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

<table>
<thead>
<tr>
<th>DSM-5 Criteria:</th>
<th>Behavioral Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of social-emotional reciprocity</td>
<td>• Recognizing own and others emotions</td>
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<td></td>
<td>• Abnormal social approach</td>
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<tr>
<td></td>
<td>• Reciprocal conversation</td>
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<td></td>
<td>• Showing objects</td>
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<td></td>
<td>• Giving objects</td>
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<td>• Wanting others to be excited when they are excited</td>
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</tbody>
</table>
## Impairments in Social Communication and Interaction

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<th>DSM-5 Criteria:</th>
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| 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

<table>
<thead>
<tr>
<th>DSM-5 Criteria:</th>
<th>Behavioral Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stereotyped and repetitive motor movements, use of objects, or speech</td>
<td>• Hand posturing/twisting</td>
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<td>• Hand/arms flapping</td>
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<td></td>
<td>• Spinning</td>
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<td></td>
<td>• Echolalia</td>
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<tr>
<td></td>
<td>• Lining up objects</td>
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<tr>
<td>Insistence on sameness</td>
<td>• Difficulty with transitions</td>
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<tr>
<td></td>
<td>• Anxiety with change in routine</td>
</tr>
<tr>
<td></td>
<td>• Examples: putting clothes on in specific order, following same routine to school, eat same foods everyday</td>
</tr>
</tbody>
</table>
# Repetitive Behaviors/Restricted Interests

## DSM-5 Criteria:

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</table>
| 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

Maureen S. Durkin, PhD, DrPH, MPH, Matthew J. Maunder, 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 Yeatman-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
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

<table>
<thead>
<tr>
<th>Economic Stability</th>
<th>Neighborhood and Physical Environment</th>
<th>Education</th>
<th>Food</th>
<th>Community and Social Context</th>
<th>Health Care System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>Housing</td>
<td>Literacy</td>
<td>Hunger</td>
<td>Social integration</td>
<td>Health coverage</td>
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<tr>
<td></td>
<td>Income</td>
<td>Language</td>
<td>Access to healthy options</td>
<td>Support systems</td>
<td>Provider availability</td>
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<tr>
<td></td>
<td>Expenses</td>
<td>Early childhood education</td>
<td>Higher education</td>
<td>Community engagement</td>
<td>Provider competency</td>
</tr>
<tr>
<td></td>
<td>Debt</td>
<td>Vocational training</td>
<td>Education</td>
<td>Discrimination</td>
<td>Quality of care</td>
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<tr>
<td></td>
<td>Medical bills</td>
<td>Higher education</td>
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<tr>
<td></td>
<td>Support</td>
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## Health Outcomes
- Mortality
- Morbidity
- Life Expectancy
- Health Care Expenditures
- Health Status
- Functional Limitations
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

Sources: Franz et. al. (2017)
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

A Global Collaboration to Enhance ASD Research, Practice and Policy

Support local leaders to address local priorities, using locally-customized solutions

- Public and Professional Awareness
- Advocacy
- Public Health Research
- Tool development
- Services and Policy Development
- Dissemination and Implementation

Global Autism Public Health (GAPH) Initiative

Global Autism Public Health Initiative

Advocacy Leadership Network
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)

- 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
WHO Caregiver Skills Training program (CST)

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

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®

Next Generation of Behavioral Interventions
The PST programme

Caregivers meet every two weeks for 10 group sessions... 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)
Global Reach of CST Implementation

• 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.
“Families Are @ the Heart of Everything We Do”