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International Autism Scientific Opportunities and Development: An Overview

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Why International Efforts?




- To find and deliver answers to affected individuals and families around the world
- Unique opportunities to address key scientific questions and priorities in causes, diagnosis/treatment, and dissemination that are also relevant to priorities of the US

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Why International Efforts?

Key Scientific Questions and Opportunities

- Epidemiology: What can we learn about autism risk factors by comparing prevalence and incidence around the world?
- Environmental Sciences: Can we identify environmental risk factors (e.g. toxicants, diet, infectious agents, etc.) by comparing exposures across countries? 
- Genetics: Are there population-specific genetic risk factors? (e.g. do Europeans and Africans have the same genetic risk factors?) Other populations (e.g. Middle East) offer unique opportunities for discovering autism risk genes.

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Why International Efforts?

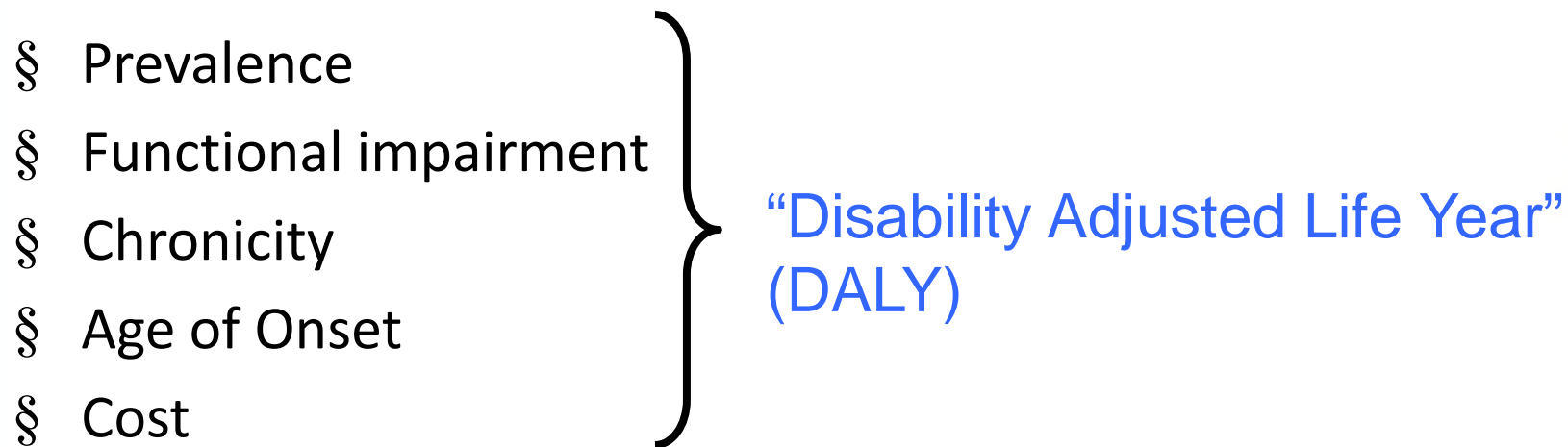
Key Scientific Questions and Opportunities

- Diagnosis and treatment: How do culture and social norms impact recognition/diagnosis and treatment?
- Dissemination: What is the best way to implement and sustain best practices, even in places with limited resources and capacity?



Measuring the Global Autism Public Health Challenge

World Health Organization “Burden of Disease”



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- Autism > Type 1 Diabetes, childhood leukemia, CF
 - Costs to society in US: ~\$35B/yr
 - Costs to families are immeasurable

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Global Challenges to Progress

- Lack of public health statistics
- Lack of public and professional awareness
- Lack of training and expertise
- Stigma



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Strategies for addressing these challenges Involve the following: *

- Increase public and professional awareness of ASD
- Implement efforts that facilitate collaborative research and research training
- Address immediate needs by enhancing service delivery via training in diagnosis and intervention




**From Autism Speaks Global Autism Public Health (GAPH) Initiative Strategic Plan, 2008*

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Key tactics for addressing challenges*

- Prioritize and coordinate activities in awareness, research and service development
- Local ownership of efforts; Outside experts serve as advisors and facilitators. Priority set by local stakeholders (e.g. service development vs. awareness, epidemiology vs. genetics, etc.) 
- Driven by collaboration with local government, professionals and families
- Adapt evidence-based solutions to accommodate cultural/social factors, and available resources and infrastructure

**From Autism Speaks Global Autism Public Health (GAPH) Initiative Strategic Plan, 2008*

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Countries in which collaborative efforts with Autism Speaks are underway to develop awareness, research, and services :

- Qatar (*Shafallah Center for Children with Special Needs*)
- Mexico (*Carso Health Institute/Telmex, CLIMA, MoH*)
- Albania (*Albanian Children's Foundation, MoH, MoE*)
- Ireland (*Irish Autism Action*)
- Philippines (*Autism Hearts Foundation, First Gentleman's Foundation, Autism Society of Philippines*)
- Chile (*MoH*)



Scientific Opportunity: **Epidemiology**

- Goals:

- Enable epidemiological studies to allow comparison of statistics across countries, and to identify potential environmental risk factors
- Generate public health statistics to inform policy development

- Main Barriers:

- Limited availability of translated/adapted “gold standard” screening and diagnostic instruments
- Lack of clinical expertise



Scientific Opportunity: **Epidemiology**

■ Progress:

- Screening and diagnostic instruments have been adapted in languages spoken by 1.75 billion people
- A standardize international training program for the use of screening and diagnostic instruments launched by UMACC, WPS, and Autism Speaks (e.g. NIMH collaboration in India)

Translations of diagnostic instruments completed or in progress

Country	Language
China/Taiwan	Mandarin
Korea	Korean
India	Hindi, Bengali, Marathi, Konkani
Bangladesh	Bengali
Saudi Arabia/Egypt/Qatar	Arabic
South Africa	Zulu



Scientific Opportunity: **Epidemiology**

- Progress (continued):
 - International Autism Epidemiology Network (>100 members from 30 countries) to facilitate sharing, collaboration (e.g. iCARE), and mentoring (CDC-Autism Speaks collaboration)
 - Epidemiology studies in South Korea, India, Taiwan, South Africa (add-on to NIH HIV/AIDS project), and Ireland (Autism Speaks sponsored with support by CDC); Studies are in development in Mexico, Albania, and Philippines



Scientific Opportunity: Genetics

- Goal:
 - Enhance the identification and understanding of genetic risk factors in different populations around the world.
- Main Barriers:
 - Lack of adapted “gold standard” screening and diagnostic instruments for case ascertainment
 - Limited capacity, especially in molecular and statistical genetics



Scientific Opportunity: Genetics

- Progress:

- Autism Genome Project , successful international research consortium involving participants from 19 countries (funded by Autism Speaks, NIH, Genome Canada, CIHR, MRC, HRB, & Hilibrand Foundation)
- Diagnostic instrument adaptation and clinical/research training (e.g. MENA ADI-R translation and adaptation effort)
- Research collaborations (e.g. Autism Genetics in Special Populations Meeting funded by NIMH and Autism Speaks, Qatar-AGP collaboration)



Scientific Opportunity: **Diagnosis & Treatment**

- Goal:
 - Enable early diagnosis and intervention worldwide
- Main Barriers:
 - Lack of adapted “gold standard” screening and diagnostic instruments
 - Limited capacity and expertise, especially in behavioral intervention
 - Lack of low-cost, community-based treatment solutions to maximize coverage and impact



Scientific Opportunity: **Diagnosis & Treatment**

- Progress:

- Infant siblings research in US (funded by NICHD and Autism Speaks) and UK (funded by MRC and others), with expansion into Europe and other territories planned

- Pan American Autism Awareness and Training Initiative (PAAATI) a collaboration among Carso Health Institute (Mexico), NICHD/NIH, CIHR (Canada), AAP, Autism Speaks, and the CDC.



Scientific Opportunity: **Diagnosis & Treatment**

- Progress (continued):
 - Development of screening and diagnosis research (e.g. MENA newborn screening meeting with Shafallah Center, Hamad Medical Corporation, Autism Speaks, and NICHD/NIH)
 - With the WHO, exploring partnership efforts aimed at disseminating evidence-based information and implementing cost-effective and feasible solutions to the global autism community in the context of WHO's mhGAP Action Program (child mental health priority)



Scientific Opportunity: **Diagnosis & Treatment**

- Progress (continued):
 - Diagnosis training (Qatar, Saudi Arabia, Albania)
 - Intervention/services training; developing and piloting community-based, cost-effective training programs (Albania, Mexico)
 - Exploring distance learning technology for professional and parent training (Mexico)
 - Facilitate and implement DG Sanco-funded project to establish diagnosis and intervention standards in Europe (in collaboration with IAA)



Conclusions

- International development in autism research presents unique opportunities to address key scientific questions in multiple IACC priority areas.
- Outcome from these international efforts will benefit both the international and the domestic autism communities.
- While each country has its own priorities, common themes such as adaptation of screening and diagnostic instruments and capacity building in both research and services provide robust foundation for future development and collaborative activities.



Conclusions

- Investing in awareness, training, and service development helps build trust with partner communities and enhances the overall quality of research. It is the right/ethical thing to do.
- Progress is already being made in collaboration with NIH, CDC, and various IACC members. Additional investment and collaboration in international research and development by the NIH and CDC are needed to accelerate progress and enhance impact on the global autism community.



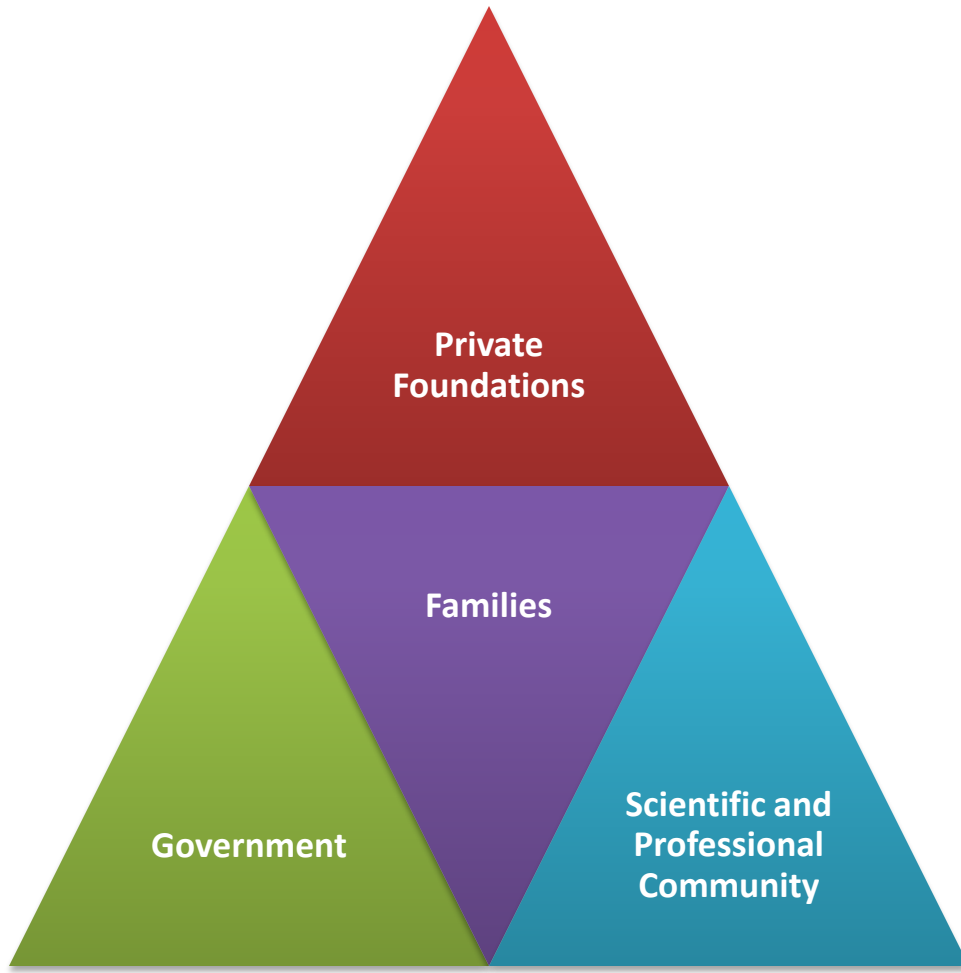
Thank You

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Together We Will Build a Better Tomorrow



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Thank You!