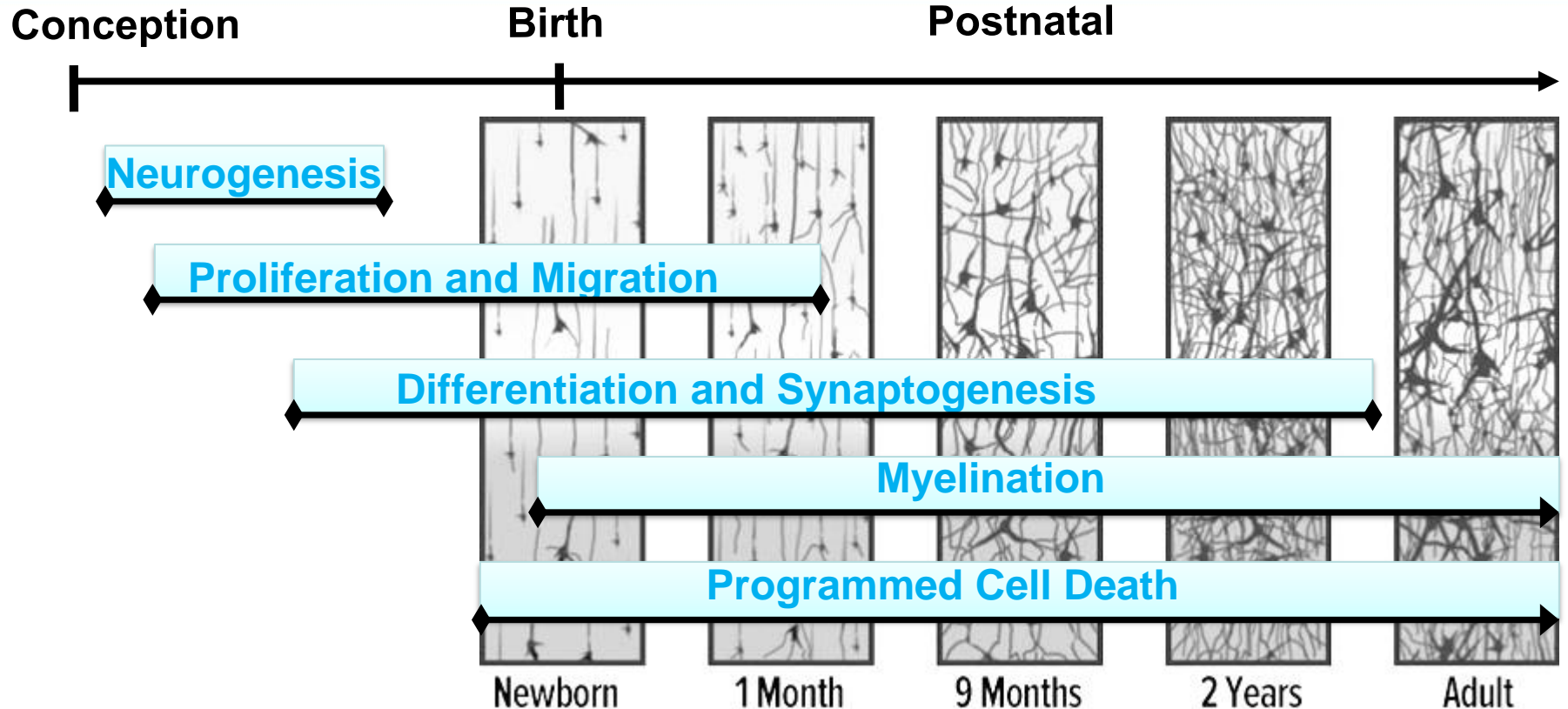U.S. Department of
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Control and Prevention

What is Autism Spectrum Disorder?

❑ **Persistent deficits in social communication and interactions**

❑ **Restricted interests or repetitive patterns of behavior**

➤ Symptoms must

  ▪ Be present during early development
  ▪ Cause clinically significant impairment in functioning
  ▪ Not be better explained by intellectual disability or global abnormality of development

❑ **Spectrum is an essential part**

➤ Deficits range from mild to severe

Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5); American Psychiatric Association, 2013.

Timeline for Brain Development: Neuron Growth and Connections

Findings indicate that children with autism had altered patterns in the frontal cortex

Corel, JL. Cambridge, MA: Harvard University Press; 1975.
Stoner R, Chow ML, Boyle MP, et al. N Engl J Med 2014; 370:1209-19.

Complexity of Autism Spectrum Disorder

❑ **Complex and heterogeneous**
  ➤ Likely starts in early brain development, becomes apparent in early childhood
  ➤ Symptoms and severity vary greatly–"phenotypic heterogeneity"

❑ **Associated co-morbidity**
  ➤ Cognitive impairment defined as IQ ≤70 (~30%)
  ➤ Developmental regression with onset by age 2 years (20-30%)

❑ **Other associated conditions (limited data)**
  ➤ Sleep and gastrointestinal disturbances
  ➤ Anxiety, depression, ADHD, aggression

What We Know About the Causes of Autism

❑ **The heterogeneous presentation of autism suggests that**
  ➢ A single cause does not exist
  ➢ Multiple etiologies probably contribute to the constellation of symptoms that are diagnosed as autism spectrum disorder

❑ **Early work focused on genetics, but now researchers accept that**
  ➢ Genetic susceptibility involves complex patterns of many genes
  ➢ Various environmental influences may be involved

Genetic Risk Factors

❑ **High monozygotic (identical) twin concordance: 30-90%**
- ➤ Risk also increased among dizygotic (fraternal) twins (concordance 0-24%) and siblings

❑ **Many plausible genes identified, few consistently replicated**
- ➤ Much focus on genes associated with specific aspects of development, neurological connections, or brain structure

❑ **Focus is shifting from changes in single genes to**
- ➤ Identifying genetic susceptibility to environmental or other agents
- ➤ Changes to genes that affect their function (epigenetics)

❑ **Complex pattern suggests involvement of many genes and various environmental exposures**

Environmental Risk Factors and Life Events Under Intense Investigation

❑ **Maternal and neonatal immune function**
  ➢ Consistent: rubella infection
  ➢ Under investigation: infection, autoimmune disorders

❑ **Obstetric experience**
  ➢ Consistent: preterm birth, C-section, advanced maternal and paternal age
  ➢ 13% of ASD may be attributable to a suboptimal prenatal environment that leads to preterm birth or C-section
  ➢ Under investigation: breech presentation, induction of labor

Environmental Risk Factors and Life Events Under Intense Investigation

❑ **Medications, hormones and chemicals**

➤ Consistent: valproate, thalidomide

➤ Under investigation: newer generation antidepressants, vitamins, folate, metals, air pollutants, flame retardants, pesticides

➤ Example: SSRIs (e.g., fluoxetine) have been associated with an increased risk of autism

  ▪ Results have been mixed

  ▪ Difficult to separate the impact of the drug from that of the underlying disease

What Do We Know and How Can We Learn More?

- ❑ **Autism is complex and heterogeneous**
  - ➤ Studies must be large and detailed to identify risk factors associated with only certain aspects or phenotypic subtypes of autism

- ❑ **Early genetic studies focused on small, select samples**
  - ➤ Family studies are not generalizable to all ASD
  - ➤ Symptom variability among individuals hinders gene finding

- ❑ **Environmental exposure data are often retrospective or imprecise**
  - ➤ Rarely captured for critical period of brain development

- ❑ **Limited number and scope of population-based studies with detailed data**
  - ➤ ASD diagnosis and recruitment is cost-intensive and time-intensive

ASD: autism spectrum disorder

Study to Explore Early Development – SEED

- **Multisite case-control study of children aged 2.5–5 years in 6 states**
  - CA, CO, GA, MD, NC, PA
- **Two overarching goals:**
  - Describe phenotypic variability (differences in symptoms) among children with autism
  - Evaluate etiologic risk factors for the development of autism in refined subgroups, for example:
    - The role of infection and immune function
    - The role of specific obstetric complications (preterm delivery, C-section, and assisted reproductive technology)
    - How phenotypic variability among children is associated with genetic or environmental risk factors

Study to Explore Early Development – SEED

❑ **Extensive data collection provides detailed information**

  ➢ Infection and immune function

  ➢ Reproductive and psychiatric history

  ➢ Medications and occupational exposures

  ➢ Genetics and phenotypic characteristics

  ➢ Child's developmental characteristics
    and co-occurring conditions

❑ **Progress to date**

  ➢ *Phase 1 – Data analysis underway*

    ▪ 750 children with autism spectrum disorder (ASD)

    ▪ 750 children with non-ASD developmental delays, and 750 controls

  ➢ *Phase 2* data collection underway to double the study size by 2016

❑ **SEED will be the largest multi-site study of ASD in the United States**

www.cdc.gov/ncbddd/autism/seed.html

Other Current Studies of Autism Etiology

❑ **Childhood Autism Risks from Genetics and the Environment (CHARGE)**

   ➢ Northern California case-control study of genes and environmental exposures

❑ **Early Autism Risk Longitudinal Investigation (EARLI)**

   ➢ Multi-site study of the prenatal and early childhood experiences of younger siblings of children with autism

❑ **Early Markers for Autism Study (EMA)**

   ➢ California, case-control study examining multiple biologic markers collected during pregnancy and the neonatal period

❑ **Potential for collaboration and data pooling among these studies hold promise for accelerating our advances in knowledge**

beincharge.ucdavis.edu/
www.earlistudy.org/
www.ehib.org/project.jsp?project_key=AUTM07

Future Directions in Autism Research

❑ **Expand and pool studies investigating causes and correlates**

❑ **Incorporate both genetics and environment in etiologic studies**

❑ **Disease heterogeneity suggests effects for small, susceptible subgroups that would not be distinguished among the population**

  ➢ Genetic and phenotypic subtyping is needed in large studies
  ➢ Longitudinal characterization of ASD over the life course of individuals may help distinguish etiologically distinct subgroups

❑ **Surveillance must continue to monitor trends in prevalence**

ASD: autism spectrum disorder

Surveillance for Autism Spectrum Disorder Key Findings and Trends

Jon Baio, EdS

Behavioral Scientist, Developmental Disabilities Branch
Division of Birth Defects and Developmental Disabilities
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

**U.S. Department of
Health and Human Services**
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Control and Prevention

How Common is Autism Spectrum Disorder?

❑ **Estimates of population prevalence vary widely across time and location**

❑ **Different case ascertainment methods**

❑ **Different case definitions**

❑ **Challenges in tracking autism prevalence**

Autism and Developmental Disabilities Monitoring Network (ADDM)

❑ **Objective: To understand the magnitude and characteristics of the population of children with autism and related developmental disabilities**

➢ Currently there are 11 funded ADDM sites, plus CDC/MADDSP

➢ Autism prevalence among 8 year olds is monitored in all sites

➢ Piloting autism surveillance among 4 year olds in six sites

➢ Some sites track Cerebral Palsy (4) or Intellectual Disability (7)

Current ADDM Network Sites, Surveillance Years 2010 and 2012
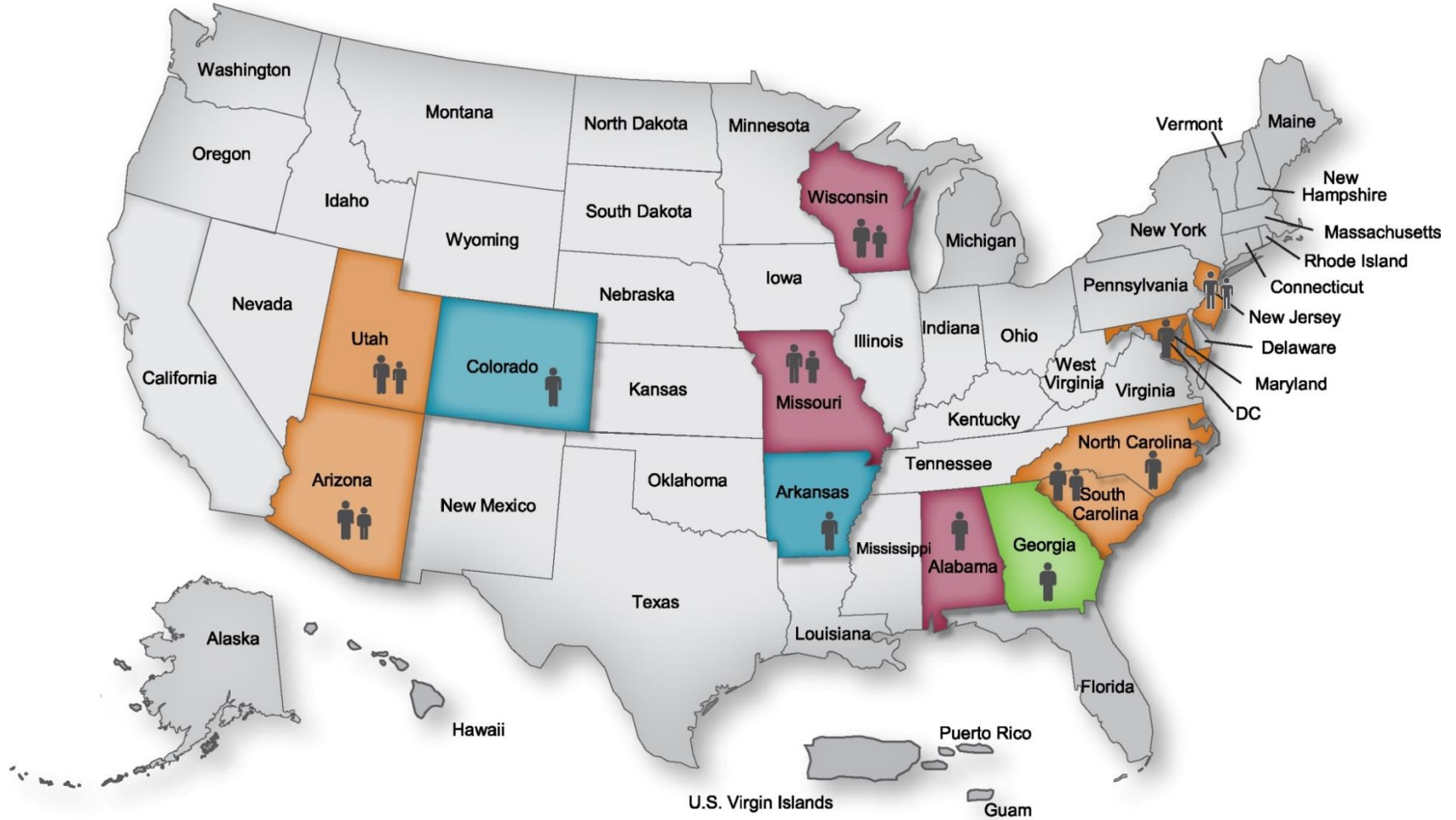
Legend:
- Monitoring 8 year olds
- Monitoring 4 and 8 year olds

- Autism
- Autism, Cerebral Palsy
- Autism, Intellectual Disability
- Autism, Cerebral Palsy, Intellectual Disability, Vision Impairment, and Hearing Loss

CS229603-A

ADDM = Autism and Developmental Disabilities Monitoring

ADDM Network Methods for ASD Case Ascertainment

❑ Multisite, multisource (educational and healthcare settings) records-based surveillance methodology

Phase 1:

> Screening and abstraction of records at multiple data sources in community

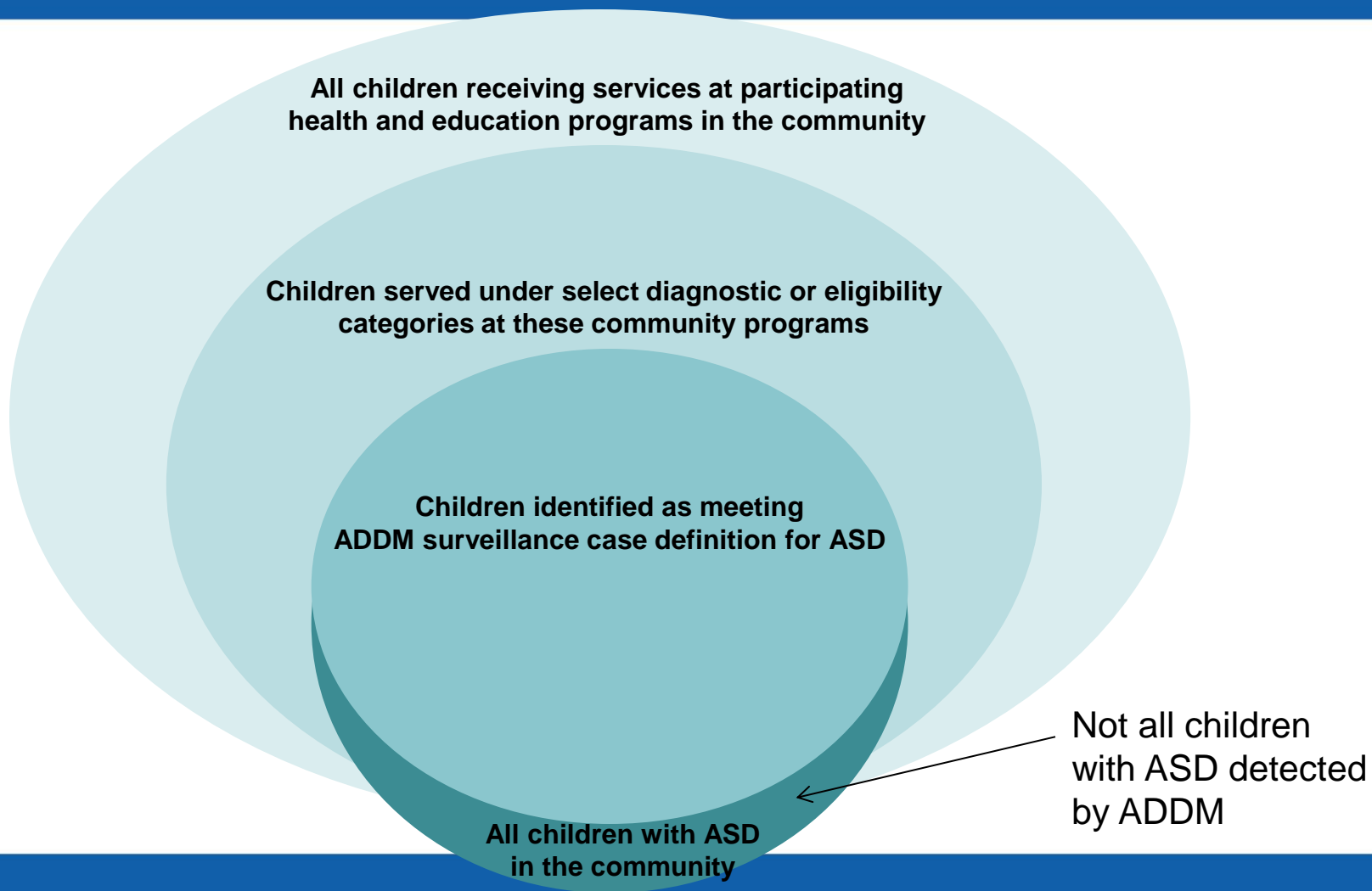*Records meeting requirements for abstraction go on to phase 2*

Phase 2:

> All abstracted evaluations reviewed by trained clinicians to determine ASD case status

Children with described behaviors that are consistent with DSM-IV-TR criteria for autism are considered for inclusion as ASD surveillance cases

ADDM Methodology: Case-finding "Net"

All children receiving services at participating health and education programs in the community

Children served under select diagnostic or eligibility categories at these community programs

Children identified as meeting ADDM surveillance case definition for ASD

Not all children with ASD detected by ADDM

All children with ASD in the community

ASD: autism spectrum disorder
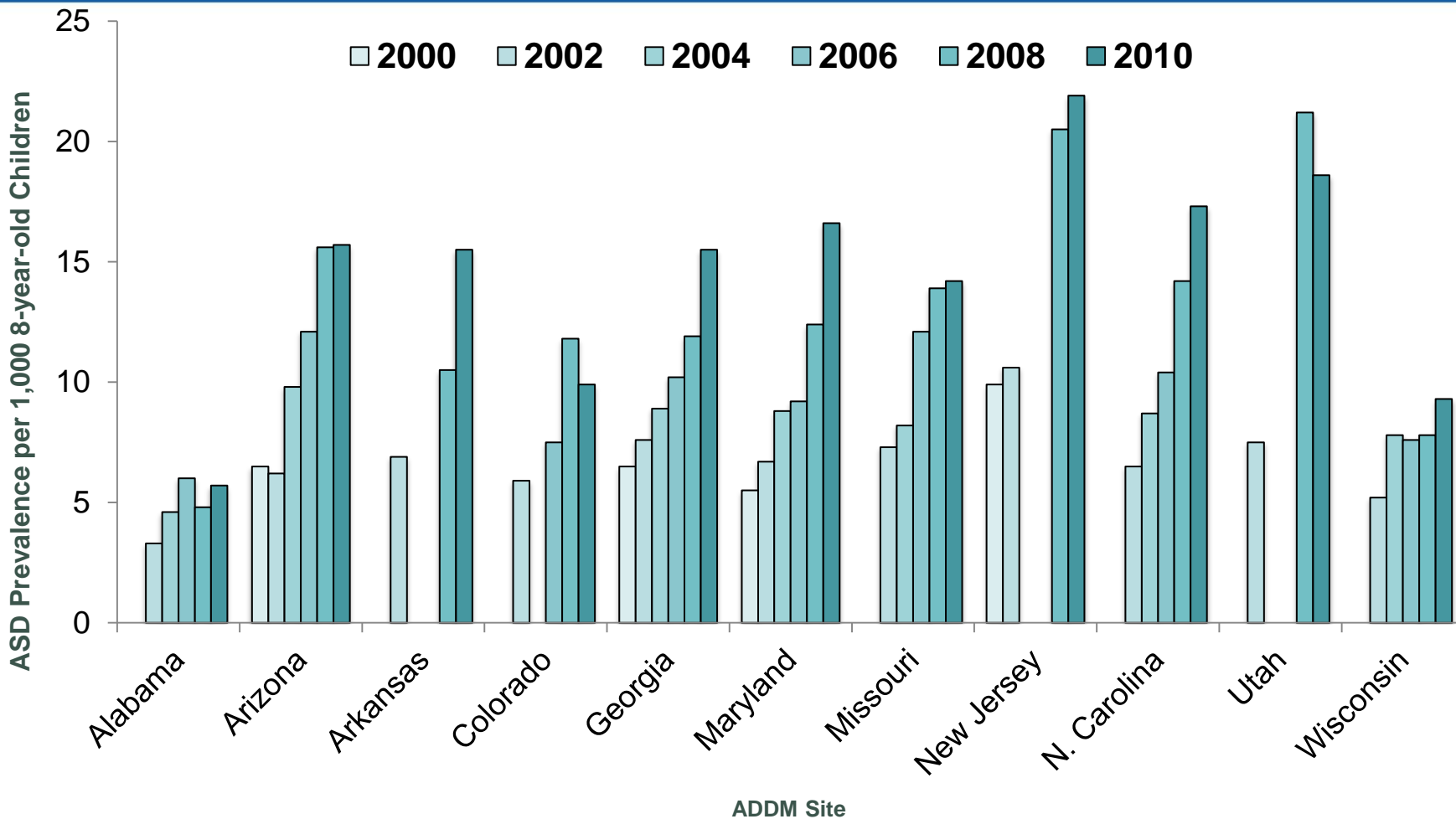MMWR Surveillance Summaries March 28, 2014 / 63(SS02);1-21

ADDM Network Autism Estimated Prevalence Among 8 Year-Old Children, All Sites

| Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Estimated Prevalence (per 1,000 Children)
2000	1992	6	6.7
2002	1994	14	6.6
2004	1996	8	8.0
2006	1998	11	9.0
2008	2000	14	11.3
2010	2002	11	14.7

ADDM: Autism and Developmental Disabilities Monitoring Network
MMWR Surveillance Summaries: February 9, 2007 / 56(SS-1); December 18, 2009 / 58(SS-10);
March 30, 2012 / 61(3); March 28, 2014 / 63(SS-02).

Change in Autism Estimated Prevalence Among ADDM Sites

MMWR Surveillance Summaries. February 9, 2007 / 56(SS-1), 1-40; December 18, 2009 / 58(SS-10), 1-24; March 30, 2012 / 61(3);1-19; March 28, 2014 / 63(SS02);1-21.

Median Age of Earliest ASD Diagnosis
Children Aged 8 Years, ADDM Network, 2002-2010
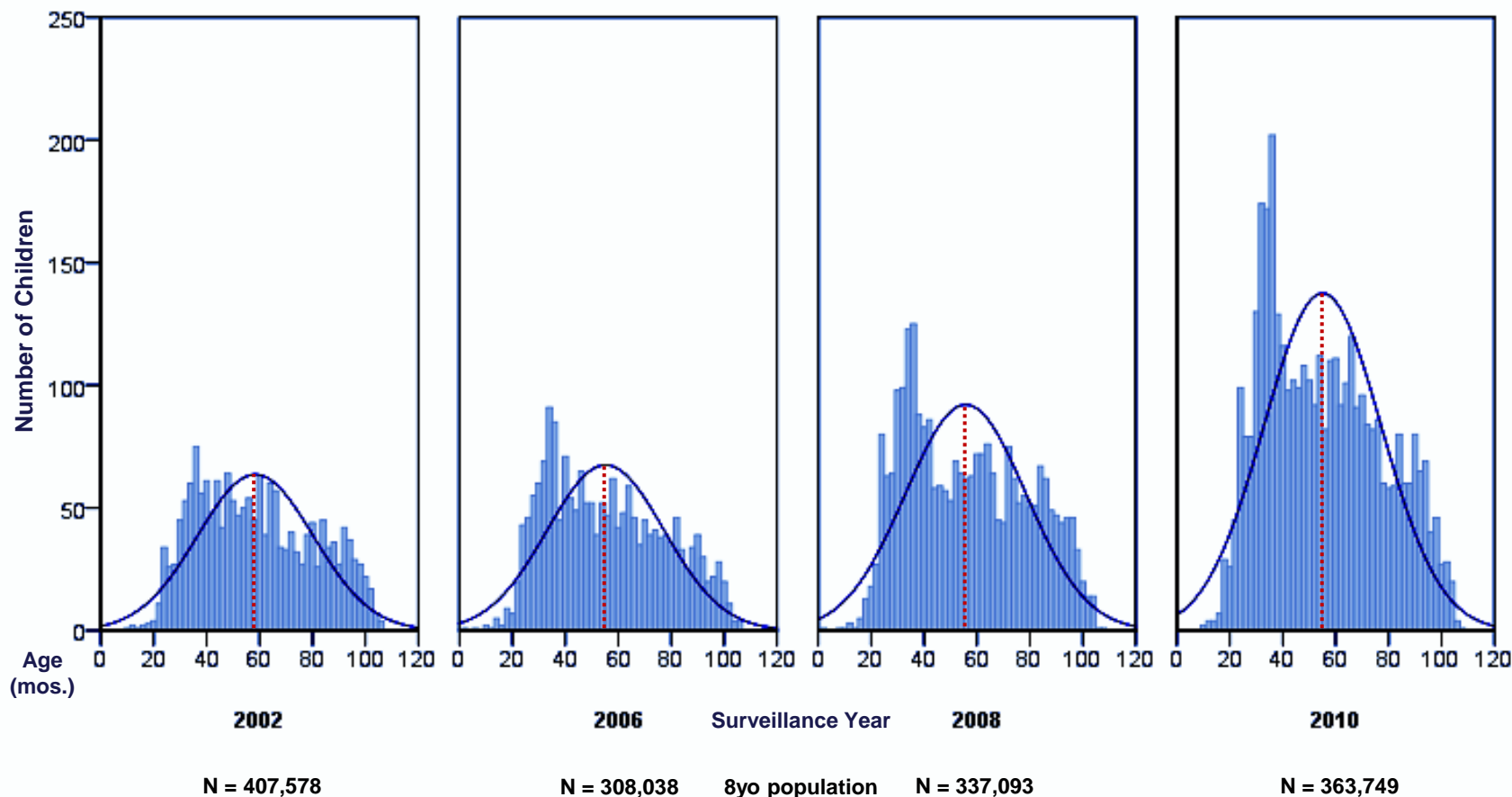
MMWR Surveillance Summaries. February 9, 2007 / 56(SS-1), 1-40; December 18, 2009 / 58(SS-10), 1-24; March 30, 2012 / 61(3);1-19; March 28, 2014 / 63(SS02);1-21.

# Characteristics of Children with ASD Among Children Aged 8 Years, 2010

❑ **Combining data from 11 ADDM sites:**

➢ Boys were 4.5 times as likely to be identified with ASD

➢ White children were approximately 30% more likely to be identified with ASD than black children and were almost 50% more likely to be identified with ASD than Hispanic children.

❑ **Among the seven sites with sufficient data on intellectual ability:**

➢ 31% had IQ scores in the range of intellectual disability (IQ ≤70)

➢ 23% had IQ scores in the borderline range (IQ = 71–85)

➢ 46% had IQ scores in the average or above average range of intellectual ability (IQ >85)

Prevalence of ASD by Most Recent IQ Score and by Sex and Race/Ethnicity—Seven Sites*, 2010
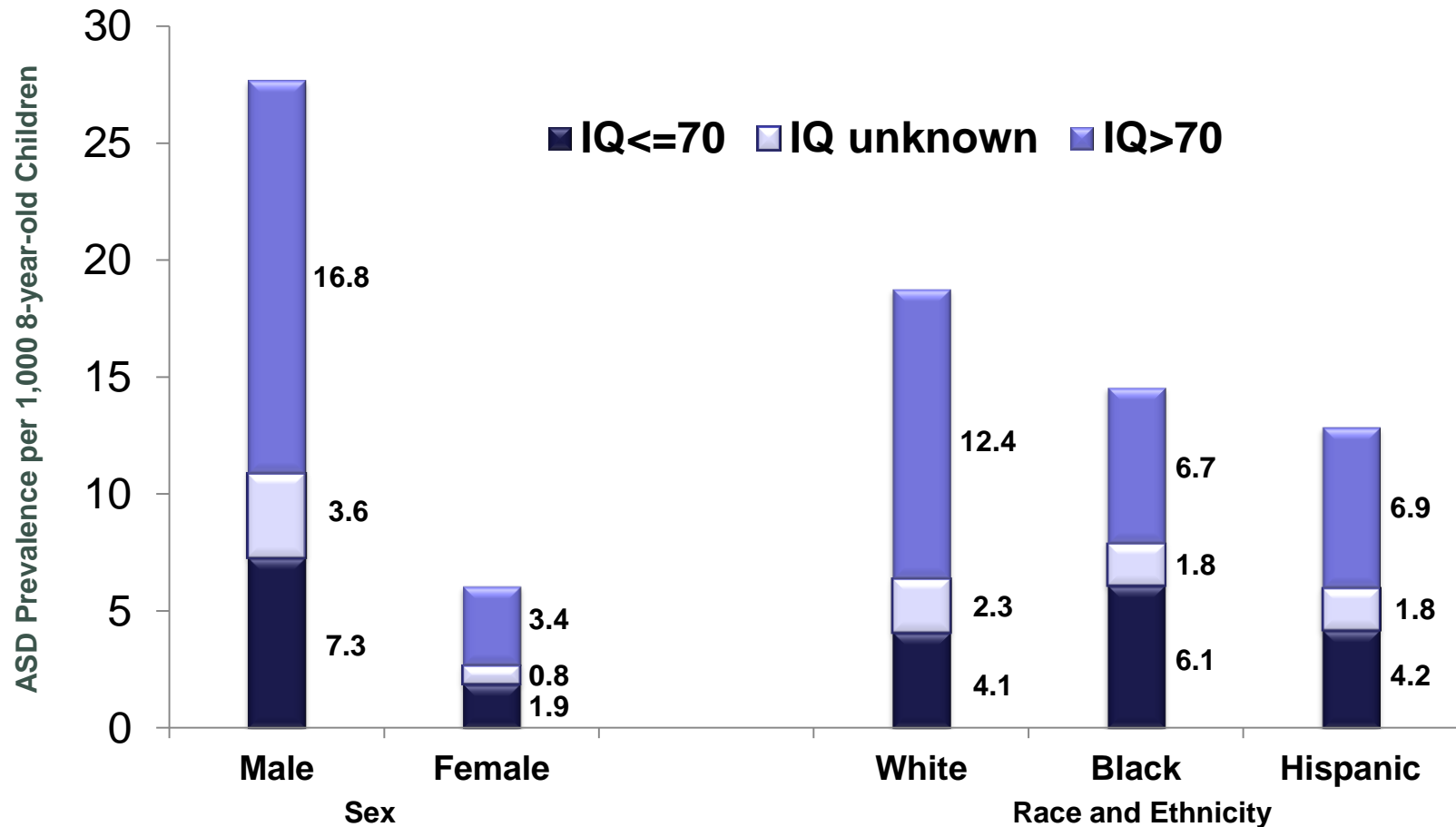
* Includes sites that had intellectual ability data available for ≥70% of children who met the ASD case definition.

MMWR Surveillance Summaries March 28, 2014 / 63(SS02);1-21.

Variation in Estimated Prevalence of ASD
11 sites, United States, 2010
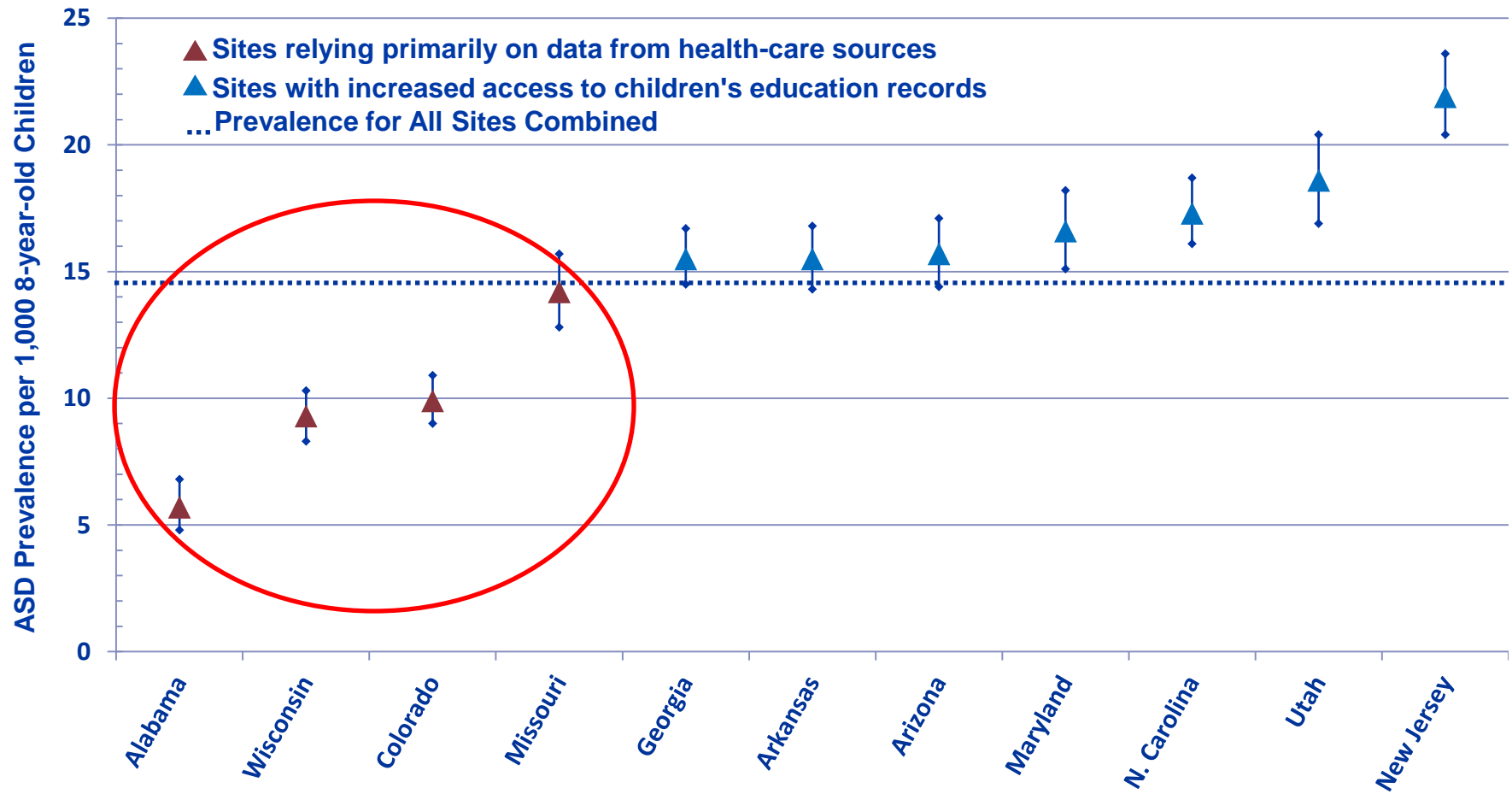
ASD: autism spectrum disorder
MMWR Surveillance Summaries March 28, 2014 / 63(SS02);1-21.

ADDM Methodology

❑ **Strengths**

  ➢ Large, population-based study of autism

  ➢ Record review methodology maximizes population coverage

  ➢ Multiple-source case ascertainment, including both health and special education records in most sites

  ➢ Coding scheme and systematic review of behavioral descriptions to determine case status

  ➢ Information on presence of other developmental disabilities

❑ **Limitations**

  ➢ Underascertainment of children with undocumented symptoms and children not being served in abstraction facilities or public special education programs

  ➢ Imprecision of population counts, especially in latter part of each decade

Implications of ADDM Network Findings

❑ **More children are being recognized as having autism**

  ➢ More children with ASD have average or above average intellectual ability

  ➢ Still concerned that 20% are not classified with autism by community providers, others are not recognized as early as they can be

❑ **ASD continues to pose a substantial healthcare burden**

❑ **Better identification is occurring among certain subgroups**

  ➢ Still concerned about disparities in prevalence across sites and among children of minority race/ethnicity, low socioeconomic status

Ongoing Efforts to Understand Autism Prevalence

❑ **Continue monitoring to evaluate trends in estimated prevalence and changes in characteristics of children diagnosed with ASD**

❑ **Investigator-initiated analyses within ADDM**
  ➢ Timing and stability of diagnosis of ASD
  ➢ Incorporating DSM-5 criteria
  ➢ Socioeconomic disparities
  ➢ Intellectual functioning
  ➢ Geospatial analyses
  ➢ Birth characteristics
    ▪ Parental age
    ▪ Multiple births
    ▪ Gestational age and birthweight

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

Surveillance Data Provides More Than Just A Number

Provides a more complete picture of autism

Informs early identification efforts

Helps identify potential risk factors

Guides our research and the research of other scientists

Parents Struggle for Answers

- ❑ **Early signs of ASD may be subtle**
- ❑ **There are no specific physical signs**
- ❑ **Inconsistent skills**
  - ➢ Strengths and weaknesses
- ❑ **Regression of skills in up to one-fourth of children with ASD**
- ❑ **Some have consistently delayed milestones**
- ❑ **Parents often suspect their child**
  - ➢ Has language delays
  - ➢ Has a hearing loss
  - ➢ Was "too good" as a baby
- ❑ **Too often, may be told to "wait and see"**

ASD: autism spectrum disorder

Babies with ASD Have Observable Early Behavioral Differences

❑ **Observer blinded review of first birthday party videos document**

- ➢ Decreased looking at others
- ➢ Decreased looking to name
- ➢ Decreased gesture

❑ **Parents identify symptoms of ASD prior to diagnosis**

- ➢ At 10 months if there is an older sibling with ASD
- ➢ At 14 months if there is an older, typical sibling
- ➢ At 16 months if an only child

ASD: autism spectrum disorder
Osterling JA, Dawson G, Munson JA. Dev Psychopathol. 2002;14:239-51.
Herlihy L, Knoch K, Vibert B, Fein D. Autism. 2013 Nov 11.

Early Identification of ASD
A Public Health Issue

❑ **Children with autism have language, cognitive and adaptive delays and challenging behaviors**

➢ Impact their health and functioning
➢ Impact the health and functioning of their families

❑ **Significant lag time exists between the first concerns identified by families and ASD diagnosis**

➢ Most children with ASD have noted developmental concerns before the age of **2 years**
➢ But the median age of diagnosis is **4 years, 5 months**

Cycle of Developmental Health

Developmental Monitoring

Screening

Assessment

Services and Supports
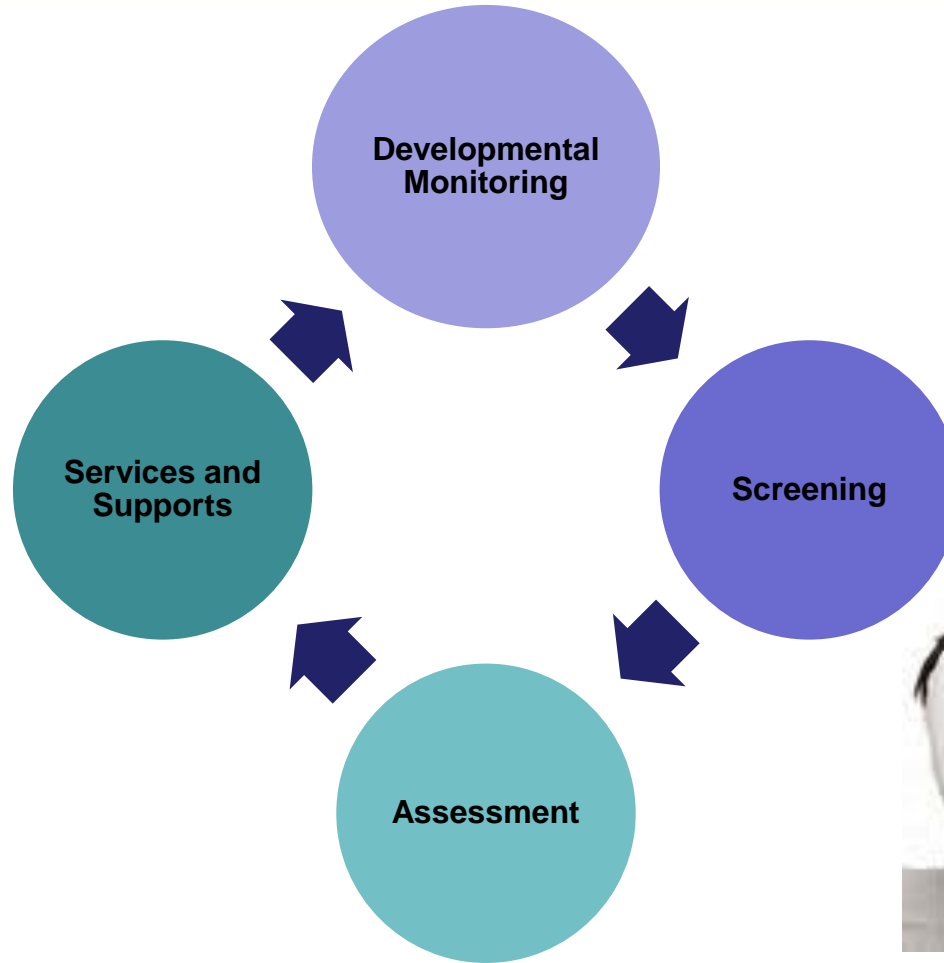
Healthcare Providers Need to Provide Developmental Monitoring and Screenings

- ❑ **Well-child visits for <u>all</u> children should include:**
  - ➢ Developmental Monitoring
    - ▪ Informal probing about development and behavior at every well-child visit
  - ➢ Developmental Screening
    - ▪ Use a validated screening tool at 9, 18, and 24 or 30 months
    - ▪ ASD-specific screening 18 and 24 or 30 months

- ❑ **If concern identified from screening**
  - ➢ Refer for evaluation
  - ➢ Refer for intervention

Developmental Monitoring at 18 Months–Red Flags

❑ **Social/Emotional**

➢ Typical behavior: Simple pretend, explores with parent nearby

🚩 Behavior associated with ASD: doesn't notice or mind when caregiver comes or goes

❑ **Language/Communication**

➢ Typical behavior: Points to show what she wants, has several single words

🚩 Communication difference associated with ASD: doesn't point to show things to others

🚩 Language delay associated with ASD: doesn't gain new words or has fewer than 6 words
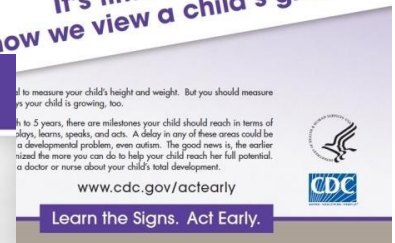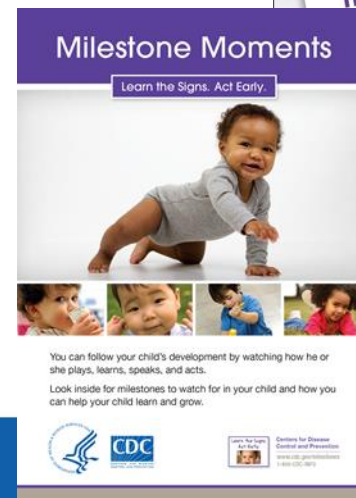
Tools for Developmental Monitoring
"Learn the Signs. Act Early."

❑ **Learn the Signs:**

➢ Resources for monitoring key developmental milestones among all children

➢ Red flags that can indicate concern

❑ **Act Early:**

➢ Discuss concerns

➢ Proactive screening

➢ Refer for evaluation and services

➢ Find resources for early intervention and family support

www.cdc.gov/actearly

Parents Need to Expect D... Monitoring and Sc...

- **In 2007, 52% of parents of young childr... healthcare provider asked about their ... but only 21% report that they were give... screening questionnaire**

- **By 2009, 47% of pediatricians surveyed... implemented developmental screening...**

- **Literature review on promotion of gene... ASD screening in primary care**

  - Screening strategies were successful ...
  - Few studies reported on referral rates
  - Little known about evaluation or receipt of services.

Schieve LA, Rice C, Yeargin-Allsopp M. Matern Child Health J. 2012;16 Suppl 1:S151-7.
Radecki L, Sand-Loud N, O'Connor KG, et al. Pediatrics. 2011; 128:14-9.
Daniels AM, Mandell DS. J Autism Dev Disord. 2013;43:2844-54.

The Modified Checklist for Autism in Toddlers (M-CHAT)

❑ **20 item questionnaire**

➢ Less than 10% of children will require standardized follow-up second stage screening; of children who do, about 30% continue to screen positive, and almost all will be diagnosed with ASD or other developmental delays

❑ **Sample items**

➢ Does the child

▪ Like to be swung?

▪ *Take interest in other children?

▪ Like climbing?

▪ Ever pretend to talk on the phone?

▪ *Ever use index finger to point to ask? To indicate interest?

▪ *Bring objects to show?
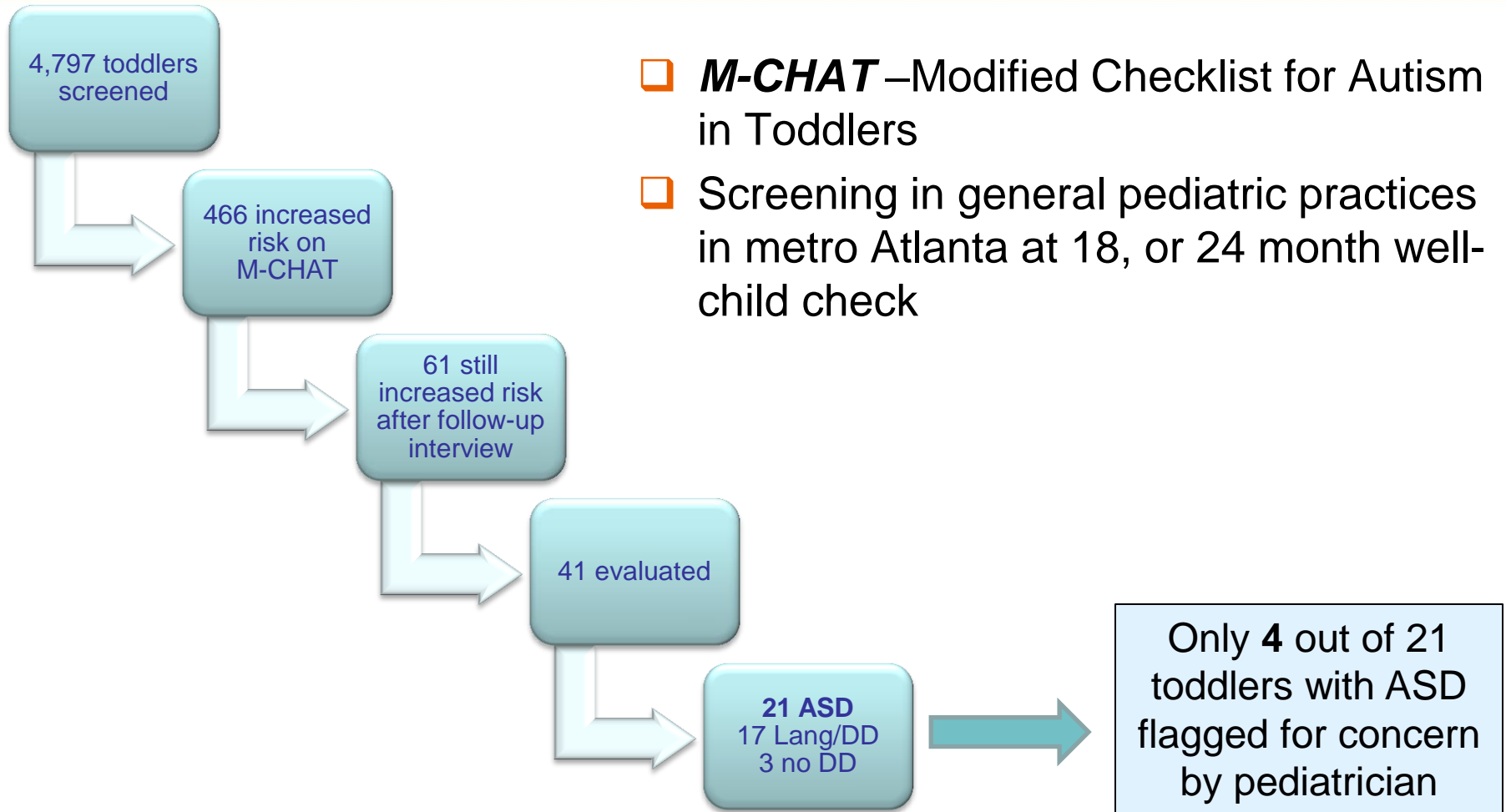
▪ Look you in the eye?

▪ Seem oversensitive to noise?

Positive results on the questionnaire should be followed by the M-CHAT clinician administered interview

*more sensitive screening question

Robins DL, Casagrande K, Barton M, et al. Pediatrics. 2014;133:37-45.

Early ASD Screening Outperforms Clinical Judgment

4,797 toddlers screened

466 increased risk on M-CHAT

61 still increased risk after follow-up interview

41 evaluated

21 ASD
17 Lang/DD
3 no DD

Only **4** out of 21 toddlers with ASD flagged for concern by pediatrician

- ❑ *M-CHAT* –Modified Checklist for Autism in Toddlers
- ❑ Screening in general pediatric practices in metro Atlanta at 18, or 24 month well-child check

Robins DL. Autism. 2008;12:537-56.
www.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D..html

Obstacles to Successful Screening Programs

❑ **"Don't defer, refer."**

❑ **Only 61% of children who screened positive on developmental tests in pilot programs that achieved 85% screening were referred for further evaluation**

  ➢ 26% of low income, primarily Hispanic children screened positive on M-CHAT questionnaire without follow up interview

  ➢ Of those, only 30% were referred, and only half of them were seen

❑ **Capacity for timely diagnostic evaluations**

❑ **Availability of effective intervention**

King TM, Tandon SD, Macias MM, et al. Pediatrics. 2010;125:350-60.
Windham GC, Smith KS, Rosen N, et al. J Autism Dev Disord. 2014.
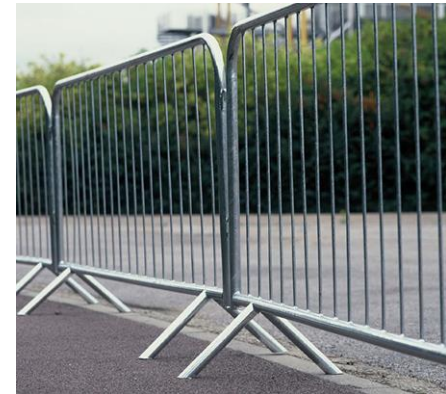
Steps to Successful Screening Programs

❑ **Healthcare providers**

➢ Monitor development at each well-child visit

➢ Use validated screening tools at established intervals, and any time a concern is raised

▪ Use validated screening tool

➢ Include developmental screening in EHR

➢ "Don't defer, refer."

❑ **Parents**

➢ Ask about your child's development

➢ Learn the signs

➢ Be persistent, follow-up if concerned

❑ **Community-wide tools**

➢ *Birth to 5: Watch Me Thrive*

➢ *Learn the Signs. Act Early.*

EHR: electronic health record

Birth to 5: Watch Me Thrive!

1 in 4 young children are moderate to high risk of developmental delay (NSCH, 2011/2012)

❑ ***Birth to 5: Watch Me Thrive!* is a coordinated federal effort to encourage healthy child development, universal developmental and behavioral screening for children, and support for the families and providers who care for them.**

  ➢ Celebrate Milestones
  ➢ Promote Universal Screening
  ➢ Identify Possible Delays and Concerns Early
  ➢ Enhance Developmental Supports

Birth to 5: Watch Me Thrive
Celebrate your child's milestones
www.hhs.gov/watchmethrive

Additional Ways That Professionals Can Support Parents of Young Children

❑ **Maintain on-going parent-professional communication about development**

  ➤ If concern raised by parents, express professional concern and listen to parents

❑ **Know and teach early warning signs of delay**

❑ **Provide referrals as appropriate**

  ➤ Know the resources and places to refer in your area

  ➤ Follow-up with family

  ➤ Coordinated care within a Medical Home

    ➤ Accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective care

    ➤ Manage and facilitate pediatric care in partnership with the family

NATIONAL CENTER FOR MEDICAL HOME IMPLEMENTATION
A cooperative agreement between the Maternal and Child Health Bureau/HRSA and the American Academy of Pediatrics

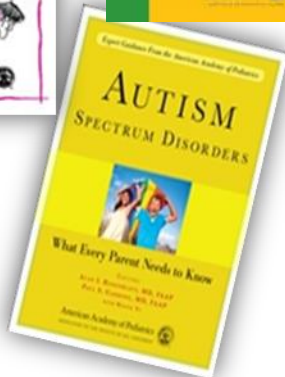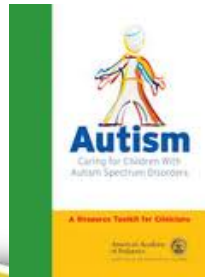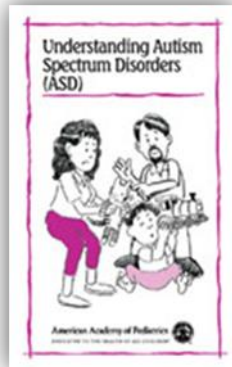Daniels AM, Mandell DS. J Autism Dev Disord. 2013;43:2844-54.

Resources Available for Clinicians, Parents, and Caregivers

Available References from the American Academy of Pediatrics and CDC

www.aap.org/autism
http://brightfutures.aap.org/
www.cdc.gov/actearly

Evidence-based Interventions for Children and Youth with ASD

Samuel L. Odom, PhD

Director, Frank Porter Graham Child Development Institute
University of North Carolina at Chapel Hill

Reasons for Concern About Intervention and Treatments for Autism Spectrum Disorder: Poor Long Term Outcomes

❑ **Many young adults with ASD continue to live at home following completion of secondary school**

❑ **Little participation in education or employment after high school**

❑ **With effective programs positive outcomes possible**

❑ **It is never too late to start, but acting early can make a difference**

Shattuck et al., 2012

Definition of Successful Outcome of Intervention and Treatment

❑ **Practices that produce positive life outcomes**
  ➢ Behavioral
  ➢ Developmental
  ➢ Health

❑ **Productive member of society**
  ➢ Living independently or with support
  ➢ Social and community participation with support

❑ **Cure is not a reasonable expectation at this time**

WHEN THEY GRADUATE:
1) SOMETHING TO DO
2) SOMEWHERE TO BE
3) SOMEONE TO LOVE.
GOOD LUCK !!

Howlin, Good, Hutton, & Rutter, 2004; Howlin et al.,2005; Wehman et al.,2014

Determining Which Interventions for ASD Produce Positive Outcomes

❑ **Treatment and program practices need to be based on scientific evidence of efficacy**

❑ **Challenges**

  ➢ Other interventions with little or no evidence of effectiveness
    ▪ Antifungal treatment
    ▪ Hyperbaric oxygen
    ▪ Numerous others

  ➢ **Behavioral interventions monitor behavior**
    ▪ Need rigorous, systematic review of improvements over time

❑ **Well-planned, systematic, scientifically-based interventions are the way forward**

Siri and Lyons, 2012.

Basing Treatment on Scientific Evidence

❑ **Treatments of choice are behavioral and must be individualized to each child**

  ➤ Traditional applied behavioral analysis approaches
  ➤ Naturalistic behavioral approaches
  ➤ Developmental, social-pragmatic, or relationship based conceptual frameworks

❑ **For some behavioral symptoms, medications help**

❑ **Two classes or types of interventions**

  ➤ Comprehensive Treatment Models (CTMs)
  ➤ Focused Intervention Practices

Odom, Hume, Boyd, & Stabel, 2012; Shahill, Tillberg, & Martin, 2014
CTMs: Comprehensive Treatment Models

Comprehensive Treatment Models (CTMs)

- ❑ **Address multiple core needs of children with ASD**
  - ➢ How to communicate and interact with others
  - ➢ How to function independently
  - ➢ How to reduce restrictive and repetitive behavior

- ❑ **Procedural manuals and checklists**

- ❑ **Evidence of effectiveness through RCT or accumulated body of research**

- ❑ **In 2001, National Academy of Sciences Committee identified 10 CTMs**

- ❑ **In 2010, we identified 30 CTMs**

Comprehensive Treatment Models Supported by Evidence

❑ **Earliest historic CTMs**
- ➤ Lovaas*
- ➤ TEACCH (Schopler)**

❑ **Other CTMs with strong evidence of model coherence and positive outcomes for children with ASD**
- ➤ Early Start Denver Model*
- ➤ LEAP*
- ➤ May Institute**
- ➤ Pivotal Response Treatment**
- ➤ Princeton Child Development Institute**

❑ **Outcomes reported in published research**
- ➤ Increases in IQ scores
- ➤ Positive changes in adaptive behavior
- ➤ Improvements in communication, social, and play skills

* RCT evidence
**Accumulated research evidence
Odom, Boyd, Hall, & Hume, 2014; Rogers & Vismara, 2014

Examples of Prominent Comprehensive Treatment Models

Name	Settings	Hours per Week	Instructional Practices	Targeted Behaviors
Lovaas Model	Clinic or Home	25-40 hours per week	Discrete trial training; naturalistic intervention	Imitation; language concepts
Early Start Denver Model	Home and Clinic	15 hours per week by therapist; embedded daily by parents	Joint adult-child activities; based on natural routines and play; child-preferred activities	Heavily focused on language, play, and social communication

Lovaas (1987), Rogers & Dawson (2010)

Examples of Prominent Comprehensive Treatment Models

Name	Settings	Hours per Week	Instructional Practices	Targeted Behaviors
LEAP Model	Inclusive Early Education Classroom	15-20 hours (3-4 hours per day x 5 days)	Naturalistic intervention; peer-mediated	Social skills, communication, behavior

Strain & Bovey (2011)

Examples of Outcomes Reported

Name	Measures	Outcomes	Studies
Lovaas Model	Stanford-Binet/Bayley Vineland Education placement	- Autism symptoms + IQ + Adaptive behavior + Educational placement + Language	Lovaas (1987), McEachin, Smith, Lovaas (1993)
Early Start Denver Model	ADOS/ADI-R EEG Mullen Vineland	- Autism symptoms + Changes in EEG + IQ + Language + Adaptive behavior	Dawson, Rogers et al. (2010) Dawson et al. (2012)
LEAP	CARS Mullen Preschool Language Scale SSRS	- Autism symptoms + Language + Visual reception + Positive social behavior	Strain & Bovey (2011)

+ = Significant difference between treatment and control

- = Decrease in symptoms in treatment vs. control

CARS = Childhood Autism Rating Scale; Mullen = Mullen Scales of Early Development; SSRS = Social Skills Rating System;

Vineland = Vineland Adaptive Behavior Scale

Focused Intervention Practices

❑ **Teachers and other service providers use these interventions to create individualized programs for children and youth with ASD and their families**

❑ **Target specific skill development**

❑ **Current emphasis on identifying individual interventions that have scientific evidence of efficacy**

➢ Evidence-Based Practices or EBPs

❑ **Examples include**

➢ Visual supports:
  ▪ visual reminders about steps in a task
➢ Discrete trial training:
  ▪ adult to child individual instruction

Odom, Collet-Klingenberg, Rogers, & Hatton, 2010

Systematic Reviews of the Literature for Evidence-based Practices (EBPs)

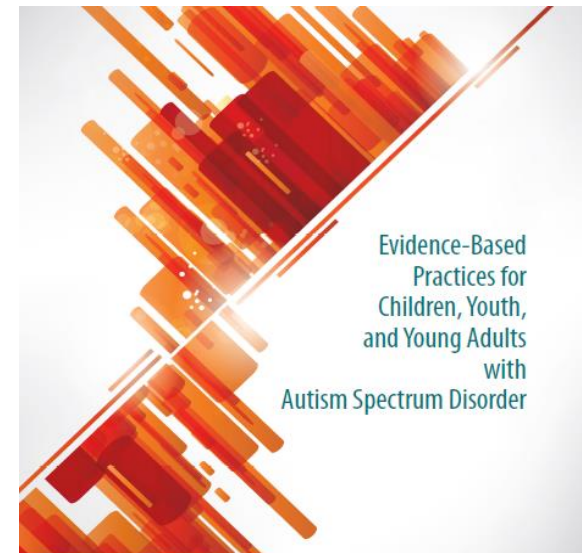❑ **In 2009, 11 practices with an evidence base**

  ➢ Reviewed by National Standard Project from National Autism Center

❑ **In 2010, 24 EBPs**

  ➢ National Professional Development Center (NPDC)
  ➢ Included 10 years, 1997-2007

❑ **In 2014, 27 EBPs**

  ➢ Second review by NPDC
  ➢ Included 22 years, 1990-2011
    ▪ 29,101 possible studies ➜456 studies
    ▪ RCT, quasi-experimental, single case design
  ➢ Strength of Evidence Criteria
    ▪ **2 or more RCTs or quasi-experimental design**
    ▪ **5 or more SCD**

autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/2014-EBP-Report.pdf

Evidence-Based
Practices for
Children, Youth,
and Young Adults
with
Autism Spectrum Disorder

Connie Wong, Samuel L. Odom,
Kara Hume, Ann W. Cox, Angel Fettig,
Suzanne Kucharczyk, Matthew E. Brock,
Joshua B. Plavnick, Veronica P. Fleury, and Tia R. Schultz

Autism Evidence-Based Practice Review Group
Frank Porter Graham Child Development Institute
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Odom, Collet-Klingenberg, Rogers, & Hatton., 2010.; Wong, Odom et al., 2014
RCT: randomized clinical trial
SCD: single case design

Types of Evidence-Based Practices Identified in National Autism Center Review

- ❑ **Basic ABA techniques**
  - ➢ Prompting
  - ➢ Reinforcement
- ❑ **Multicomponent ABA**
  - ➢ Discrete trial teaching
  - ➢ Pivotal response training
  - ➢ Functional communication training
- ❑ **Other theoretical**
  - ➢ Visual supports
  - ➢ Social narratives
  - ➢ Technology-aided intervention
  - ➢ Cognitive behavior intervention
  - ➢ Exercise

ABA = Applied Behavior Analysis

Evidence-Based Practices Validated for Infants and Toddlers with ASD and Their Families

❑ **Early Intervention Provider will select EBPs or methods from these 10 to target child's needs**

  ➢ Antecedent-based Intervention
  ➢ Functional Behavioral Analysis
  ➢ Modeling
  ➢ Naturalistic Intervention
  ➢ Parent-mediated Implemented Intervention
  ➢ Pivotal Response Training
  ➢ Prompting
  ➢ Reinforcement
  ➢ Social Skills Training
  ➢ Video Modeling

Using Knowledge Gained through Research for Individualized Interventions

❑ **Evidence–Based Practices are the building blocks for individualized interventions for children and youth with ASD**

❑ **Following lead of clinical psychology and evidence-based medicine**
  ➢ Assess learning needs
  ➢ Specify the goal
  ➢ Select practice most likely to produce change

❑ **Ongoing monitoring of effects**
  ➢ Increases in using words to communicate
  ➢ Decreases in stereotypic behavior
  ➢ Increased tolerance of transitions

Odom, Hume et al., 2012

Accessing Services for Children with ASD

- ❑ Early intervention programs active in all states (http://ectacenter.org/contact/ptccoord.asp)
- ❑ Public schools required to provide a free and appropriate public education beginning at age 3
  - ➢ Individuals with Disabilities Education Act (IDEA)
- ❑ Medicaid waivers funding some services (http://medicaidwaiver.org/)
- ❑ Private insurance will cover therapy services in some states (http://www.autismspeaks.org/advocacy/states)
- ❑ National Professional Development Center on ASD
  - ➢ Online modules for the original EBPs (http://autismpdc.fpg.unc.edu/)
  - ➢ New modules for toddlers (http://asdtoddler.fpg.unc.edu/)
- ❑ Center on Secondary Education for Students with ASD (http://csesa.fpg.unc.edu/)