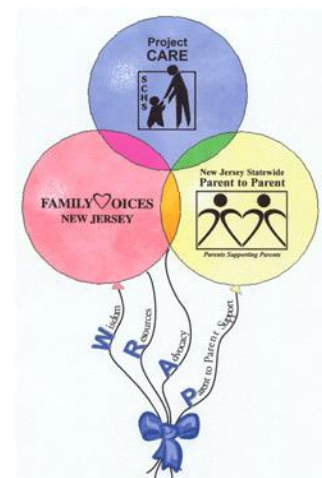
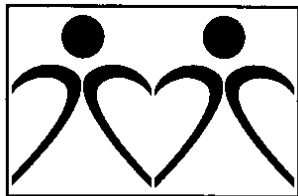




# Deepa Srinivasavaradan New Jersey



Family  oices  
New Jersey



New Jersey Statewide  
Parent to Parent

*Parents Supporting Parents*



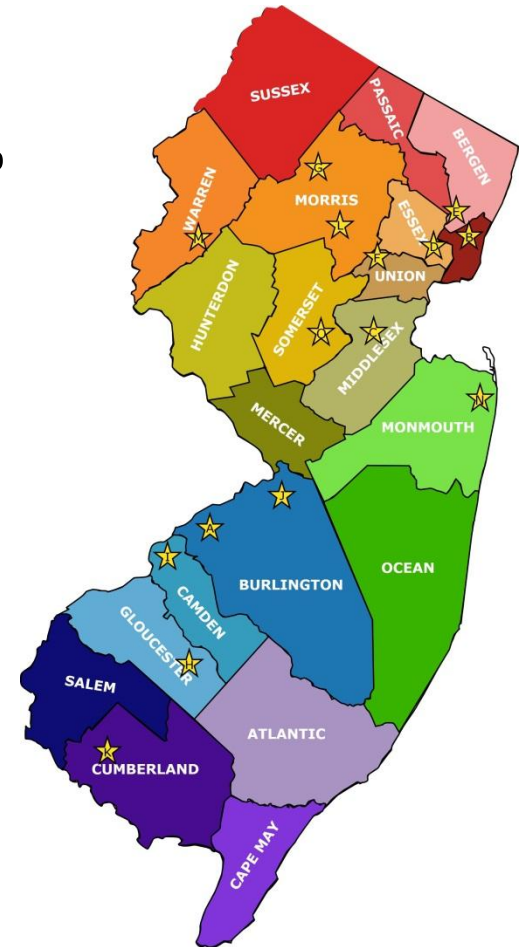
MILITARY  
FAMILY SUPPORT  
**360°**  
Center



**ONE-STOP CENTER**  
ASSISTING FAMILY MEMBERS  
OF MILITARY PERSONNEL WHO  
HAVE A DEVELOPMENTAL DISABILITY

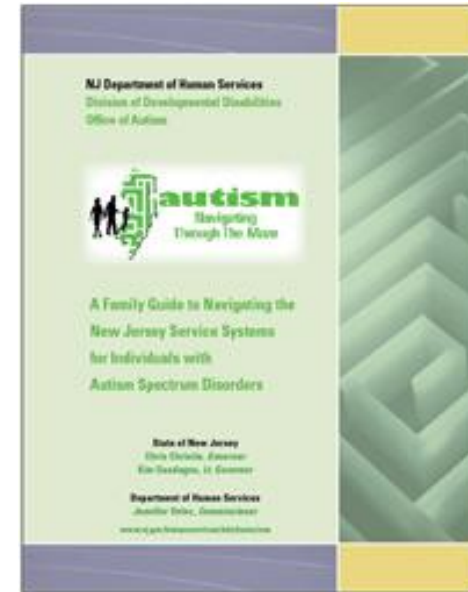
# New Jersey Overview

- 8,938,275 people, 23% children under age 18
- Diversity of adults: 57.6% White Not Hispanic; 19% Hispanic; 14.7% Black; 9.2% Asian; 2.7% other
- Diversity of children: 53% White; 26% Hispanic; 12% Black; 9% other
- Highest prevalence of autism (1 in 45)
- Differences by gender: 1/28 boys, 1/133 girls
- Differences by race: 1/44 white, 1/47 Hispanic, 1/48 Asian, 1/56 Black
- 41% of those identified screened by age 3
- Average age of diagnosis at age 4
  - Autistic disorder 3 years 4 months
  - PDD-NOS 3 years 9 months



# NJ Act Early State Team

- NJ Department of Health Division of Family Health Services
  - Special Child Health & Early Intervention Services
  - Improving Pregnancy Outcomes/Central Intake
- NJ Department of Children & Families
  - Help Me Grow; Project LAUNCH; Home Visiting; CSOC
- NJ Department of Human Services
  - Division of Development Disabilities, Office on Autism
- Boggs Center on Developmental Disabilities (UCEDD)
- NJ Council on Developmental Disabilities
- Statewide Parent Advocacy Network (PTI, F2F, FFCMH, P2P, etc.)
- Governor's Council for Medical Research & Treatment of Autism
- Center of Excellence on Autism at Montclair State University
- American Academy of Pediatrics-NJ Chapter
- Disability Groups (Autism NJ, POAC, Autism Family of Services, the Arc)



# New Jersey Department of Health Special Child Health and Early Intervention Services

**Early  
Identification  
& Monitoring**

**Family  
Centered Care  
Services**

**Early  
Intervention  
Services**

**Newborn Screening &  
Genetic Services**



**Mission:** To assure that all children with special health needs have access to comprehensive, community based, culturally competent, and family centered care.



- Special Child Health & EI Services
  - Birth Defects & Autism Registry (mandatory reporting)
  - Early Intervention
    - Regional Early Intervention Collaboratives (System Point of Entry) with family support staff
    - Targeted Evaluation Teams
    - Service Coordination Units
    - Service provider agencies
  - Special Child Health County Case Management Units
  - Specialized Pediatric Services
    - Multi-disciplinary outpatient evaluations, diagnose or confirm medical conditions, develop plans for comprehensive care
    - Centers of Excellence (Child Evaluation Centers, FASD Centers, Tertiary Care Centers, other)
  - Early ID of ASD Guidelines for Healthcare Professionals



# NJ System Components

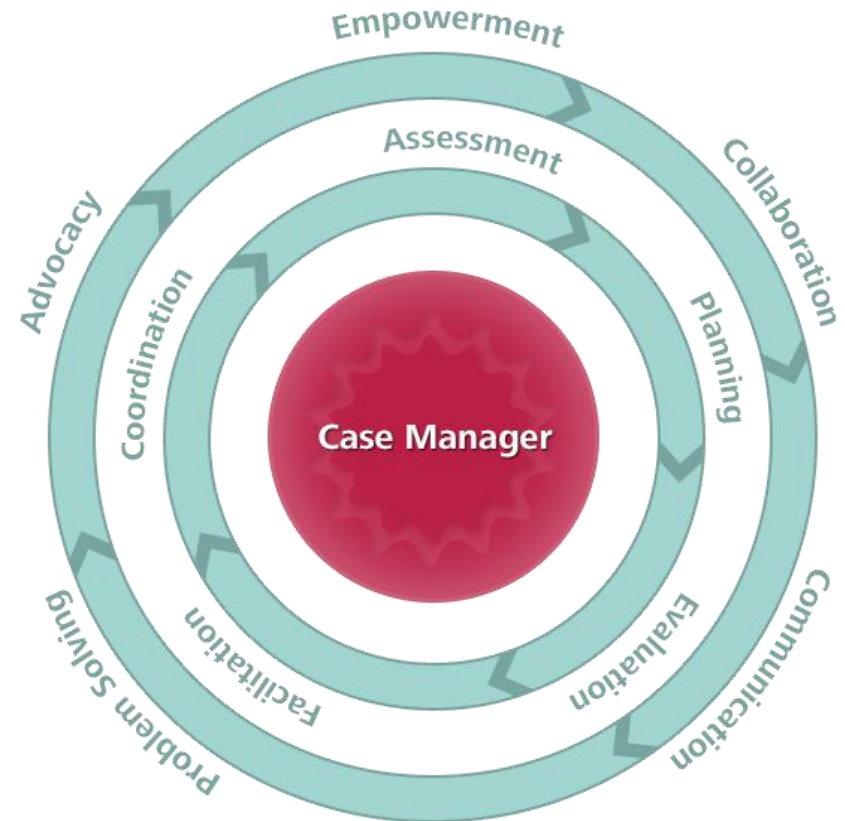
- The Autism Registry (part of Birth Defects Registry):
  - Children 0 through 21 diagnosed with Autism
  - Autism includes:
    - Autistic Spectrum Disorder
      - Autistic Disorder
      - Asperger Syndrome
      - Pervasive Developmental Disorder Not Otherwise Specified
    - Childhood Disintegrative Disorder
    - Rett Syndrome
  - Purpose:
    - Plan for and provide services to children with Autism and their families
    - Measure the prevalence of Autism in New Jersey
    - Conduct thorough and complete epidemiologic surveys of Autism





# NJ System Components

- **Autism Registry**
  - Record of all reported cases of ASD
  - Automatic connection to county SCHS Case management units
  - Tracking to determine if & what services were offered to registered children & families

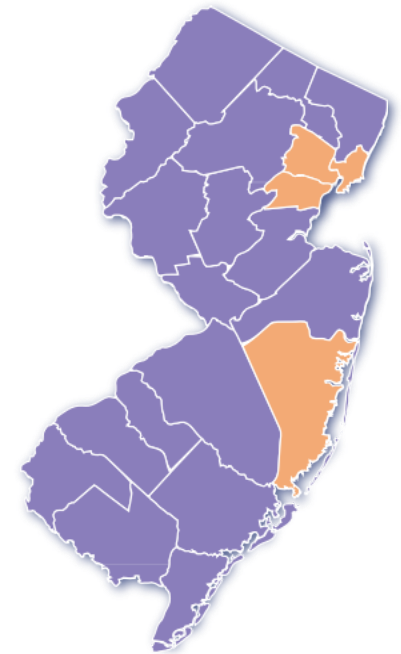


Learn the Signs.  
Act Early.



# NJ Autism Study

- CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network Site in NJ - the New Jersey Autism Study
  - Established in 2000 as an ADDM Network site in collaboration with the New Jersey Department of Health & investigators from Rutgers-New Jersey Medical School
  - Tracks # of 4 and 8 year olds with ASD, ID, or both, in selected areas in NJ (Essex, Hudson, Ocean, Union counties)
  - Offers training on the identification & diagnosis of ASD, makes presentations on ASD tracking & scientific findings, sponsors workshops on ASD topics, & assists families and policy makers in understanding the scope & consequences of ASD





# Healthcare Financing



- Insurers must pay for therapies for children with ASD & other Developmental Disabilities
  - Maximizing Reimbursement Under NJ's Autism & Other DD Insurance Mandate guide
  - Healthcare Financing Fact Sheet Series
  - Healthcare Advocacy Toolkit; Health Advocacy Across the Lifespan
- Children can stay on parents' insurance to age 30
- NJ Family Care (Medicaid & State Children's Health Insurance Program)
  - NJ SCHIP covers children up to 350% of FPL
- EI services at no cost to families up to 300% FPL; sliding fee scale for others
- Catastrophic Illness in Children Relief Fund (uncovered medical debt)
- NJ Children's System of Care for Children with I/DD



- Parent Training & Information Center (EI & Special education)
- Family to Family Health Information Center/Family Voices
- Statewide Parent to Parent
- NJ Inclusive Child Care Project
  - Training & On site TA including on Red Flags in Child Development; Rights & Resources; etc. to child care centers & family child care
- Act Early Ambassador
  - Follow up to trained FQHCs, outreach to early childhood
- Learn the Signs Parent-Led Screening Training to FQHCs, early childhood/Head Start (collaboration with Boggs Center UCEDD)
- Quick Peek Screenings support to families
- Family Resource Specialists stationed at SCHS CMUs, Autism Clinical Enhancement Programs, FQHCs, etc.



# NJ State Plan Impact Statement

- All children from NJ, from all racial, cultural, and linguistic backgrounds are identified early for ASD and other developmental disabilities, and receive supports and services that are evidence-based, person centered, adequately funded, and supported, and promote full community inclusion and participation.



Learn the Signs.  
Act Early.



# NJ State Goals

- Identification

- Increase rates of screening using validated tools

- Primary care providers
- Home visitors

- Continue to reduce age of identification

- Reduce racial gaps in identification

- Increase reporting of identified children to the registry



- Services

- Strengthen supports for families

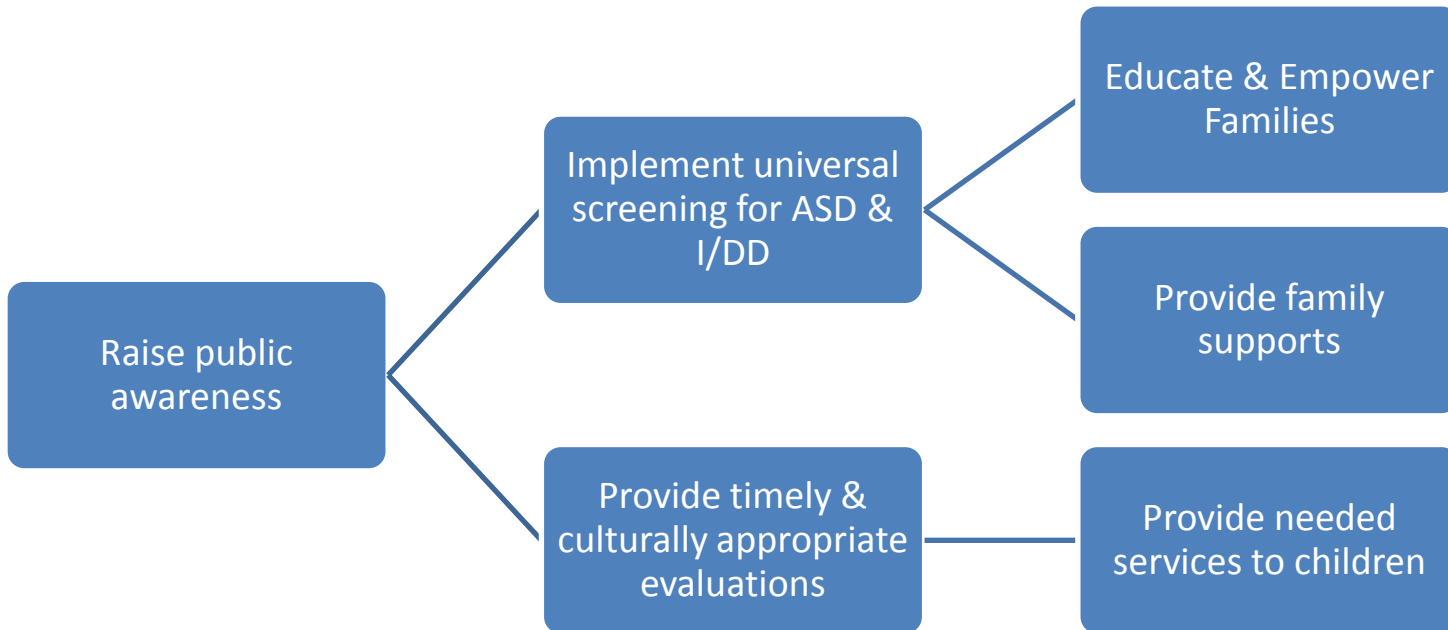
- Enhance community inclusion

- Improve use of evidence-based interventions for children with ASD & other DD in EI, special education, transition to adult life

- Reduce financial burden on families



# NJ State Action Plan



# Learning Objectives

- Bring together the members of our state team to learn together, revisit our goals, plan our strategies, and integrate activities to improve early identification of children in NJ
- Learn about neighboring state systems, promising practices, challenges, and future opportunities; hear about the various screening tools; and receive national information in health and education service coordination for young children with ASD and other developmental disabilities.





# Next Steps

- Revisit & Update Action Plan Logic Model
- Review recommendations from previous reports on ASD in NJ
- Identify areas of continued need
- Strengthen dissemination including LTSAE State website/webpage which includes resources & information (celebrating milestones videos, blog entries, fact sheets, etc.) & connects to all early childhood resources
- Reconvene Act Early State Team within context of Community of Care Consortium for CYSHCN & their Families

