


Highlights from the National Center on Birth Defects and Developmental Disabilities

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Director

2018 CDC New Health Official Orientation

Thursday, May 3, 2018

Vision and Mission

Vision:

Babies are born healthy.
Children reach their potential.
And everyone thrives.

Mission:

We:

- work to save babies by studying and addressing the causes of birth defects;
- help children reach their potential by understanding developmental disabilities;
- reduce complications of blood disorders; and
- improve the health of people living with disabilities.

Organizational Chart

Science and Public Health Team

Stuart K. Shapira, MD, PhD
Chief Medical Officer
Associate Director

Resource Management Office

Vicki Kipreos, PMP
Management Officer

James Scales
Chief

National Center on Birth Defects and Developmental Disabilities

Coleen Boyle, PhD, MSHyg
Director

Stephanie Dulin, MBA
Deputy Director

Health Communication Science Office

Betsy Mitchell, PhD
Associate Director

Policy, Planning and Evaluation Team

Sascha Chaney
Associate Director

Division of Human Development and Disability

Georgina Peacock, MD, MPH
Director

Division of Blood Disorders

Craig Hooper, PhD
Director

Division of Congenital and Developmental Disabilities

Peggy Honein, PhD, MPH
Director

SAVING BABIES

HELPING CHILDREN

PROTECTING PEOPLE

IMPROVING HEALTH

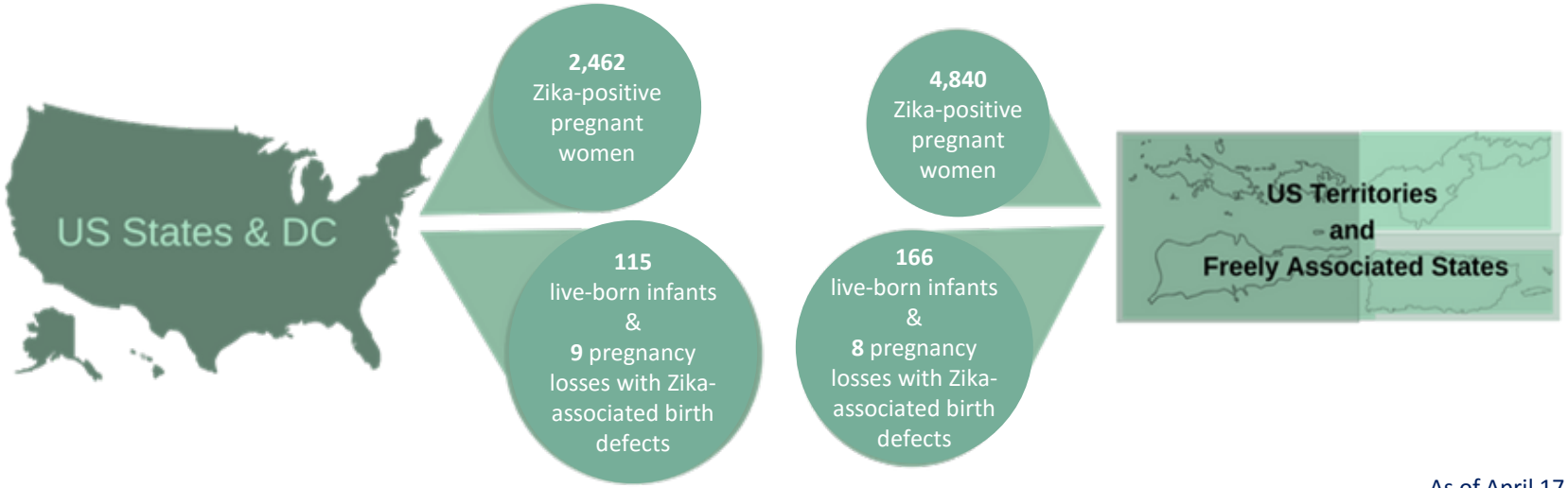
Thematic Areas

SAVING BABIES

Zika and Other Emerging Threats to Mothers and Babies

Zika: impact on mothers and babies

- Pregnant women with laboratory evidence of possible Zika virus infection and their infants
  - Infants who test positive for Zika virus infection and their mothers
  - Infants followed for at least **24 months**



As of April 17, 2018

Zika: Data for Action

Three-Component Surveillance Approach

Zika pregnancy and infant surveillance

1 **US Zika Pregnancy and Infant Registry**

Zika Virus Infection

Conception — Delivery — Infancy — Childhood

2 **Adapted Birth Defects Surveillance**

Possible Zika Exposure

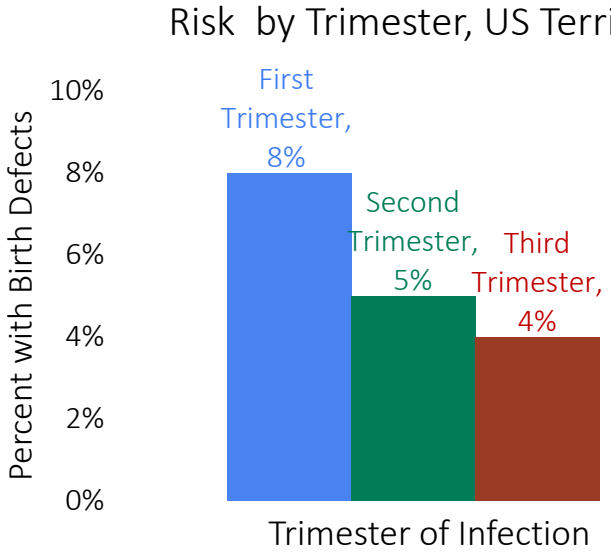
Conception — Delivery — Infancy

Referral to services

3 **Local Health Department Surge Capacity**
(Contractual field assignees)

What We've Learned from Pregnancy/Infant Surveillance

Among pregnancies with laboratory evidence of Zika, about **5-10%** of fetuses/infants had Zika-related birth defects



Zika virus infections in the **first trimester** pose the **highest risk**

The **proportion of babies affected by birth defects** is **similar** for **symptomatic** and **asymptomatic** women who had a **confirmed** Zika virus infection during pregnancy

Zika: Demonstrating Impact

Largest cohort of women with Zika during pregnancy

monitoring over

7,200

pregnancies

Identified increase in birth defects associated with Zika

Before Zika:
About **3** per 1,000 births

With Zika in pregnancy:
About **60** per 1,000 completed pregnancies

States with existing birth defects surveillance systems cut time to release data in half

Before Zika:
About 2 years after end of the birth year to report data

After Zika:
About 1 year after end of the birth year to report data

The Problem:

We only understand Zika's impact on newborns

We don't know what the health outcomes will be for greater than 90% of the children born with congenital Zika virus infection.

Our Questions about Zika:

What other disabilities might these children have as they age and can we help them thrive?

Severe Motor Impairment

High Fever

?

Feeding Difficulties

Sleeping Difficulties

Insufficient Information

Severe Developmental Delay

Cerebral Palsy

?

Retinal Abnormalities

Pneumonia

?

Hearing Impairment

Seizures

?

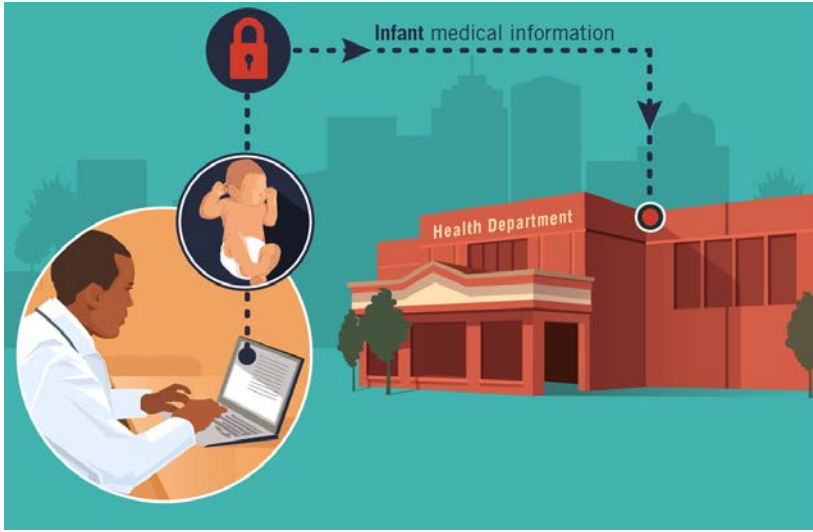
Visual Impairment

At birth:
Head circumference in normal range

At 12 months:
Acquired microcephaly

Health Departments Have a Critical Role

- Educate healthcare providers about Zika
- Coordinate testing
- Report cases to the Registry
- Support babies and families

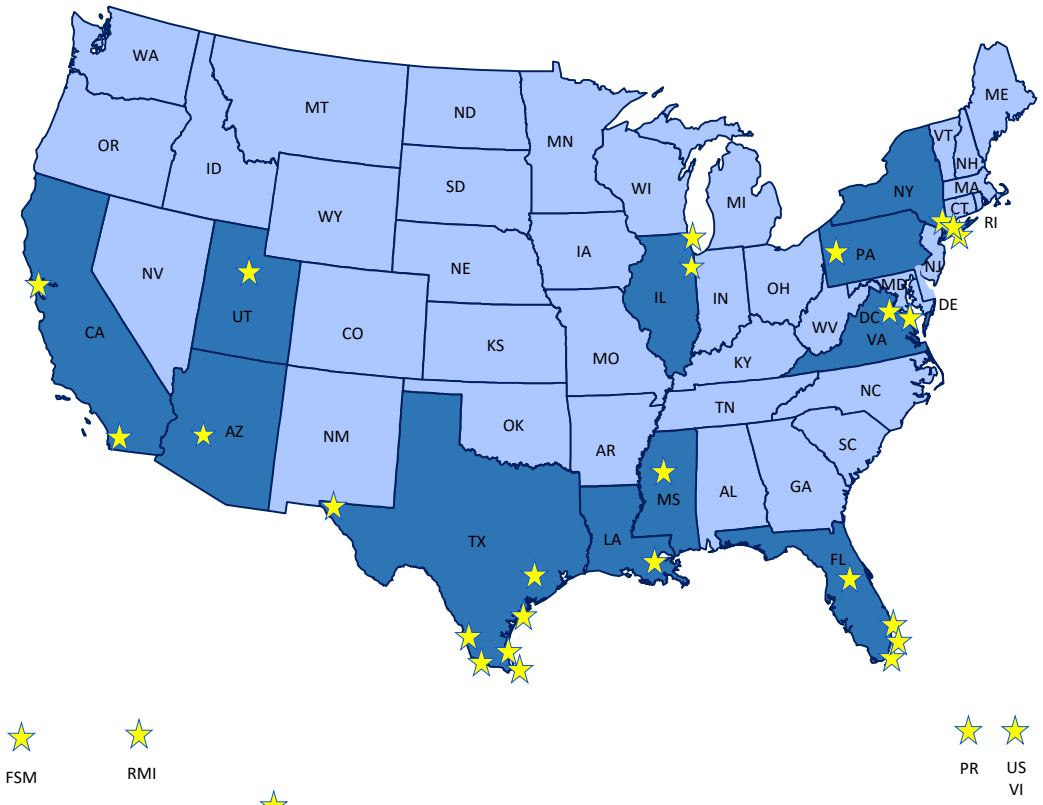


CDC's Local Health Department Initiative (LHDI) Field Assignee Placements

State/Territory	Health Department
American Samoa	• American Samoa Dept. of Public Health
Arizona	• Maricopa County Dept. of Public Health
California	• Alameda County Public Health Dept. • County of San Diego Health and Human Services
Florida	• Florida Dept. of Health-Orange County • Florida Dept. of Health-Palm Beach County • Florida Dept. of Health-Broward County • Florida Dept. of Health-Miami-Dade County
Federated States of Micronesia	• Kosrae Dept. of Health Services
Illinois	• Kane County Health Dept. • Chicago Dept. of Public Health
Louisiana	• New Orleans Health Dept.
Mississippi	• Mississippi State Dept. of Health
New York	• Metropolitan Area Regional Office (New York State Dept. of Health) • Congenital Malformations Registry (New York State Dept. of Health) • Suffolk County Dept. of Health Services
Pennsylvania	• Alleghany County Health Dept.**
Puerto Rico	• Dept. of Health of Puerto Rico
Republic of the Marshall Islands (RMI)	• RMI Ministry of Health and Human Services
Texas	• City of El Paso Dept. of Public Health • City of Laredo Health Dept. • Hidalgo County Health and Human Services Dept. • City of Brownsville Public Health Dept. • Cameron County Dept. of Health and Human Services • Corpus Christi-Nueces County Public Health District • Harris County Public Health
US Virgin Islands	• USVI Dept. of Health
Utah	• Salt Lake County Health Dept.
Virginia	• Fairfax County Health Dept.
Washington, DC	• District of Columbia Dept. of Health

***Field Assignee in PA deployed via LHDI, provides support for Neonatal Abstinence Syndrome (NAS) not Zika.*

LHDI Site Map*



*As of April 2018

Zika and Beyond: What have we learned?

Data for Action: Protecting mothers and babies from emerging and known threats

Rapidly identify emerging threats to mothers and babies

Consistently collect information about impact of threat on pregnancy, birth defects, and infant health

Transform data into action through development of clinical guidance

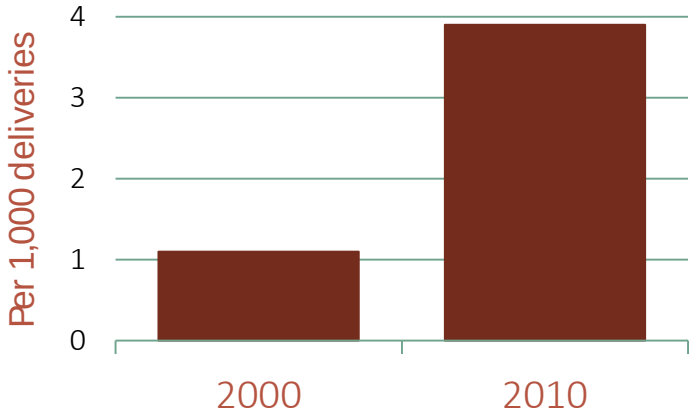
Provide support to and collaborate with state and local health departments

Making the Case:

Impact of Sustained Prenatal Opioid Exposure on Mothers

About **1** in **3**
women of reproductive age
filled an opioid prescription
between 2008 – 2012.

Opioid abuse and dependence
during pregnancy increased
4-fold
between 2000 and 2010.

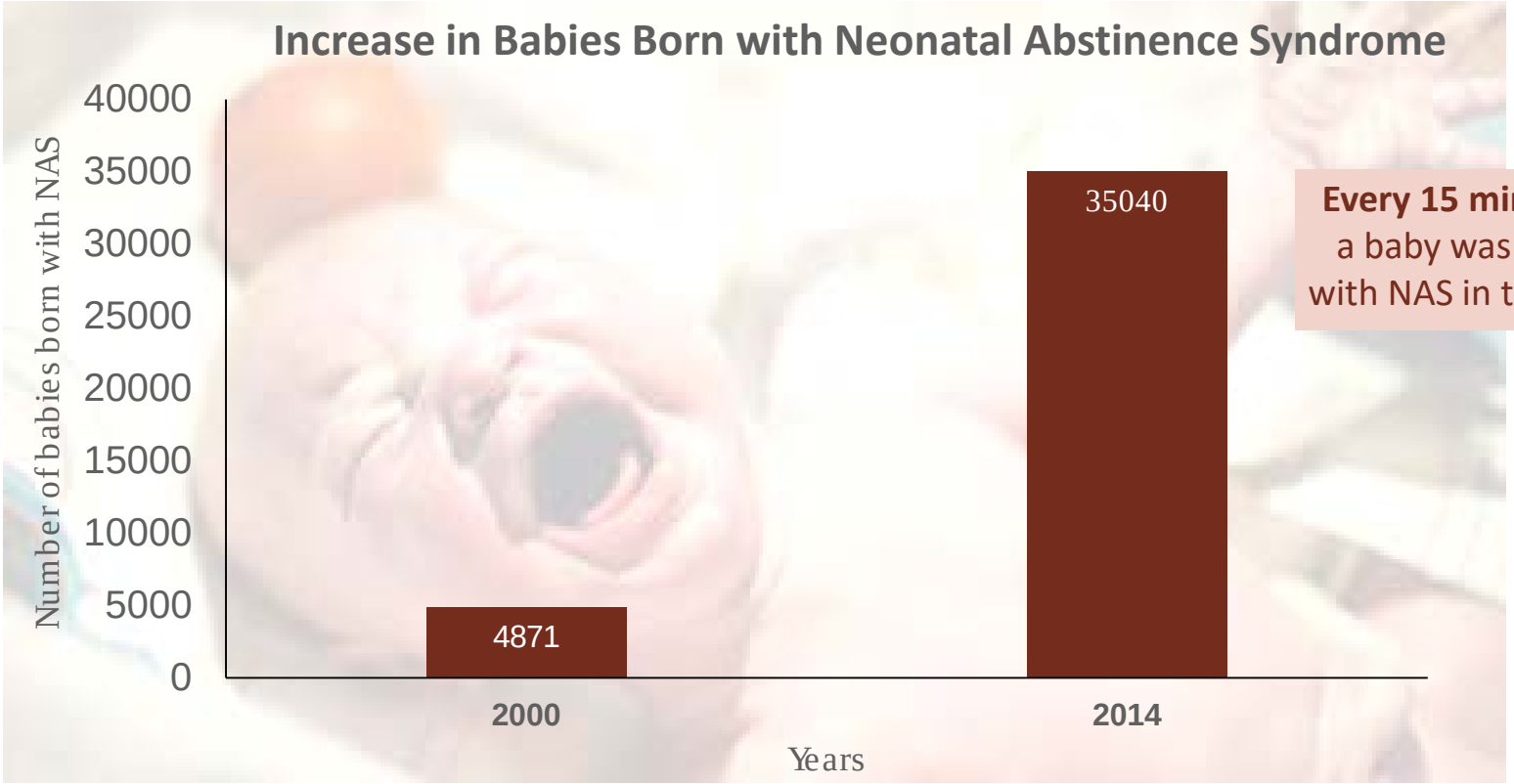


Ailes EC, Dawson AL, Lind JN, et al. MMWR. 2015 Jan 23;64(2):37-41.

Maeda A, Bateman BT, Clancy CR, et al. Anesthesiology. 2014 Dec;121(6):1158-65.

Making the Case:

Impact of Prenatal Opioid Exposure on Babies

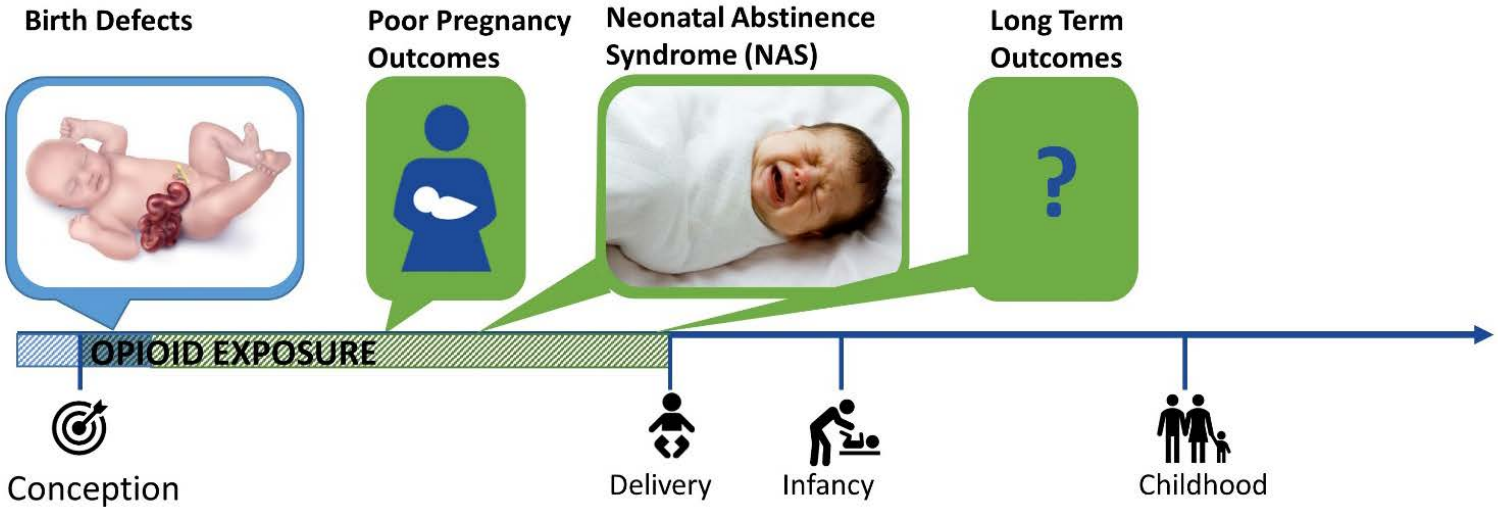


Every 15 minutes, a baby was born with NAS in the U.S.

Winkelman TNA, Villapiano NL, Kozhimannil KB, Davis MM, Patrick SW. Incidence and Costs of Neonatal Abstinence Syndrome among Infants with Medicaid: 2004–2014. Pediatrics.

What can we do?

Leveraging existing systems to respond to the opioid epidemic

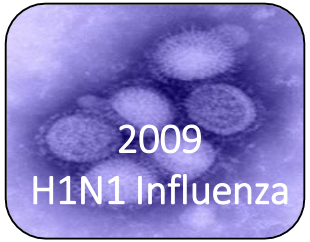


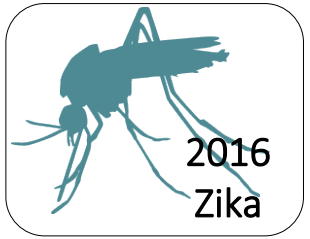
System to monitor emerging threats

1. Monitor mothers and babies with sustained exposure to opioids during pregnancy
2. Adapt birth defects surveillance to rapidly monitor associated outcomes, including NAS
3. Local health department surge capacity, in collaboration with state health department

Future Directions

- ✓ Preparedness needs to include plants to protect the most medically vulnerable, including pregnant women and their infants
- ✓ Protecting mothers and babies during every emergency response through surveillance of pregnancies and birth outcomes
- ✓ Incorporating notifiable diseases into CDC's ongoing birth defects research study through data linkage
- ✓ Opportunity to extend this work through a FY19 Initiative: Surveillance of emerging and known health threats to mothers and babies





HELPING CHILDREN

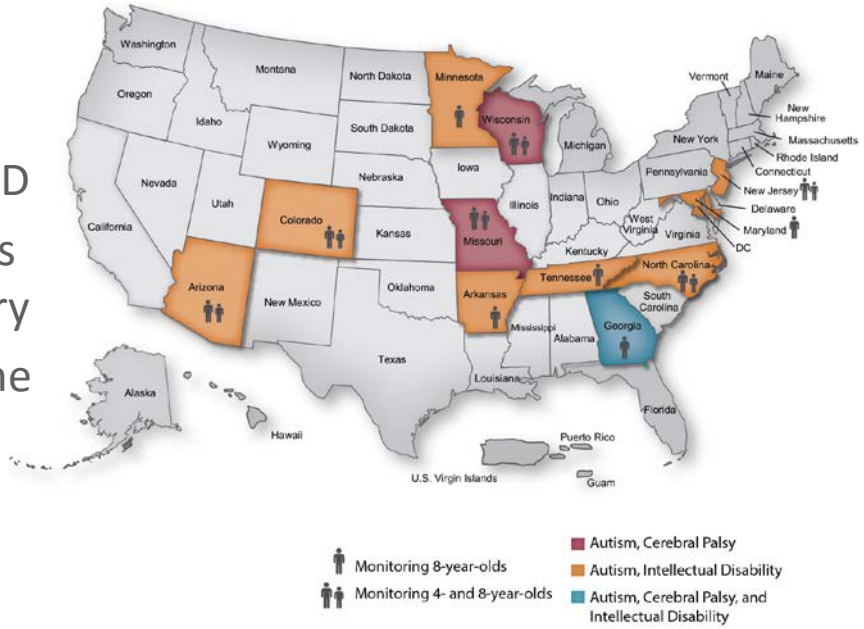
Autism and Developmental Disabilities Monitoring (ADDM) Network

A partnership with state/local health departments and universities/colleges across the United States to better understand the number and characteristics of children with autism spectrum disorder (ASD)

Goals:

- Estimate ASD prevalence
- Describe the population of children with ASD
- Compare ASD prevalence in different groups of children and different areas of the country
- Identify changes in ASD prevalence over time
- Understand the impact of ASD and related conditions in US communities

Current ADDM Network Sites, Tracking Years 2014–2016



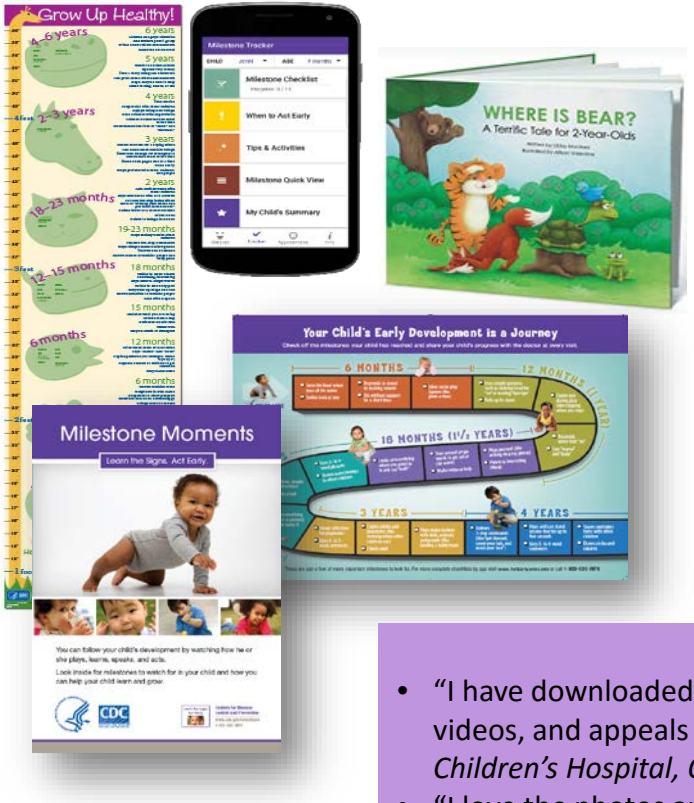
What Have We Learned from ADDM about Children with ASD?

Constants over time	Changes over time
More boys than girls identified with ASD	Decreased disparities in identification of ASD in racial/ethnic minorities, although some under-identification still persists
Delays in early identification (fewer than half receive first developmental evaluation by 3 years of age)	Higher ASD prevalence overall (2002-2014*) and within individual geographic areas (2000 – 2014)
Later age of first diagnosis (after 4 years of age	Greater proportion of children with IQ scores in the average to above average range (i.e., IQ >85)
Geographic variability	

*ASD prevalence stayed about the same between 2000 and 2002 and between 2010 and 2012

Learn the Signs. Act Early.

www.cdc.gov/ActEarly



CDC's program to improve early identification of developmental delays and disabilities, including autism, by promoting developmental monitoring and screening so children and their families can get the services and support they need.

- Supporting 55 *Act Early Ambassadors* in 49 states and 3 territories
- Offer high quality tools and materials

New Milestone Tracker App – Now Available

What People are Saying:

- "I have downloaded the app for my family and recommend it to my patients. It is easy to use, has great videos, and appeals to all audiences which I appreciate." *Elise Gentile, MS, APRN, CPNP, Advocate Children's Hospital, Oak Lawn, IL*
- "I love the photos and videos on Milestone Tracker, it helps me to know exactly what milestones my son should be reaching." *Jasmine B., mother of 1-year-old, Atlanta, GA*

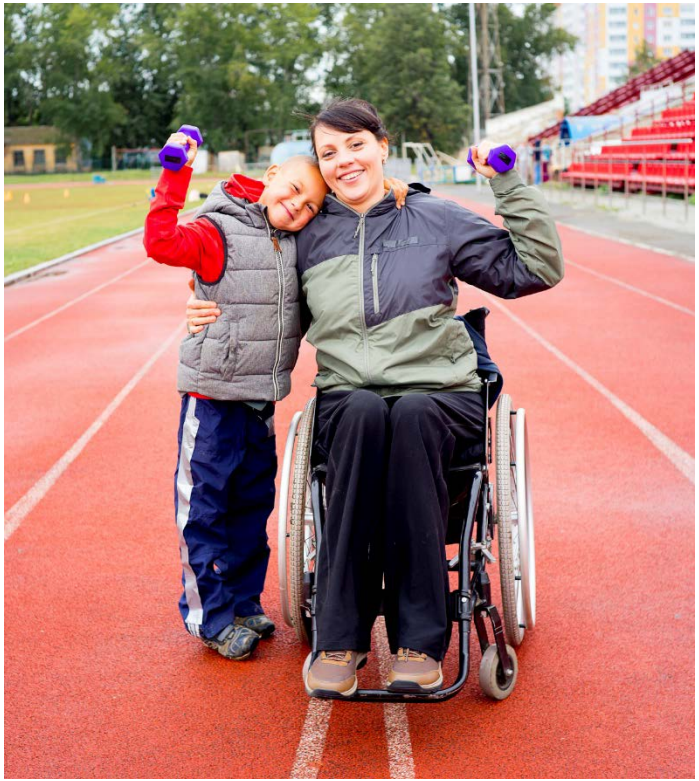
IMPROVING HEALTH

CDC Early Hearing Detection and Intervention (EHDI)

- Late-identified deaf and hard of hearing (D/HH) infants are at risk for developmental delays
  - Approximately 1-3 of every 1,000 births are D/HH
- 1-3-6 EHDI Process
  - Screening: **1** month / Diagnosis: **3** months / Intervention: **6** months
- CDC funds 49 jurisdictions to develop and use EHDI Information Systems (EHDI-IS)
  - Tool that help ensure D/HH infants are identified and receive intervention
  - Over 6,300 D/HH identified early in 2016
- Successes
  - State Implementation of advanced EHDI-IS
  - Utah: Improved care coordination
  - Massachusetts: Linkage with Vital Records

Disability and Health State Programs

- CDC funds 19 state-based programs
  www.cdc.gov/ncbddd/disabilityandhealth/programs.html
- Promote equity in health, prevent chronic disease, and increase the quality of life for people with disabilities
- National Centers on Disability
  https://www.cdc.gov/ncbddd/disabilityandhealth/national-programs.html
- Disability and Health Data System
  www.dhds.cdc.gov/
  - BRFSS data showing differences by state in health for adults with and without disabilities
- Inclusion Resources
  www.cdc.gov/ncbddd/disabilityandhealth/disability-inclusion.html



For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

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