AUTISM SPEAKS®

Autism Awareness Interagency Roundtable Indian Health Service

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AUTISM SPEAKS®

Enhancing lives today and accelerating a spectrum of solutions for tomorrow

Autism Speaks Mission Objectives

Through partnerships and collaboration, we are committed to:

- Increasing global understanding and acceptance

- Being a catalyst for research breakthroughs

- Increasing early childhood screening and timely interventions

- Improving the transition to adulthood

- Ensuring access to reliable information and services throughout the life span

Presentation Outline

- Review behavioral characteristics associated with Autism Spectrum Disorder (ASD)

- Benefits of early identification & intervention

- Barriers & disparities

- Autism Speaks Public Health Initiatives

Behavioral characteristics associated with ASD

Impairments in Social Communication and Interaction

DSM-5 Criteria:	Behavioral Characteristics
Lack of social-emotional reciprocity	• Recognizing own and others emotions • Abnormal social approach • Reciprocal conversation • Showing objects • Giving objects • Wanting others to be excited when they are excited

Impairments in Social Communication and Interaction

DSM-5 Criteria:	Behavioral Characteristics
Lack of nonverbal communicative behaviors used for social interaction	•Eye contact during social interactions •Joint attention •Facial expressions •Gestures use (e.g. waving, pointing, shaking/nodding head)
Difficulty developing, maintaining, and understanding relationships	•Interest in other children-watching them play, playing near other children, trying to get their attention, friendships adjusting behavior to fit social context

Repetitive Behaviors/Restricted Interests

DSM-5 Criteria:	Behavioral Characteristics
Stereotyped and repetitive motor movements, use of objects, or speech	• Hand posturing/twisting • Hand/arms flapping • Spinning • Echolalia • Lining up objects
Insistence on sameness	• Difficulty with transitions • Anxiety with change in routine • Examples: putting clothes on in specific order, following same routine to school, eat same foods everyday

Repetitive Behaviors/Restricted Interests

DSM-5 Criteria:	Behavioral Characteristics
Highly restricted, fixated interests that are abnormal in intensity or focus	• May be an odd object/interest or intense interest in age-appropriate object/interest • May interfere with functional activities • Shifting attention away from special interest is often difficult
Hyper or hyporeactivity to sensory input	• Adverse response to sounds or textures • Excessive smelling • Apparent indifference to pain/temperature

Benefits of Early Identification and Intervention

Benefits of Early Identification and Intervention

(Wong, Odom, Hume, Cox, Fettig et al, 2015)

- Comprehensive Treatment Models
  - Set of practices designed to achieve broad impact on core deficits of ASD
  - Examples: UCLA Young Autism Program, Pivotal Response Training, TEACCH, LEAP model, Denver model

- Focused intervention practices
  - Designed to address single skills, building blocks for comprehensive models
  - Examples: Discrete Trial Teaching, prompting, PECS, DRO, FBA, naturalistic intervention, parent-implemented intervention

Benefits of Early Identification and Intervention

- Children with ASD who receive intervention see gains in development
  - Increases in developmental level/IQ
  - Improvements in speech-language functioning
  - Improvements in social-communication behaviors
  - Improvements in daily living /adaptive functioning
  - Decreases in challenging behaviors

Barriers and Disparities

A Lifetime of Disparity

Access to mental health services across the lifespan in the US

Autism Spectrum Disorder Among US Children (2002–2010): Socioeconomic, Racial, and Ethnic Disparities

Maureen S. Durkin, PhD, DrPH, MPH, Matthew J. Maenner, PhD, Jon Baio, EdS, Deborah Christensen, PhD, Julie Daniels, PhD, Robert Fitzgerald, PhD, Pamela Imm, MS, Li-Ching Lee, PhD, Laura A. Schieve, PhD, Kim Van Naarden Braun, PhD, Martha S. Wingate, DrPH, and Marshalyn Yeargin-Allsopp, MD

- Population-based analysis of the CDC's Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network
- Diverse geographic locations in the US
- 8 year old children who meet the diagnostic criteria for ASD
- Race/ethnicity categories: nh-white, nh-black, Hispanic; Other

A Lifetime of Disparity

Access to mental health services across the lifespan in the US

- A positive SES gradient in ASD prevalence was present over the study period, creating the appearance that there is higher prevalence in high SES communities
- Racial and ethnic disparity in ASD prevalence persisted over the study period, particularly but not exclusively among children in low-SES communities
- Prevalence among Native American communities is unknown

Implications:
- Awareness and resources remain key factors for accurate diagnosis
- Negative impacts of poverty and race are additive

Social determinants of health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment	Housing	Literacy	Hunger	Social integration	Health coverage
Income	Transportation	Language	Access to healthy options	Support systems	Provider availability
Expenses	Safety	Early childhood education		Community engagement	Provider linguistic and cultural competency
Debt	Parks	Vocational training		Discrimination	Quality of care
Medical bills	Playgrounds				
Support	Walkability	Higher education			

Health Outcomes
Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

Autism Speaks Public Health Initiatives

Autism Speaks Public Health Science

Goal

Deliver innovative people-centered programs and policy solutions that are:

- **Relevant**: Responsive to stakeholder priorities; equity focused

- **Feasible**: Realistic in various cultural, social and system contexts

- **Efficient/Effective**: Evidence-based, with measurable impact

- **Sustainable**: Sustained financing and integration into existing system of care

A Global Perspective

What do we know about autism worldwide? Extreme global knowledge disparity
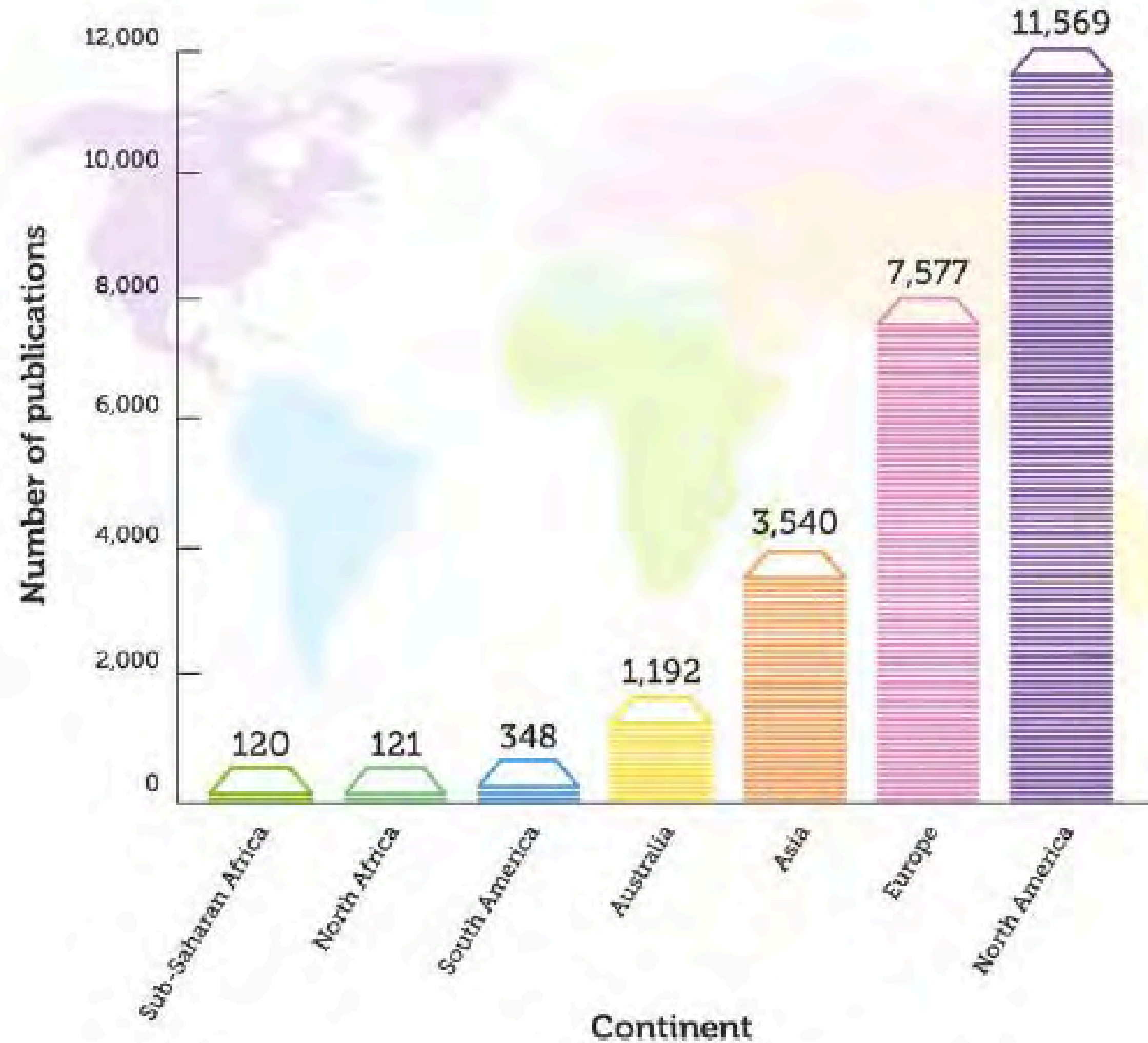
A Global Perspective

Shared challenges and learning together

☐ >90% of our families live in LMIC, where the "treatment gap" is typically >90%

☐ Though vastly different communities, many of the challenges are the same, including those found in underserved communities in the US (e.g., access, quality, costs)

Main Barriers to Progress –
- *Lack of awareness*
- *Stigma*
- *Lack of expertise/capacity*
- *Lack of evidence (more than prevalence…)*

We can support them as we learn from them: Unique and vastly more efficient opportunities to address key scientific questions

Global Autism Public Health (GAPH) Initiative
Collaborative Activities in >70 Countries (2016)
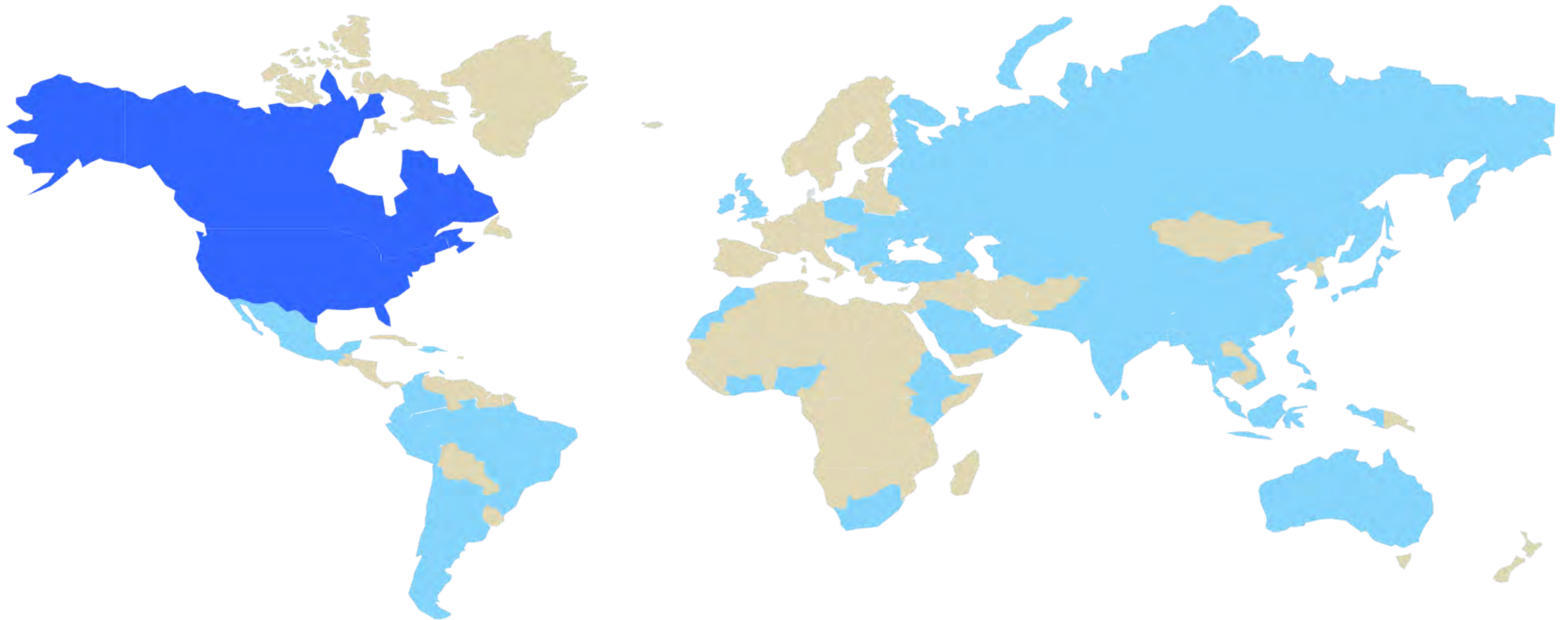
Advocacy Leadership Network (ALN)

A Global Network of Accomplished Advocates

Members are respected local leaders with record of innovation and facilitating change.

They are self-advocates, caregivers, professionals, policy-makers, friends and families.
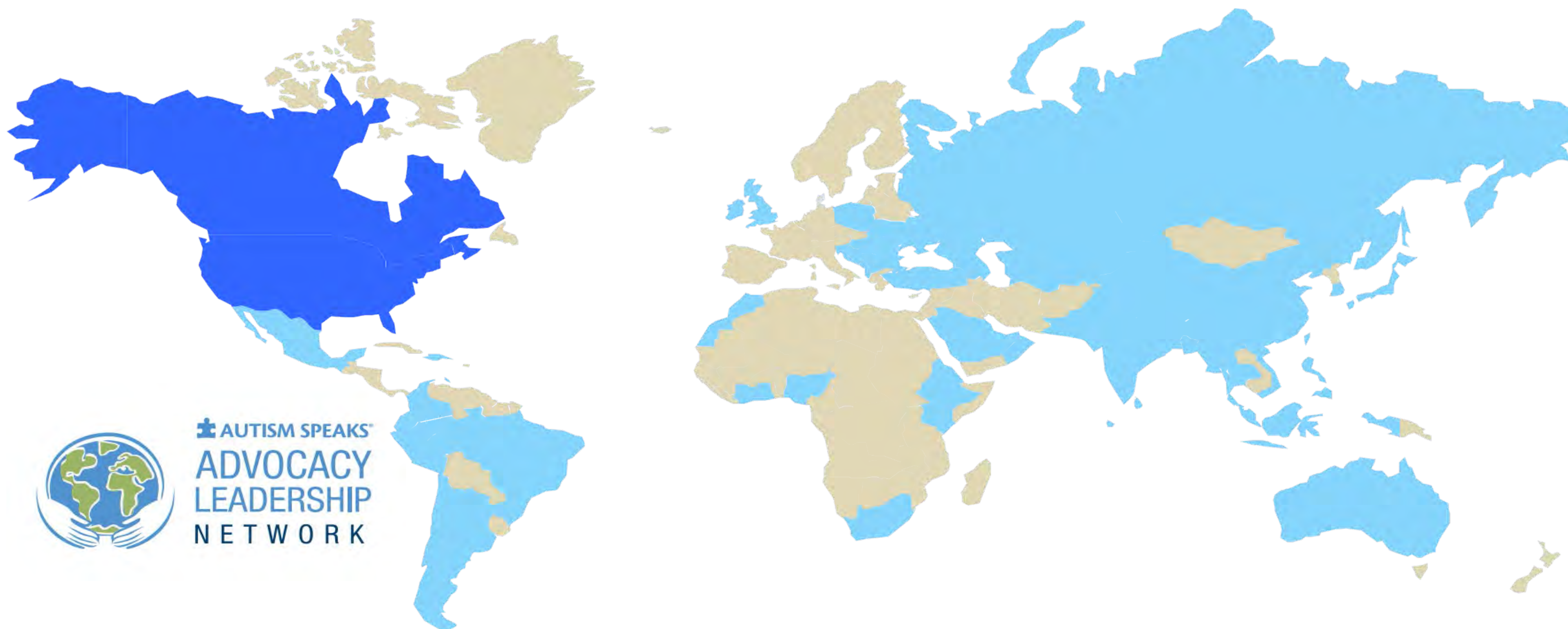
Continuous social media interactions; Biennial meetings to facilitate knowledge exchange/transfer and collaboration.

High impact network collaboration (e.g., WHA)

Advocacy Leadership Network (ALN)

52 Countries are Members of the ALN (2016)

National African American Autism Community Network (NAAACN)

NAAACN

NATIONAL AFRICAN AMERICAN
AUTISM COMMUNITY NETWORK

- Approximately a dozen grassroots organizations

- Autism from an AA perspective

- Cultivate, leverage and sustain community support via partnerships

- Prioritizing knowledge dissemination and stakeholder mobilization

- Aim to become a sustainable go-to community resource to help enhance well-being and outcome

- Stakeholders-led; Autism Speaks provides catalytic funding and technical support, including data collection and impact evaluation
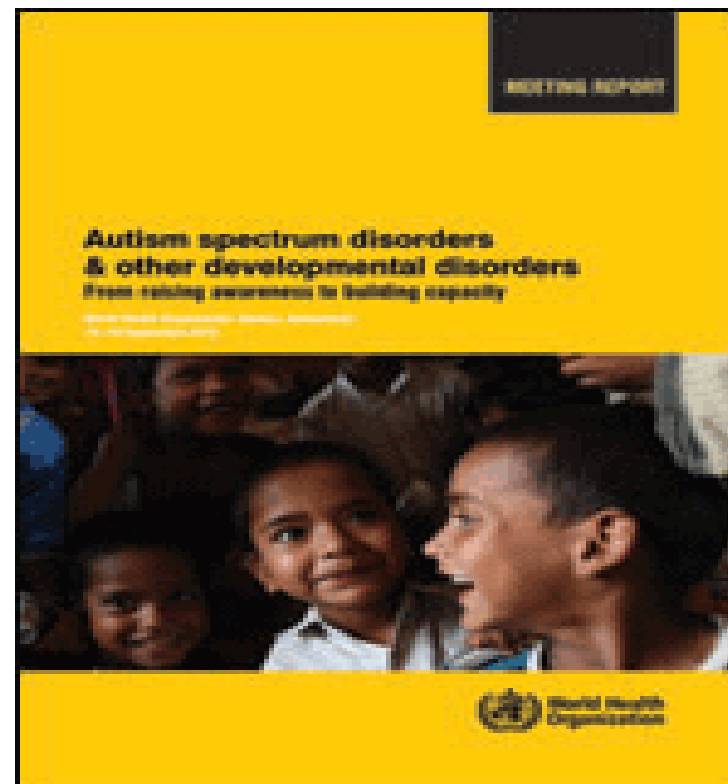
- Four Town Halls scheduled for 2018

Next Generation of ASD Diagnostics

Open Source Screening and Diagnostic (OSSDx) tool for ASD

Case for Open Source Tools:

- *Average costs of Gold Standard diagnosis is ~US$2,000*
- *A majority of per capita health expenditure in LMIC < US$300*

REVIEW ARTICLE

Autism Screening and Diagnosis in Low Resource Settings: Challenges and Opportunities to Enhance Research and Services Worldwide

Maureen S. Durkin, Mayada Elsabbagh, Josephine Barbaro, Melissa Gladstone, Francesca Happe, Rosa A. Hoekstra, Li-Ching Lee, Alexia Rattazzi, Jennifer Stapel-Wax, Wendy L. Stone, Helen Tager-Flusberg, Audrey Thurm, Mark Tomlinson, and Andy Shih

Next Generation of Behavioral Interventions

WHO Caregiver Skills Training program (CST)

World Health Organization

AUTISM SPEAKS®

World Health Organization
Parent Skills Training for Caregivers
of Children with Developmental
Delays and Disorders

A new package for capacity building - developed in
collaboration with Autism Speaks®

Examples of countries
conducting
pilots and RCTs:

*China (RCT) - Multisite
South Korea
Malaysia - Education
Russia
Romania
Ethiopia
Egypt
Jordan – Syrian camp
Peru
Pakistan (RCT) – Scale
USA – Newark*

...

The PST programme

Caregivers meet every two weeks for 10 group sessions

… to reflect on their child's strengths and difficulties
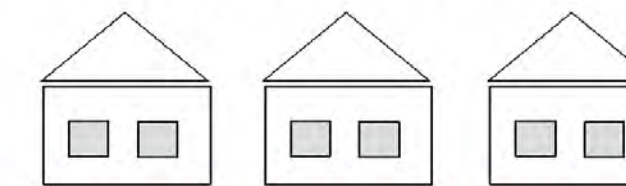
… to share their difficulties as caregivers

…and work on their personal goals

In **group sessions**, facilitators describe and show **psychoeducational strategies**…

…while **three home visits** are used to tailor the intervention and coach caregivers

The strategies taught aim to promote the development of…

….communication

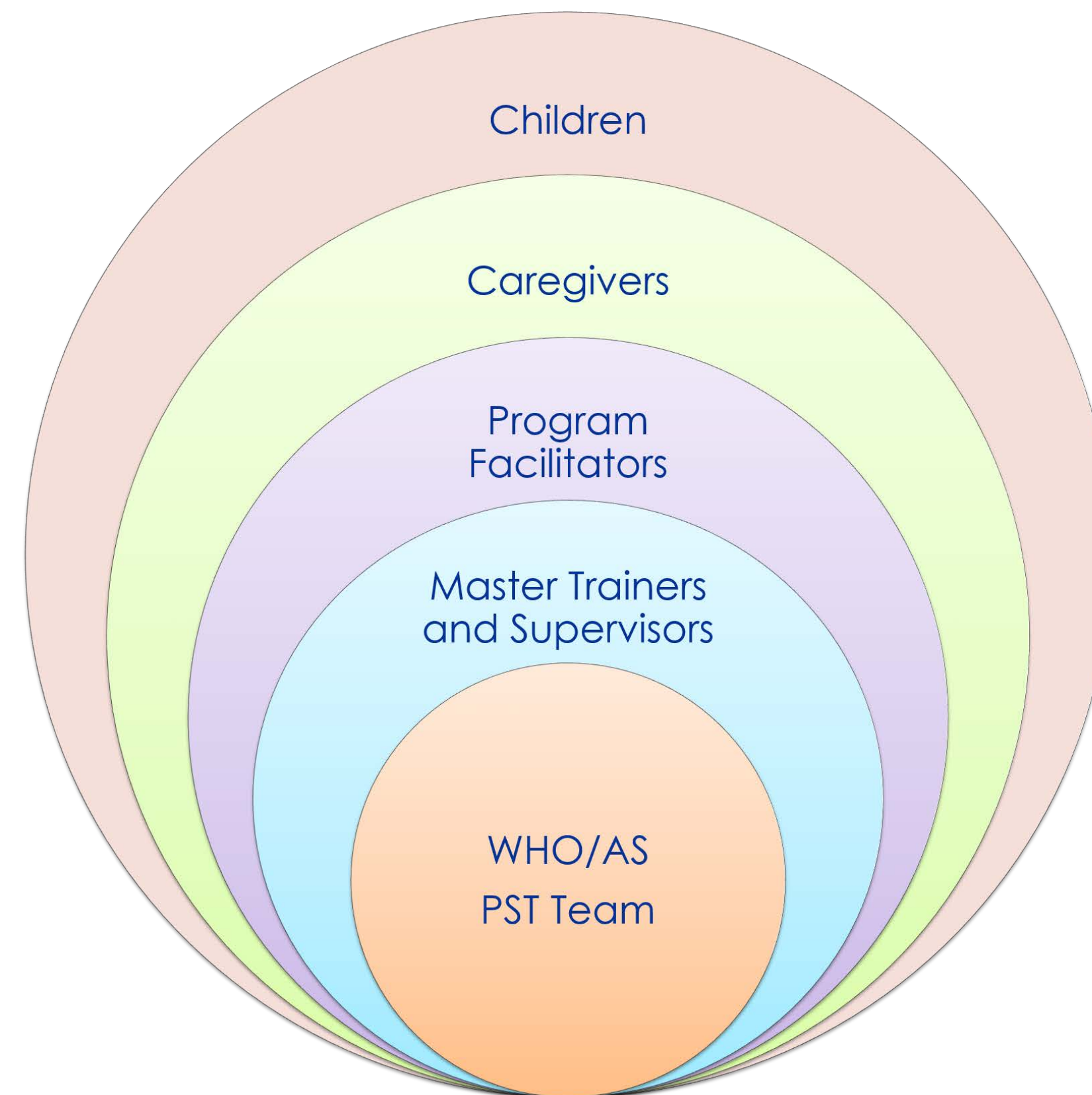… **life skills**

… **inclusion** and **social engagement**

[illustrations taken from the PST Participant Manual; artwork by Miguel Mendez]

Courtesy: WHO

Empowering Caregivers

WHO Parent Skills Training program (PST)

- 30 countries

  -Select countries (est. Treatment gap > 95%)

- 2 US communities:

  -Newark, Latino community

  -New York City, Chinese community

*Source: World Bank

Conclusion

Answers and empowerment through public health research

- There is tremendous knowledge disparity within the global autism community that hampers our ability to provide support and promote best outcomes

- The knowledge disparity is pronounced in LMIC as well as in underserved communities in HIC

- In HIC, systems of care are inefficient and quality of care is uneven

- For many of these low resource settings, even a modest investment in knowledge and capacity could lead to transformational changes for affected individuals and families

- We have proven development strategies and effective tools (e.g., GAPH) to begin iterative learning and implementation processes to establish evidence-based services in even the most challenging settings (e.g., rural Ethiopia, Syrian refugee camps)

- We can reduce inefficiency and accelerate progress in LMIC and HIC through public health-driven learning, implementation and evaluation collaborations

Thank you!

"Families Are @ the Heart of Everything We Do"