

# National Trends and Approaches To Assessing and Addressing Early Childhood Developmental Delay

Kori Flower, MD MS MPH

Division Chief and Professor

Division of General Pediatrics and Adolescent Medicine



SCHOOL OF  
MEDICINE



# **Increasing Importance of Developmental Screening and Surveillance in Children's Primary Health Care**

# Children's Primary Health Care and Role of Well Child Visits

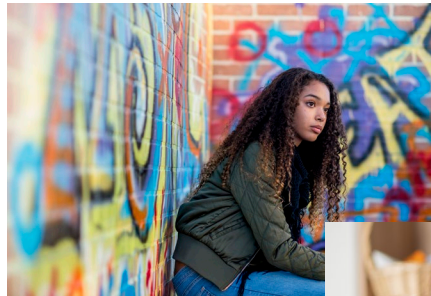
- Well child visits are one of the only mechanisms in our society for potentially reaching nearly 100% of young children
- Gateway to health opportunities
  - Initial screening
  - Further evaluation and referrals
  - Specialty care
  - Research

# Picture A Well Child Visit

In addition to this....



Picture this....



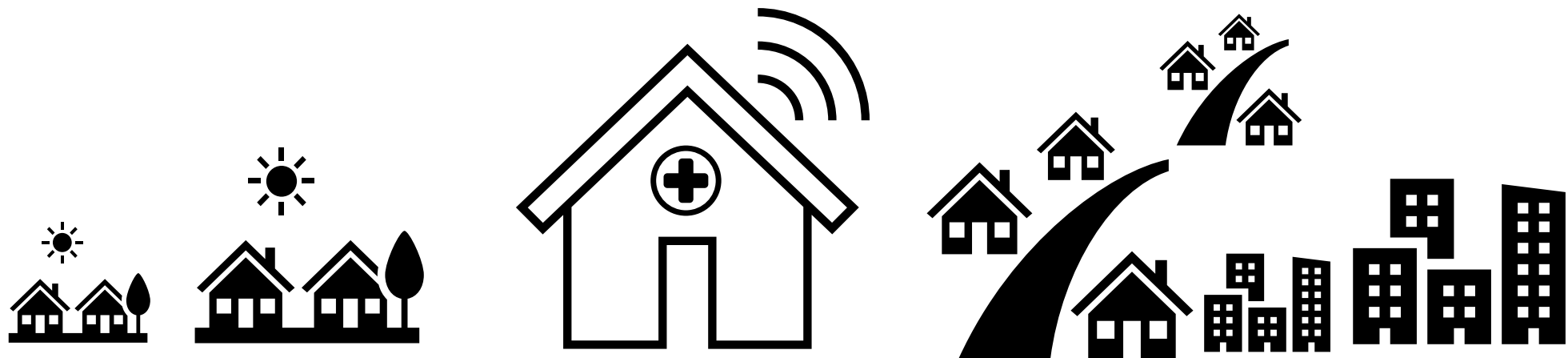
# History Of Well Child Visits

- Evolution from health surveillance/supervision to health promotion
- Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program created in 1967 to define well visits and essential services for Medicaid program
- Broadening and expansion of goal to include
  - Modifying health behaviors
  - Addressing social and environmental factors
  - Fostering resilience
  - Counseling and guiding parents



# Well Child Visits Should Occur in a Medical Home

- Care that is "accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective"
- Part of a "neighborhood" rich in connections to support services



# Frequency and Timing of Well Visits

---

Centered around immunization schedule

---

14 visits before kindergarten

---

Annual visits age 3-21

---

Frequent and universal contact creates potential to prevent and address high-prevalence problems that impact health equity

# Developmental Delay and Autism: Historically Under-Detected During Well Visits



Fig. Items required to conduct the DDI

Previous methods (Denver and informal questions in each domain) under-detected children with developmental delay and autism

- 1 in 3 children were over 6 years of age at autism diagnosis

Black and Hispanic children were less likely to be diagnosed with developmental delay and autism compared with White children



# Autism Screening: Important for Early Identification

FROM THE AMERICAN ACADEMY OF PEDIATRICS | CLINICAL REPORT | JANUARY 01 2020

## Identification, Evaluation, and Management of Children With Autism Spectrum Disorder ✓

Susan L. Hyman, MD, FAAP ✉; Susan E. Levy, MD, MPH, FAAP; Scott M. Myers, MD, FAAP;  
COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS;  
Dennis Z. Kuo, MD, MHS, FAAP; Susan Apkon, MD, FAAP; Lynn F. Davidson, MD, FAAP; Kathryn A. Ellerbeck, MD, FAAP;  
Jessica E.A. Foster, MD, MPH, FAAP; Garey H. Noritz, MD, FAAP; Mary O'Connor Leppert, MD, FAAP; Barbara S. Saunders, DO, FAAP;  
Christopher Stille, MD, MPH, FAAP; Larry Yin, MD, MSPH, FAAP; Carol C. Weitzman, MD, FAAP; David Omer Childers, Jr, MD, FAAP;  
Jack M. Levine, MD, FAAP; Ada Myriam Peralta-Carcelen, MD, MPH, FAAP; Jennifer K. Poon, MD, FAAP; Peter J. Smith, MD, MA, FAAP;  
Nathan Jon Blum, MD, FAAP; John Ichiro Takayama, MD, MPH, FAAP; Rebecca Baum, MD, FAAP; Robert G. Voigt, MD, FAAP;  
Carolyn Bridgemohan, MD, FAAP

Early identification allows  
early treatment which  
improved cognitive and  
language outcomes in some  
studies



# Centering Well Visit Around Child and Caregiver Concerns

**What would you like to talk about during today's visit?**

# Screening for Developmental Delay and Autism Is Recommended Nationally During Well Child Visits

- Updated American Academy of Pediatrics report on developmental screening (2020)
  - **Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening** Paul H. Lipkin, Michelle M. Macias, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS *Pediatrics* Jan 2020, 145 (1)
- Updated American Academy of Pediatrics report on identification and evaluation of autism spectrum disorder (2020)
  - **Identification, Evaluation, and Management of Children With Autism Spectrum Disorder** Susan L. Hyman, Susan E. Levy, Scott M. Myers, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. *Pediatrics* Jan 2020, 145 (1)



# Screening for Developmental Delay and Autism

- Standardized parent-completed screening tools recommended by American Academy of Pediatrics:
  - Developmental screening (9, 18, 24, 30 months)
  - Autism screening (18 and 24 months)
- Screening tools can elevate parent concerns
- Updated CDC tools for developmental surveillance can complement screening (2022)

## Help your child grow and thrive

Your child's early years are so very important. Tracking how your little one plays, learns, speaks, acts, and moves helps you support their development.

Download CDC's free *Milestone Tracker* app to find fun and easy activities for each age.



Track & Share  
Milestones

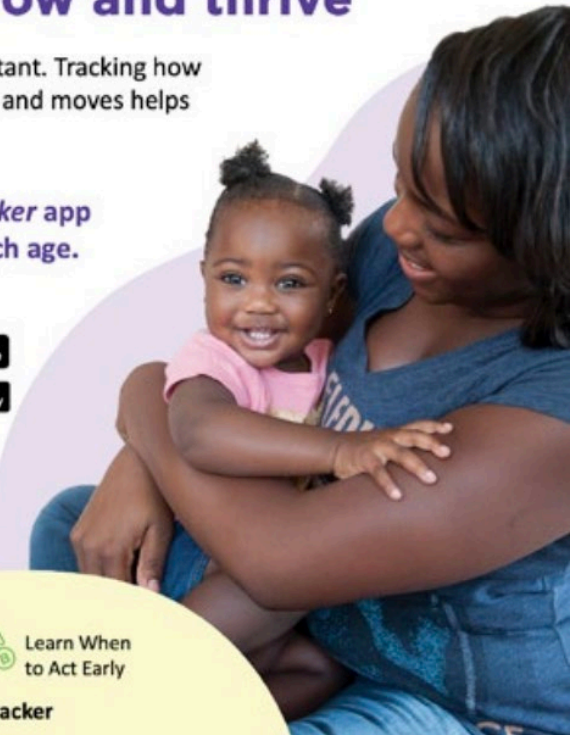


Get Tips &  
Activities



Learn When  
to Act Early

Learn more at [cdc.gov/MilestoneTracker](https://cdc.gov/MilestoneTracker)



# Updated AAP Developmental Screening Clinical Report: Key Points

- *Developmental surveillance* at all well visits
- *Standardized developmental screening tests* at 9, 18 and 30 months
- *Standardized ASD screening test* at 18 and 24 months
- *Early return visits* for concerns/risk factors
- *Refer* children with concerning screening tests to EI
- *Initiate chronic condition management* for children with developmental disorders
- *Use a strength based approach* as outlined in Bright Futures, and offer family support services

Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening Paul H. Lipkin, Michelle M. Macias, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS Pediatrics Jan 2020, 145 (1)

# Updated 2020 AAP Statement on Autism Screening: Key Points

- *Developmental surveillance* at all visits
- *Standardized autism-specific screening test* at 18 and 24 months
  - M-CHAT-R/F is most common
- Limitations to screening
  - Language barriers, poor translations, and low literacy reduce usefulness of questionnaires
  - MCHAT performs differently in Spanish Kimple KS, Steiner MJ et al. Performance of the modified checklist for autism in toddlers in Spanish-speaking patients. Clin Pediatr (Phila). 2014;53(7):632-638
  - Screening tools developed for specific linguistic and cultural groups are needed

Identification, Evaluation, and Management of Children With Autism Spectrum Disorder Susan L. Hyman, Susan E. Levy, Scott M. Myers, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS. Pediatrics Jan 2020, 145 (1)

# Evidence to Support Screening for Developmental Delay and Autism During Well Visits



## Screening makes a difference

- Children who were screened and positive were more likely to have an autism diagnosis and were diagnosed at a younger age compared with those not screened (N=36,233 children, 20 practices)

## Significant disparities

- Fewer Latino children screened



# Gaps Persist In Screening and Referral for Autism and Developmental Delay

- **Screening rates for autism remain suboptimal despite recommendations**
  - 73% were screened for autism (N=20 clinics, 36,233 children)
- **Significant disparities:** fewer Latino children screened
- **Inconsistent referral** following positive screening

## Primary Care Autism Screening and Later Autism Diagnosis Paul

S. Carbone, Kathleen Campbell, Jacob Wilkes, Gregory J. Stoddard, Kelly Huynh, Paul C. Young, Terisa P. Gabrielsen. Pediatrics Aug 2020, 146 (2)

# Challenges in Developmental Screening and Surveillance for Families with Limited English Proficiency

- Challenges include:
  - Written questionnaires and literacy levels
  - Linguistically appropriate screening forms
  - Culturally appropriate screening questions
  - Parent-facing educational materials in family's preferred language
  - Access to digital technology

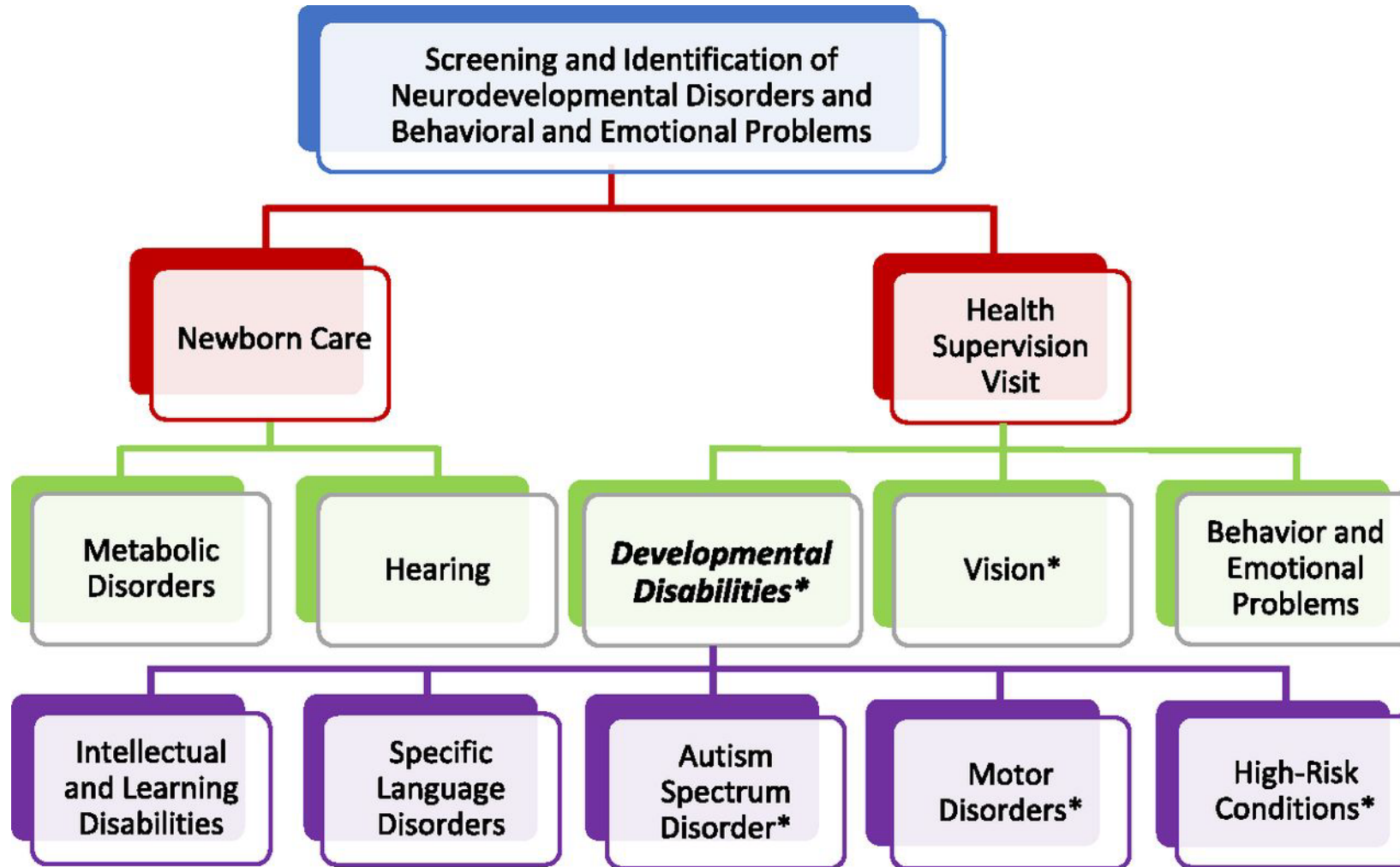
# Spanish-Speaking Families Experience More Barriers to Autism Diagnosis and Less Access to Treatment

- Latino children are diagnosed with autism:
  - Less frequently
  - At older ages
  - With more severe presentations
- Latino children with autism receive:
  - Less evidence-based care
  - Less therapy and specialty care

Zuckerman KE, Lindly OJ, Reyes NM, Chavez AE, Macias K, Smith KN, Reynolds A. Disparities in Diagnosis and Treatment of Autism in Latino and Non-Latino White Families. *Pediatrics*. 2017 May;139(5)

Zuckerman K, Lindly OJ, Chavez AE. Timeliness of Autism Spectrum Disorder Diagnosis and Use of Services Among U.S. Elementary School-Aged Children. *Psychiatr Serv*. 2017 Jan 1;68(1):33-40.

Early childhood screening for the identification of neurodevelopmental disorders and behavioral and emotional problems.



Paul H. Lipkin et al. Pediatrics 2020;145:e20193449

# Social, Emotional, and Behavioral Screening

- Clinical judgment alone has low sensitivity for detecting behavioral problems
- Detection rates lowest for children in racial and ethnic minority groups, perpetuating disparities Sheldrick RC, Merchant S, Perrin EC. Identification of developmental-behavioral problems in primary care: a systematic review. Pediatrics. 2011;128(2):356–363
- Recommendation added to AAP Periodicity Guidelines in 2022 to screen at every well visit
- Standardized parent-completed questionnaires recommended
  - Example: Pediatric Symptom Checklist
  - Sensitivity: 80%–95%
  - Available in multiple languages
- Purpose: Identify ways to build caregiver and child strengths and foster resilience

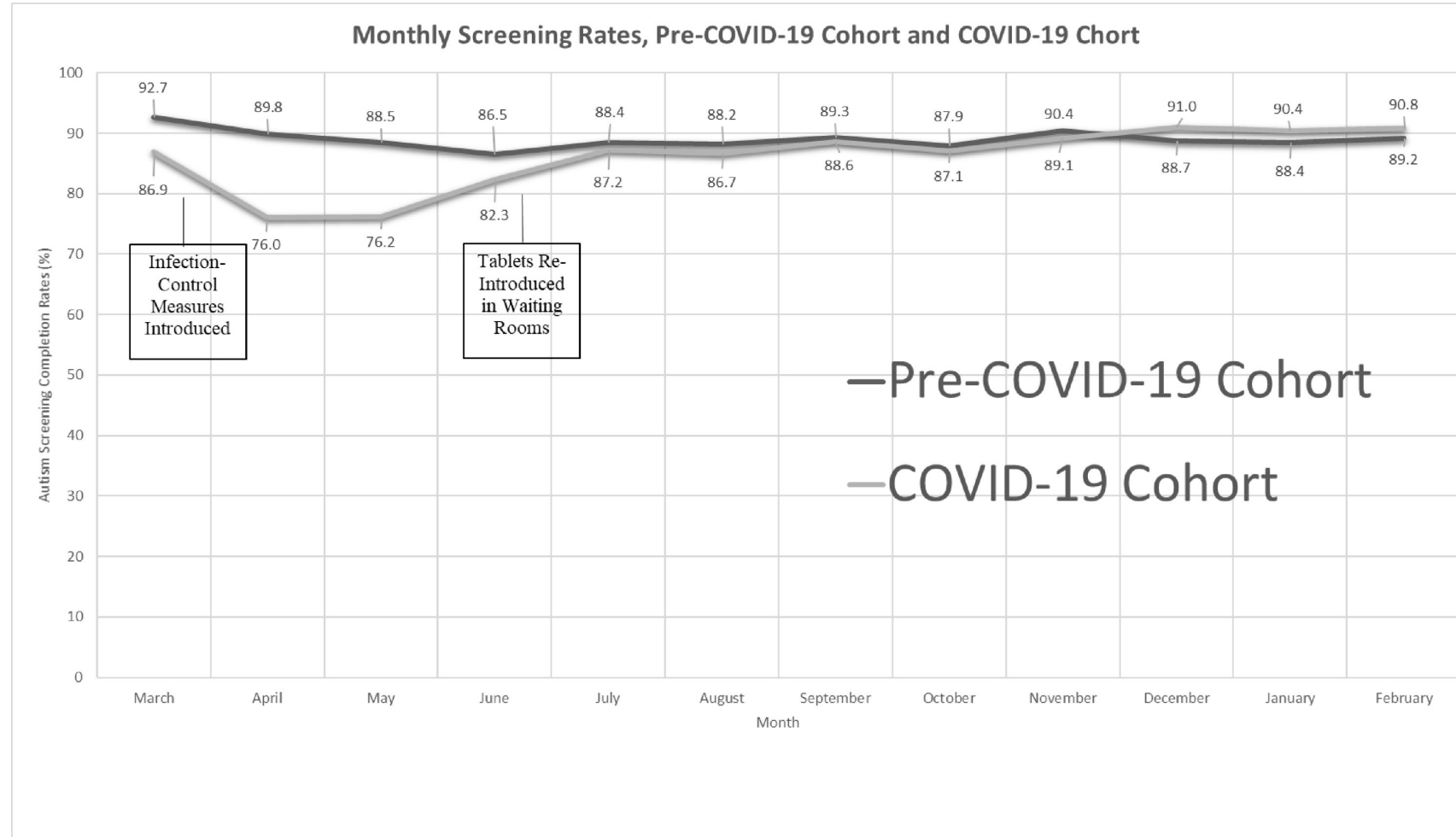




# Impact of COVID on Well Visits and Developmental Screening

# Impact of COVID on Autism Screening

- Primary care network
- 29 practices in CHOP Care Network (NY/NJ) (N=26,549 children)
- Total visits decreased by 8.3% with largest decrease for Black children
- Autism screening decreased from 89% to 86.4% during COVID



Wallis KE, Nekrasova E, Bennett AE, Fiks AG, Gerdes M, Jenssen BP, Miller JS, Shu D, Guthrie W. Autism Spectrum Disorder Screening During the COVID-19 Pandemic in a Large Primary Care Network. Acad Pediatr. 2022 Apr 20:S1876-2859(22)00232-7.

# Impact of COVID on Child Health and Development

- Mixed-methods study of 72 English and Spanish-speaking parents of infants recruited from 6 states during COVID as part of Greenlight Plus study
- Themes identified included:
  - Widespread life disruption
  - 66% of families reported less income
  - Impact on healthcare access
  - Avoidance of healthcare settings
    - Limitations to healthcare due to virtual visits
    - Prioritizing health care for children
  - Impact on family health behaviors
    - More and better family time for some families
    - Mixed impact on sleep and eating routines

“The truth is, almost nobody [other adults in her household/family] goes to visit the clinics. If not for my children who go for example to check-ups, vaccinations, whatever I have to take them to.”





# **Improving Developmental and Autism Screening, Referral, and Follow Up**

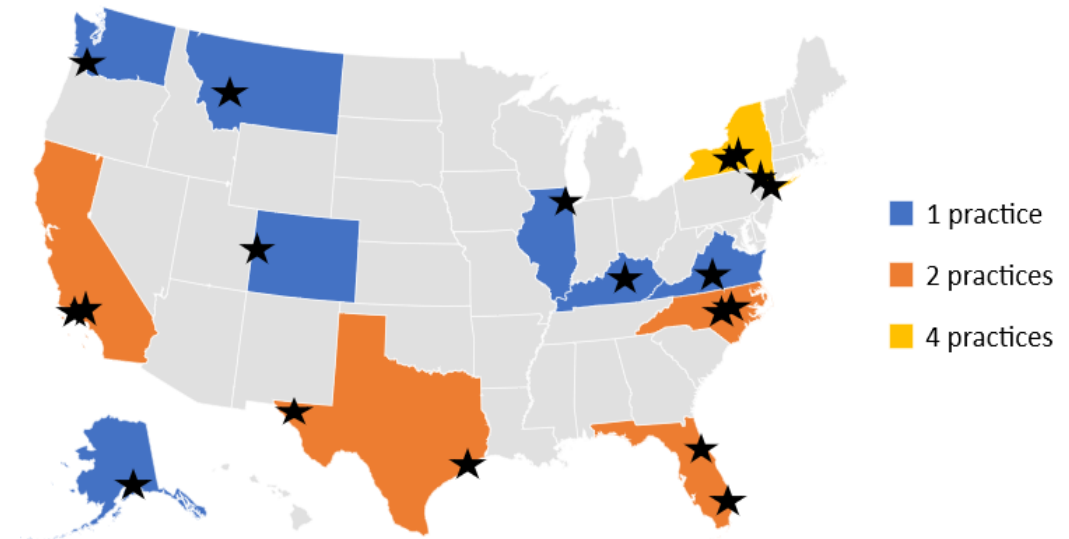
# Strategies to Improve Developmental Surveillance: Reach Out and Read

- Health care provider gives new book at well visits from birth to 5 years
- Counsels parent on book sharing
- Literacy-rich office environment
- Multiple studies support impact of model on outcomes including:
  - More frequent reading at home (High 2000)
  - Improved receptive and expressive language skills (Mendelsohn 2001)
  - Decreased social-emotional problems (Martin et al 2021)
  - Effects most pronounced for parents born outside of US and those with limited English proficiency (Sanders 2000, Silverstein 2002)



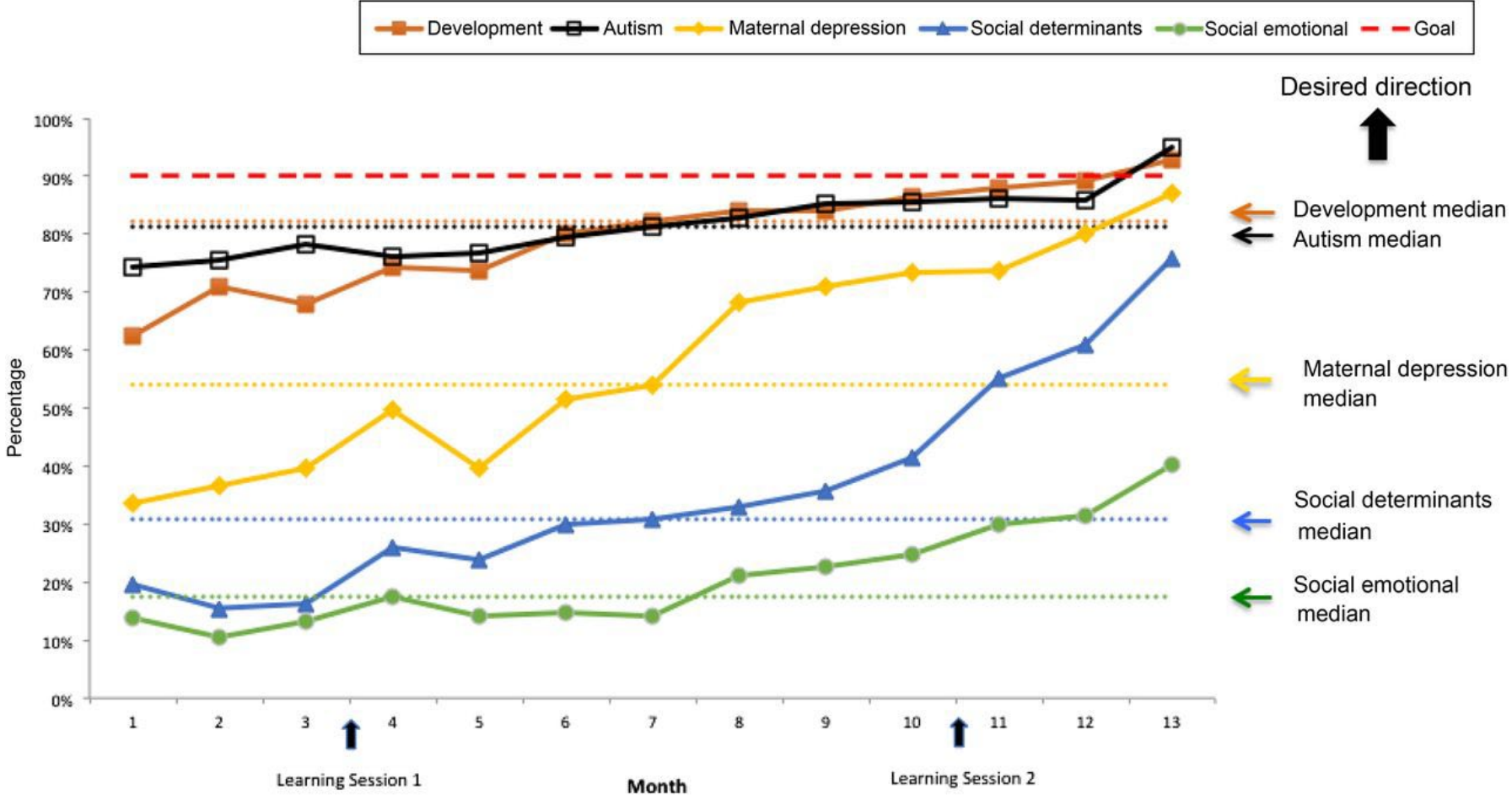
# Quality Improvement Approaches Can Increase Screening At Well Child Visits

- **Project I-SCRN:** American Academy of Pediatrics quality improvement collaborative in 19 pediatric practices
- Simultaneously improved developmental, autism, and social emotional screening



<https://pediatrics.aappublications.org/content/early/2020/08/05/peds.2019-2328>

# Percentage of Children Receiving Early Childhood Screenings



Kori B. Flower et al. Pediatrics 2020;146:e20192328

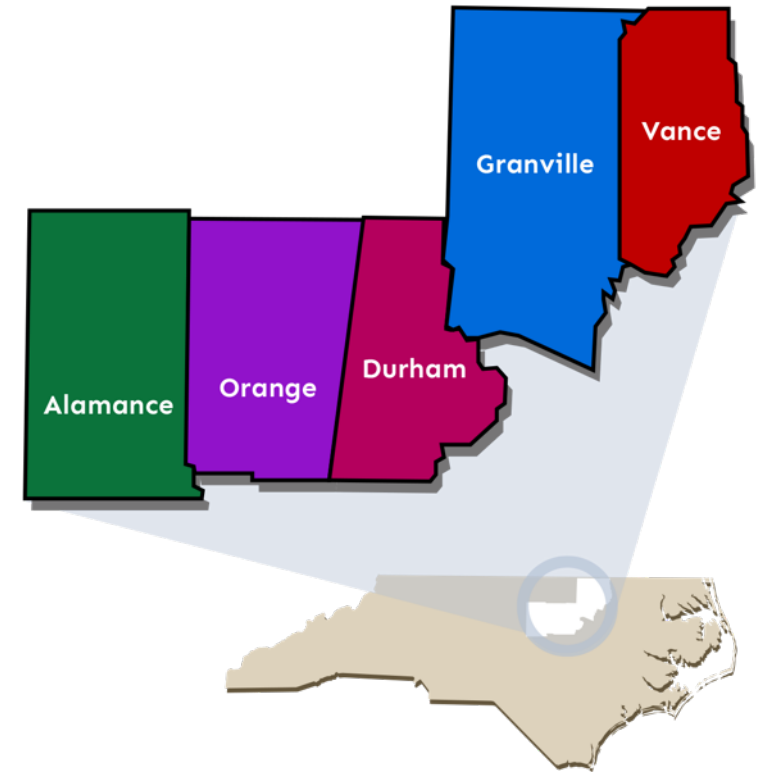




# **Addressing Developmental Needs to Optimize School Readiness**

# NC InCK: Addressing Children's Needs Holistically

- Population: All Medicaid and CHIP-insured children in 5 NC counties (95,000)
- Cross-sector project to integrate services and address children's needs holistically
- Funded by CMS
- For more information: [ncinck.org](http://ncinck.org)



NC DEPARTMENT OF  
HEALTH AND  
HUMAN SERVICES



# Kindergarten Readiness: A Measure of Overall Well-Being

- The condition of children as they enter school, based on the following five domains:



Health & physical  
development



Social & emotional  
development



Approaches  
toward learning



Language development  
& communication



Cognition & general  
knowledge

- The capacity of schools to serve all kindergartners effectively

# Kindergarten Readiness Promotion Bundle for Primary Care: An NC InCK Innovation

NC InCK Early Childhood Innovation Committee identified interventions that primary care practices can take to promote kindergarten readiness from birth to age 6



Well visit



Office-Based  
Literacy Promotion



Developmental  
screening



Social emotional  
screening



PreK referral



Parenting support  
programs



Early intervention  
referral



Early childhood  
mental health services



Community-based  
literacy programs

- **Goal:** Encourage activities to promote kindergarten readiness
- **Incentive:** Documentation via a new Medicaid code is linked to an incentive payment in the NC InCK Alternative Payment Model



# Evidence Base for Kindergarten Readiness Components Continues to Grow

Interventions to address both **parent mental health** *and* **preschool attendance** had a greater impact on mental health of children facing economic disadvantage than either of these interventions alone

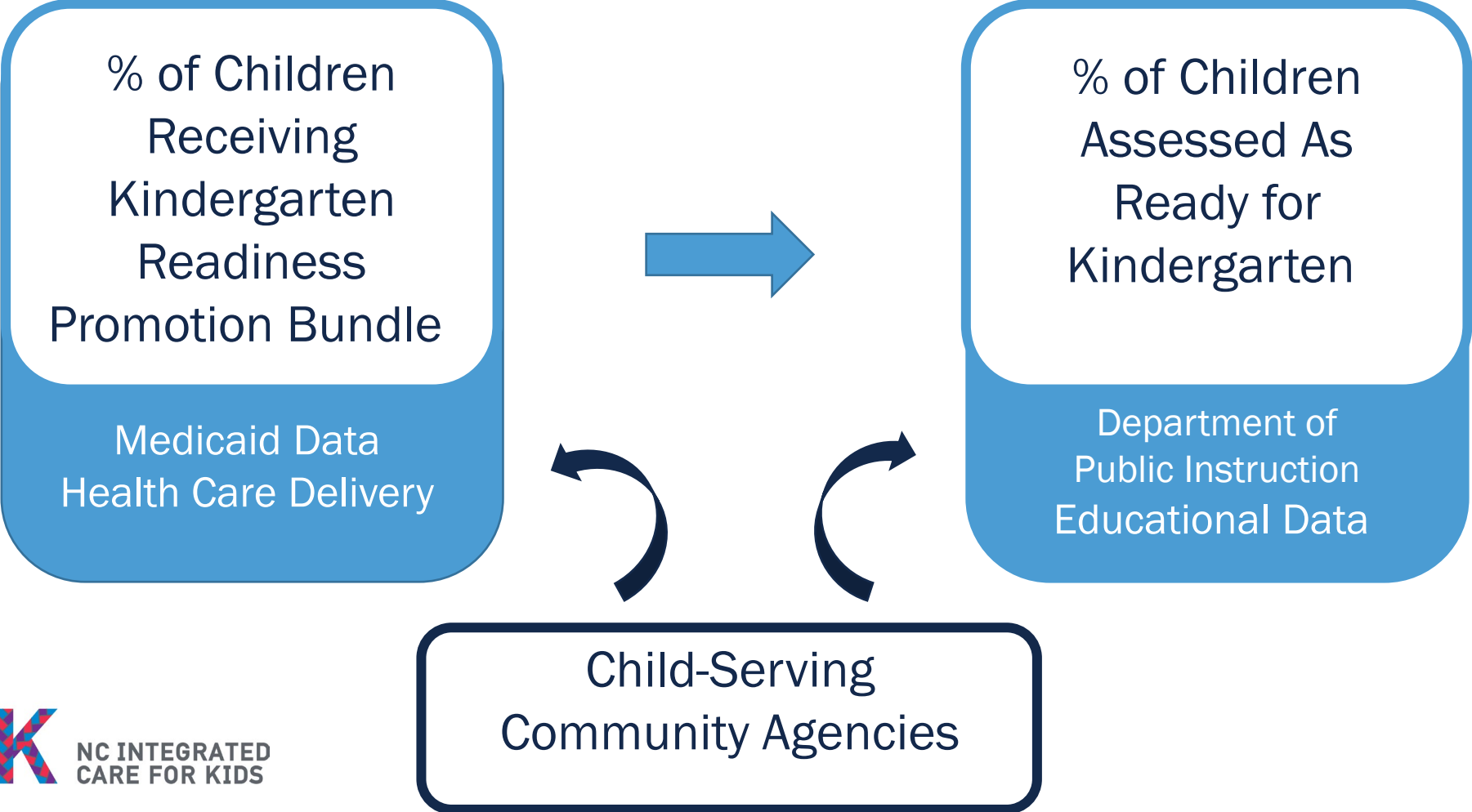
Sharon Goldfeld, Margarita Moreno-Betancur, Sarah Gray, Shuaijun Guo, Marnie Downes, Elodie O'Connor, Francisco Azpitarte, Hannah Badland, Gerry Redmond, Katrina Williams, Sue Woolfenden, Fiona Mensah, Meredith O'Connor; Addressing Child Mental Health Inequities Through Parental Mental Health and Preschool Attendance. *Pediatrics* 2023; e2022057101. 10.1542/peds.2022-057101

- Study linking primary care and school data showed that the following are associated with lower kindergarten readiness assessment scores:
  - *Failed development screen (Ages and Stages Questionnaire)*
  - Rarely read to
  - Ever food insecure
  - Needing an interpreter

Identifying Early Modifiable Predictors of Kindergarten Readiness by Linking Primary Care and School District Data

Kristen A. Copeland, Lauren Porter, Allison Reyner, Cynthia C. White, Robert S. Kahn. Presented at Pediatric Academic Societies Meeting, May 2023

# Linking Data Across Sectors to Measure the Impact on Kindergarten Readiness



# Resources for Parents and Caregivers

- Bright Futures handouts
- CDC Milestone tracker app (English/Spanish)
- Zero to Three

American Academy of Pediatrics

## BRIGHT FUTURES HANDOUT ► PARENT 18 MONTH VISIT

Here are some suggestions from Bright Futures experts that may be of value to your family.



Here are some suggestions from Bright Futures experts that may be of value to you family.

### Your Child's Behavior

Expect your child to cling to you in new situations or to be anxious around strangers.

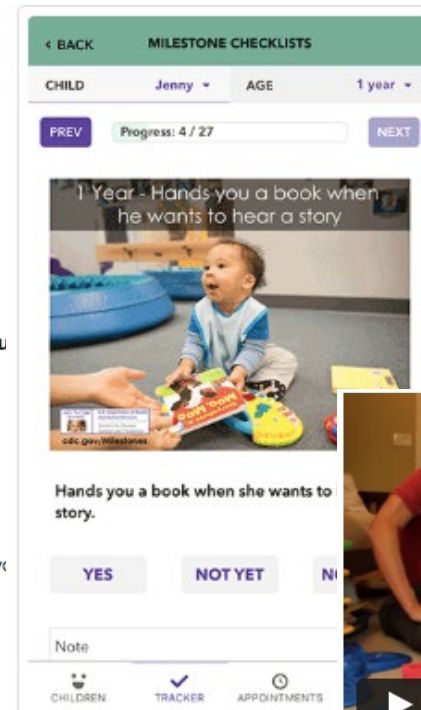
Play with your child each day by doing things she likes.

Be consistent in discipline and setting limits for your child.

Plan ahead for difficult situations and try things that can make them easier. Think about your day and your child's energy and mood.

Wait until your child is ready for toilet training. Signs of being ready for toilet training include:

- Staying dry for 2 hours
- Knowing if she is wet or dry
- Can pull pants down and up
- Wanting to learn



Watch how parents and caregivers can support the development of communication skills from birth to 3 years.

# Resources for Healthcare Providers

- Reach Out and Read Leyendo Juntos materials: myror.org or YouTube: <https://www.youtube.com/watch?v=plr29kAAXn4>
- AAP STAR Center:  
<https://screeningtime.org/star-center/#/resources>
- Simulation on discussing developmental delay:  
<https://screeningtime.org/star-center/#/simulations>



UNC

SCHOOL OF  
MEDICINE