



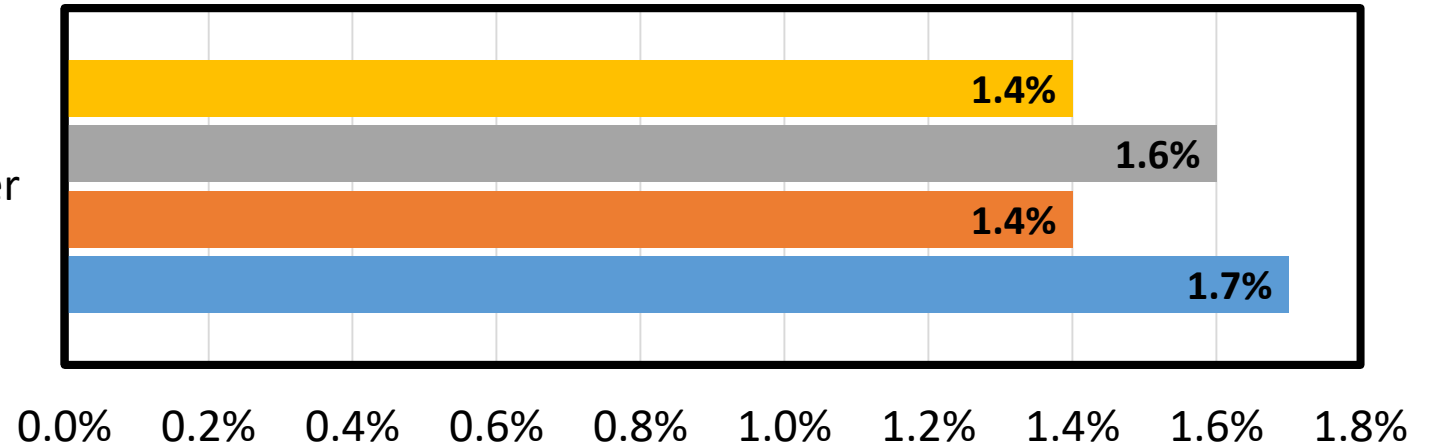
Sandy Magaña, MSW, PhD, Professor in Autism
and Neurodevelopmental Disabilities

DISPARITIES IN AUTISM DIAGNOSIS, TREATMENT AND SERVICES

Prevalence Neurodevelopmental Disorders Across Race/Ethnicity

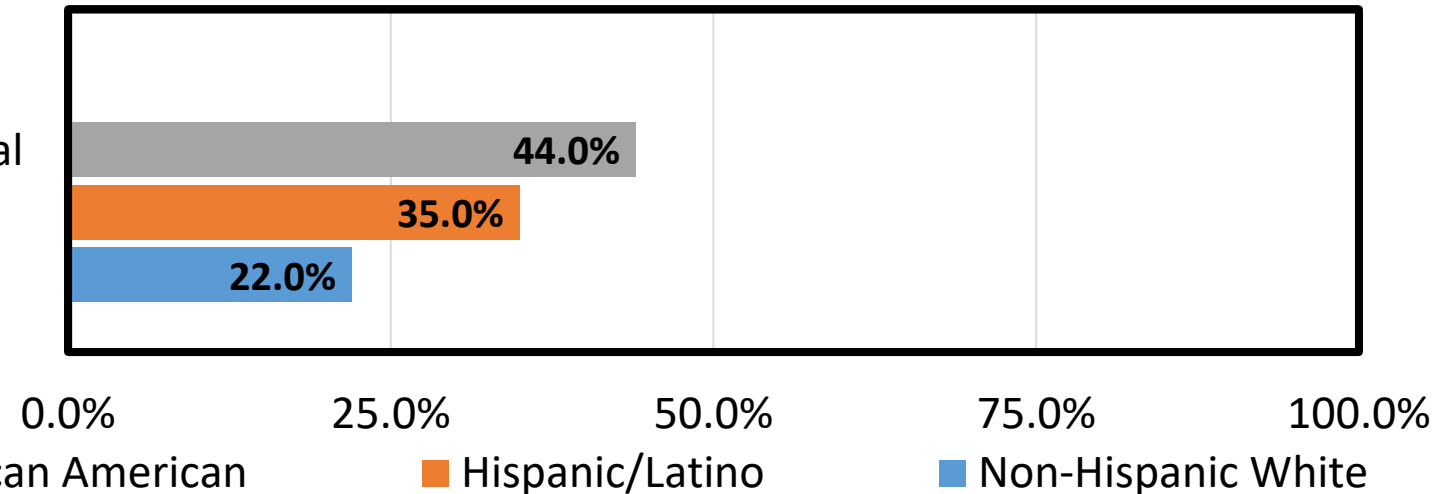
CDC 2014 Prevalence Rates

Autism Spectrum Disorder



CDC 2014 Prevalence Rates

Autism Spectrum Disorder + Intellectual Disability



■ Asian American

■ African American

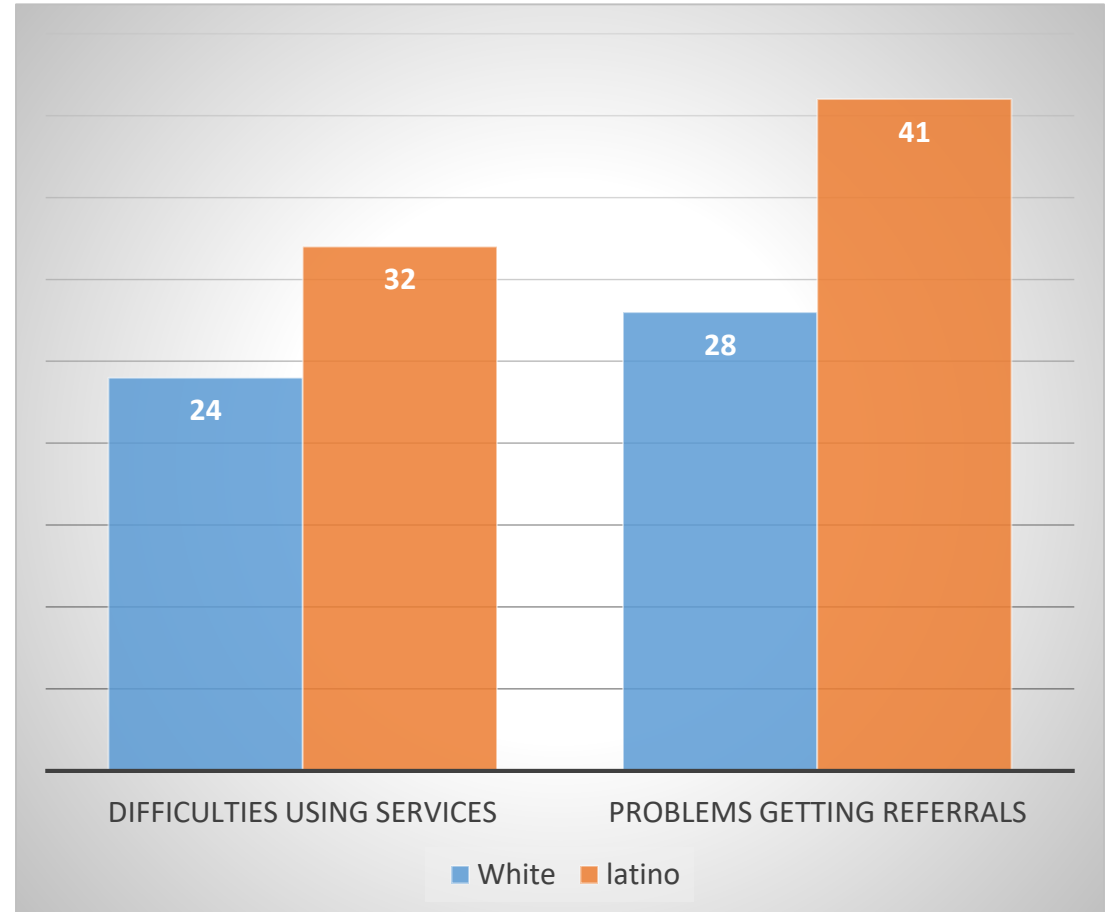
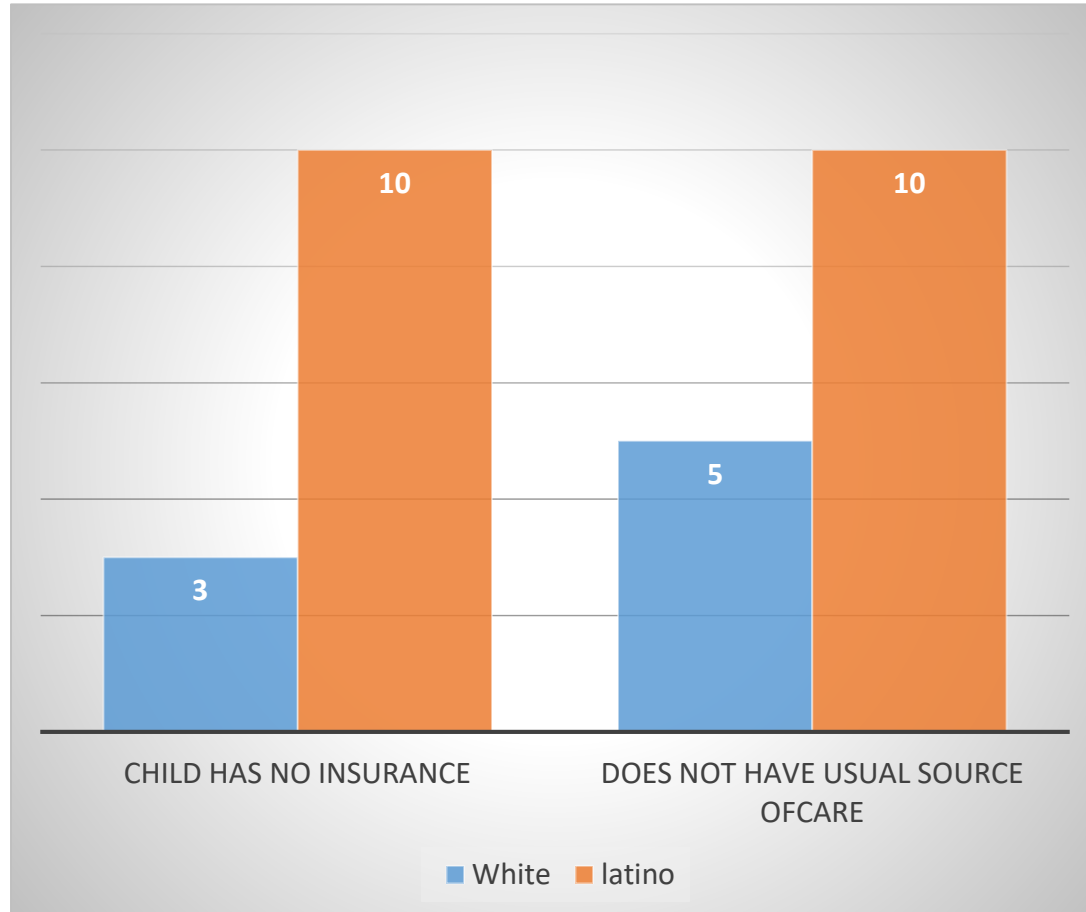
■ Hispanic/Latino

■ Non-Hispanic White

Prevalence of 8-year old children across surveillance sites, based on review of educational and/or medical records

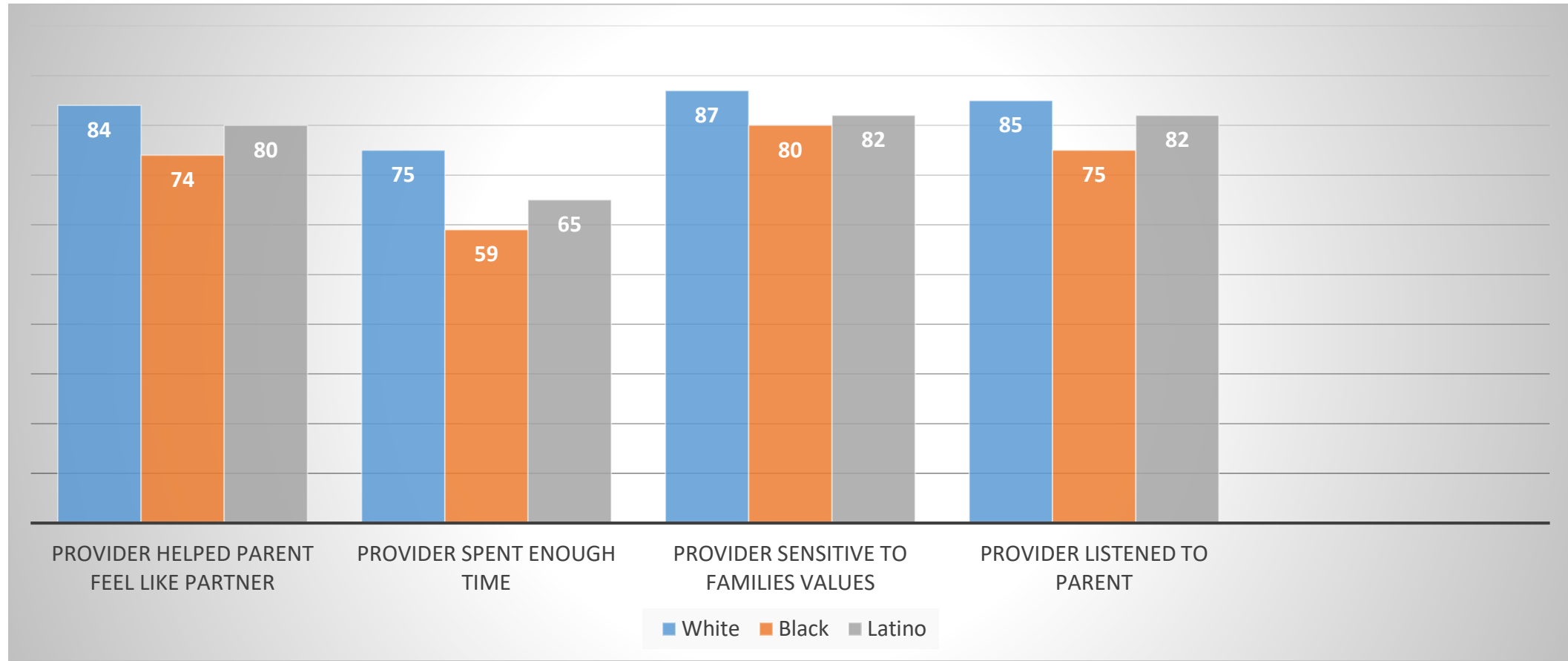
Disparities in health care access, utilization, and services

national survey of children with special health care needs, 2006 (Parish, Magaña, rose & Timberlake, 2012)



Disparities in Health Care Quality

(National Survey of Children with Special Health Care Needs, 2010)



Disparities in Specialty Services



Less Access to ABA



Greater need does not
equal more services



Fewer therapy hours and
more unmet therapy needs

Reasons for Disparities

Bias and lack of cultural training among providers

- Help parents feel more respected
- Limited bilingual and bicultural providers
- Providers often do not focus on specific barriers (e.g., transportation language, literacy levels, resources)

Limited social capital of low income and racial and ethnic groups

- Lack of information and knowledge about autism and treatments
- Language barriers
- Fewer resources to seek out and access best services
- Lack of trust of providers

Lack of trained professionals and specialized diagnostic and treatment services

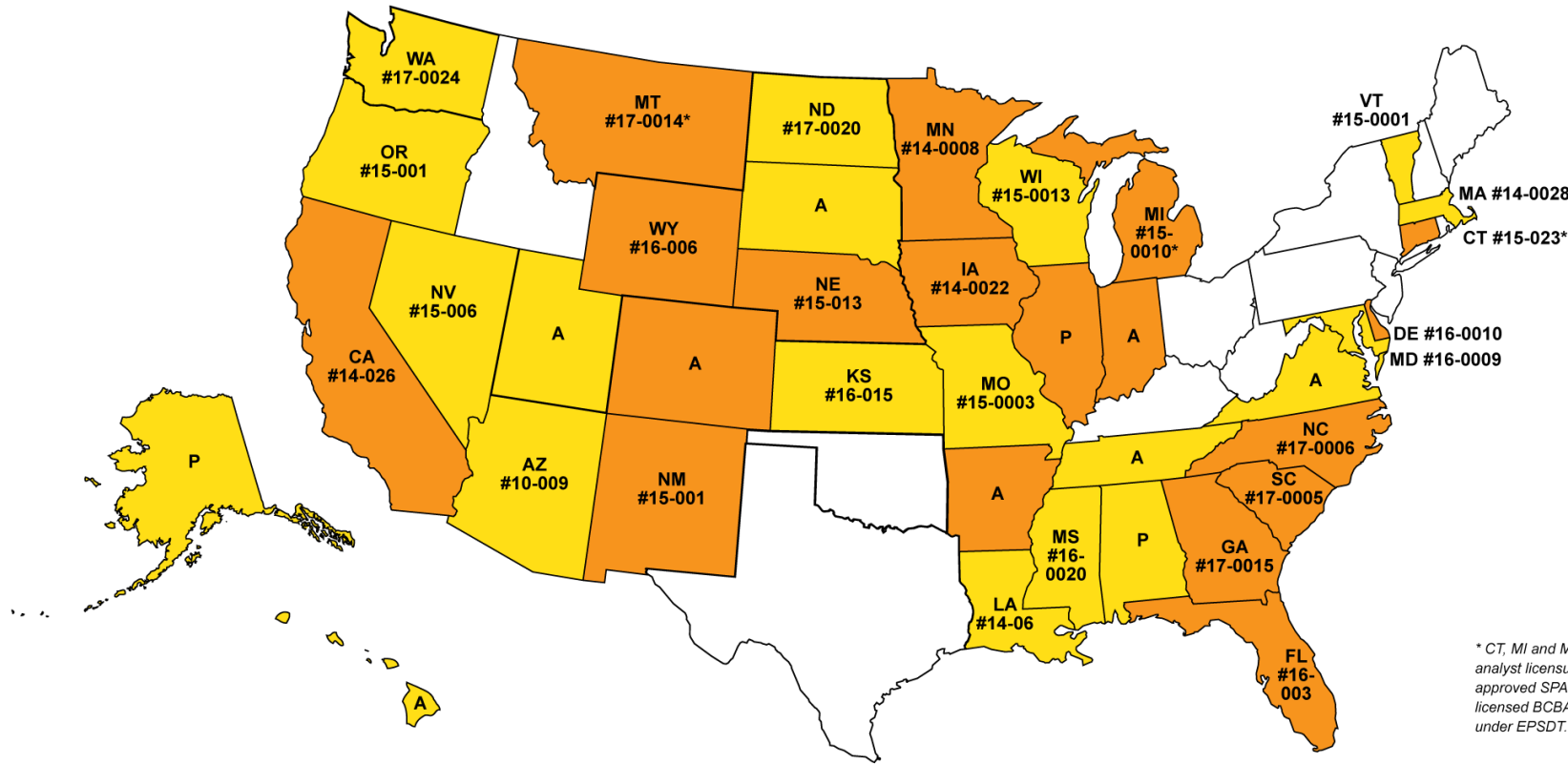
- Diagnosis and treatment is so specialized, it is expensive which increases disparities
- Need to train community providers to contribute to diagnosis and treatment

Policy Programs

- Coverage of evidence based treatments vary by states
- Medicaid is a main source of healthcare for low income children
- Medicaid does not cover ABA for example in many states

Medicaid (EPSDT) Coverage for ABA

Policies to Reduce Disparities: Medicaid Coverage of ABA



* CT, MI and MT enacted behavior analyst licensure after CMS approved SPAs allowing for non-licensed BCBAs to provide service under EPSDT.

- XX #00-0000** CMS has approved State Plan Amendments (SPAs) in **14 states** that allow for ABA to be provided by **non-licensed** Board Certified Behavior Analysts (BCBAs).*
- A or P** SPAs were not filed but state regulations have been adopted (A) or are pending (P) which otherwise recognize **non-licensed** BCBAs as approved Medicaid providers of ABA.
- XX #00-0000** CMS has approved SPAs in **13 states** that include **licensed** behavior analysts among providers approved to deliver ABA services.
- A or P** SPAs were not filed but state regulations have been adopted (A) or are pending (P) which otherwise recognize **licensed** behavior analysts as approved Medicaid providers of ABA.
- White** Implementation of coverage for ABA under EPSDT is not actively progressing or the status is unclear.

From Autism Speaks website

Community Programs to Reduce Disparities

Navigator Programs

- Connected to clinic or provider
- Professional navigators
- Community health workers

Peer-Based Programs

- Social support and shared experiences
- Information sharing/navigation
- Bridge between provider and community

Psychoeducational Programs and Parent Groups

- Culturally designed or tailored
- Address gap in knowledge and information

Parent Training/Coaching

- Teach parents evidence-based intervention strategies
- Need to be culturally tailored

Parents Taking Action: A psychoeducational program for Latino parents of children with ASD

Advisory group
formulating ideas



Promotora Model



Curriculum

Psychoeducation	Advocacy & Parent Support	Evidence-based strategies
Understanding child development	How to be an effective advocate	Play together, learn together
Understanding the autism spectrum and your child's needs	Advocacy in the school system	Creating everyday opportunities to encourage communication
What works to address symptoms of autism	Reducing stress and recognizing signs of depression	Helping your child make friends and interact with others
	Talking about autism to others and social support	Understanding and reducing challenging behaviors

Outcomes

Parents feeling empowered



Parents using EB strategies



Children accessing more EB services

Reduction in social communication problems

Adaptation and dissemination

For African American community in Baltimore, pilot being implemented

For California context to reduce disparities in Regional Center

Internationally in Bogota Colombia

Translated and adapted for Chinese Americans in Chicago

Next step: Addressing disparities through policy and scale-up

- Address policy issues such as Medicaid coverage of evidence-based care
- Create funding mechanisms to implement community-based solutions such as Parents Taking Action
- Fund research to develop evidence-based programs and services that reduce disparities, i.e., innovative, low cost ways to diagnose and treat ASD