



AUTISM SPEAKS RESOURCE IN PUBLIC HEALTH

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About Autism Speaks



Mission

Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the lifespan, for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

Autism Speaks enhances lives today and is accelerating a spectrum of solutions for tomorrow.



About Autism Speaks



Co-Founders:

Bob & Suzanne Wright

Non-Profit Foundation Founded in 2005

Led by individuals and family members affected by autism

Core Mission Areas:

- ✓ Advocacy
- ✓ Awareness
- ✓ Family Support & Resources
- ✓ Scientific Research

“improve the lives of those affected by autism spectrum disorders worldwide”



Global Autism Public Health (GAPH) Initiative

A Global Collaboration to Enhance ASD Research, Policy, and Practice



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



GLOBAL AUTISM
PUBLIC HEALTH
I N I T I A T I V E



Public and Professional Awareness
Advocacy



Public Health Research
Tool development



Services and Policy Development
Dissemination and Implementation



 **AUTISM SPEAKS[®]**
**ADVOCACY
LEADERSHIP
NETWORK**

- Epidemiology (e.g. prevalence)
- Health economics (e.g. Cost of Autism)
- Risk factors (Genomics/MSSNG & EHS/EEARN)
- Enhance access to care
(screening/diagnosis/intervention)
- Adult and life-course support and research
- Capacity building
- Inclusion into life (community data-driven advocacy)

ASD Prevalence Globally

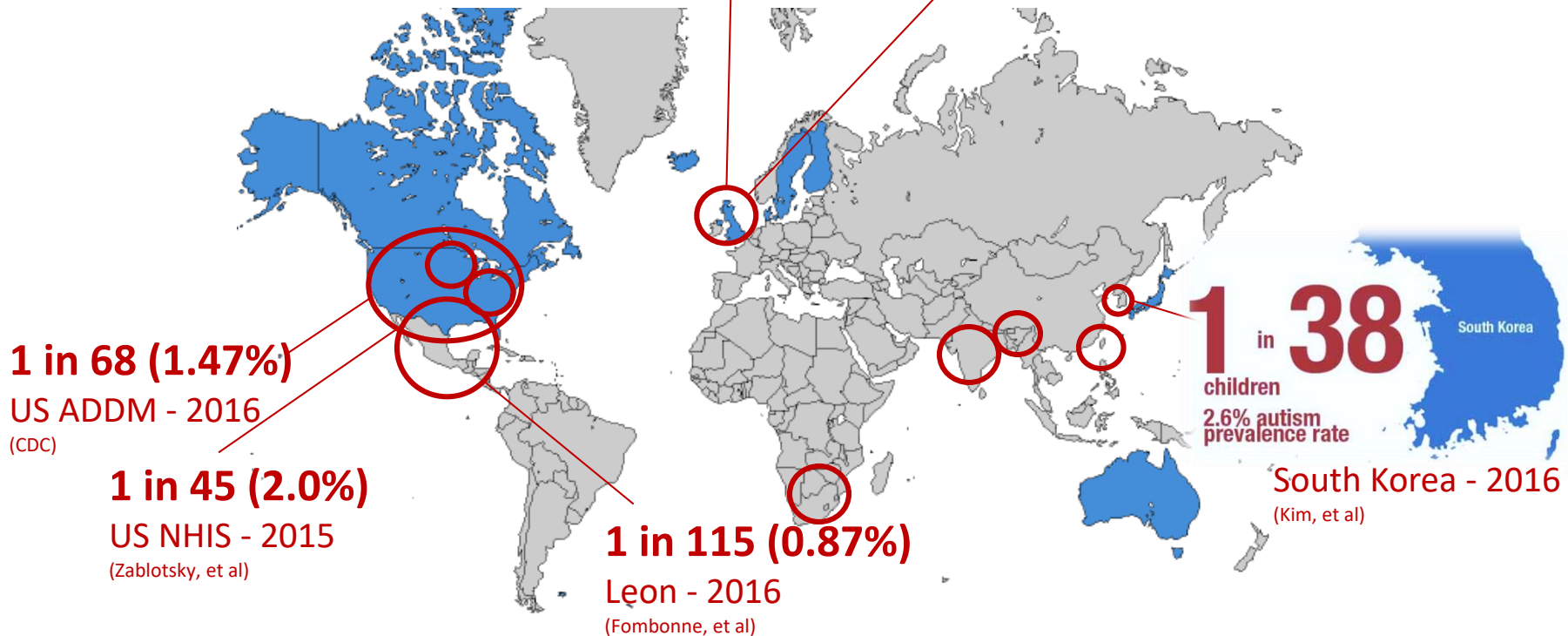


1 in 86 (1.2%)

UK - 2006
(Baird, et al)

1 in 64 (1.7%)

UK - 2009
(Baron-Cohen, et al)

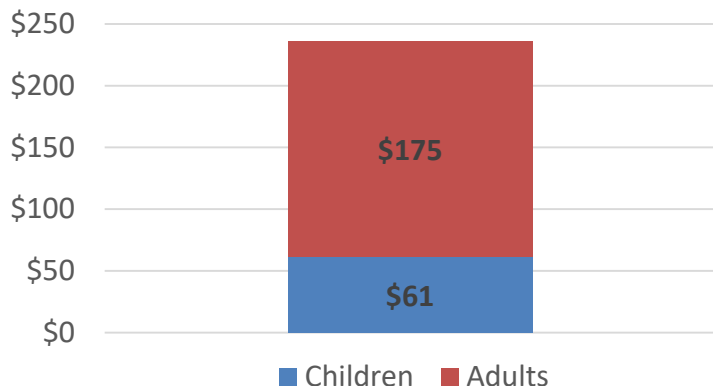


- Prior to 2010, most estimates from Western, developed countries
- Best estimates of global ASD prevalence 0.7 - 1%
- Recent estimates 2% or higher

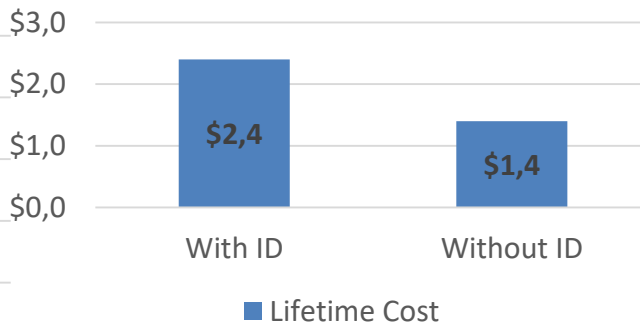
Cost of Autism



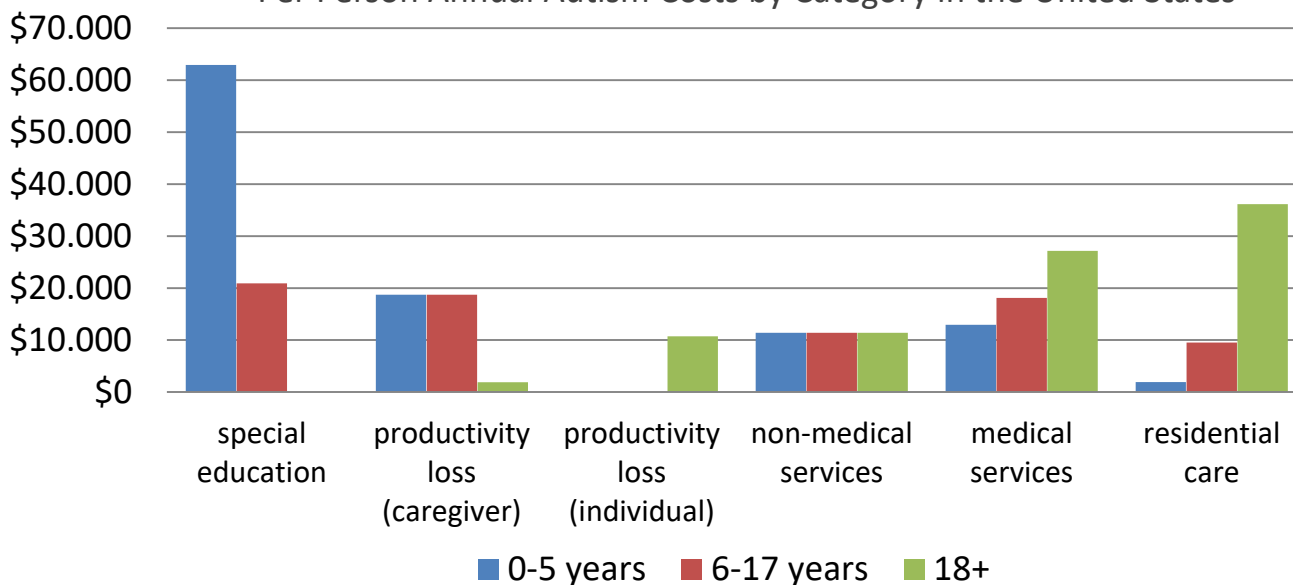
Annual Cost to US Society in Billions of \$USD



US Per Person Lifetime Cost in Millions of \$USD



Per Person Annual Autism Costs by Category in the United States

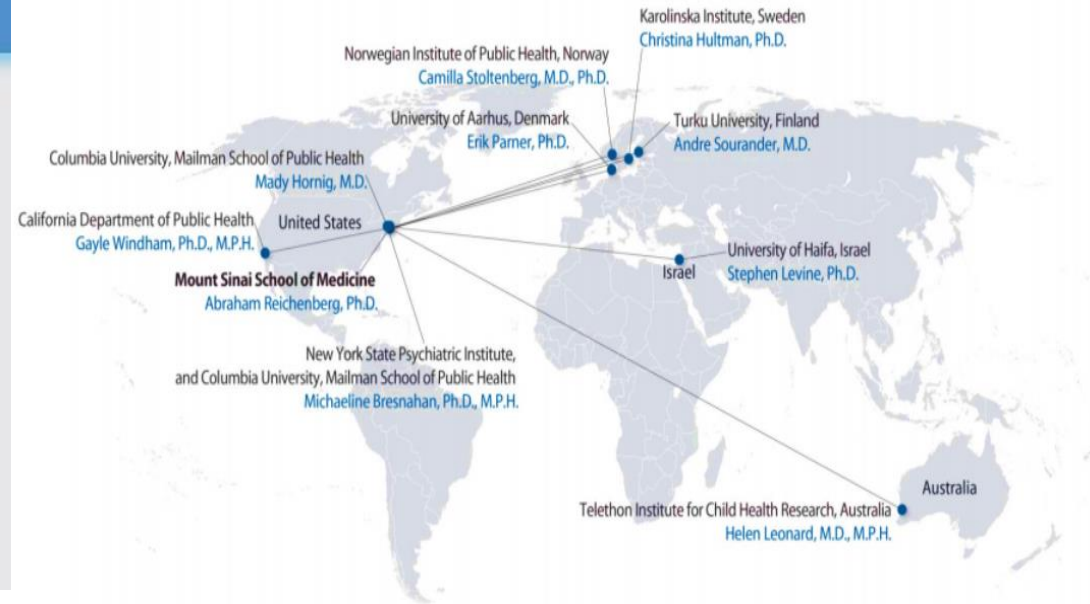


ASD Risk Factors Research



Open Science: 10,000 whole genomes from individuals with ASD and their families

ASD Risk Factors Research



- What factors may be truly contributing to the increase in ASD prevalence over time and differences between countries?
- World's largest multi-national network for environmental factor research linking registries from 7 countries includes more than 30,000 ASD cases
- Facilitating development of national autism registries (Ireland)
- Early Life Exposure Assessment Tool (ELEAT) to identify non-genetic, modifiable environmental factors across ASD research studies (EARN)
- High impact publications establishing air pollution and parental age as risk factors

- Advocated for American Academy of Pediatrics to screen all children for ASD
- Translation and/or validation of gold-standard diagnostic instruments into languages spoken by more than 1.5B worldwide (Mandarin, Hindi, Bengali, Marathi, Spanish)
- Costly, time consuming, requires specialized training; changing instruments (ADOS-2, DSM-5)
- Goal to develop open source, culturally relevant, adaptable, easy to use tools for clinical and research use, in context of broad NDDs (OSSDx)
- Piloting screening tool with World Bank and National Bureau of Statistics Nigeria as part of national household survey

REVIEW ARTICLE



AUTISM
RESEARCH

INSAR | International Society
for Autism Research

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

- Supported series of implementation science grants to adapt evidence-based services for use in low resource settings
- Through WHO partnership:
 - *Supported piloting of mhGAP Intervention Guide for Developmental Disabilities*
 - *Co-developed and piloting Parent Skills Training Program for Autism and Developmental Disabilities*

Effectiveness of the parent-mediated intervention for children with autism spectrum disorder in south Asia in India and Pakistan (PASS): a randomised controlled trial

Atif Rahman, Gauri Divan, Syed Usman Hamdani, Vivek Vajaratkar, Carol Taylor, Kathy Leadbitter, Catherine Aldred, Ayesha Minhas, Percy Cardozo, Richard Emsley, Vikram Patel*, Jonathan Green*

Summary

Background Autism spectrum disorder affects more than 5 million children in south Asia. Although early interventions have been used for the treatment of children in high-income countries, no substantive trials have been done of the interventions adapted for use in low-income and middle-income countries (LMICs). We therefore assessed the feasibility and acceptability of the parent-mediated intervention for autism spectrum disorder in south Asia (PASS) in India and Pakistan.



Lancet Psychiatry 2015

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Services Capacity Building



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®**



**Global Stakeholder
consultation**

**Community-based
Participatory Research**

**Countries conducting
Pilots and RCTs:**

*China (RCT)**

South Korea

*Malaysia***

Russia

Romania

Ethiopia

Egypt

Peru

*Pakistan (RCT)****

USA

...

Adults and Life Course



Adult prevalence

Access to care

Quality of life

Co-occurring conditions

Transition

Education

Employment

Residential Services

Life-course outcomes

Autism Researchers without Borders

Autism Speaks and the International Society for Autism Research (INSAR) enlist the support of autism researchers who wish to change the lives of millions affected by autism worldwide while advancing our understanding of autism risk factors, diagnosis and treatments.

Why?

It has been estimated that at least 1% of the global population has an autism spectrum disorder – more than 70 million individuals around the world. Even in places fortunate enough to have well-trained providers delivering evidence-based services, not all individuals will have adequate access to those services. In fact most will not. And many more will experience additional challenges related to stigma, economic hardship, or worse - human rights violations.

Why Else?

Keys to understanding the causes of autism and to developing new, broader-reaching autism services may lie in international research. Conducting research in different populations around the world creates unique opportunities to study autism, its risk factors, and its treatment in various socio-cultural and geographic conditions. Some nations have special resources and systems to generate rich datasets for autism research.

How?

In 2007, the United Nations named April 2nd World Autism Awareness Day. Since that time, as autism awareness around the world has grown, so has the demand for support - from parents, professionals, and governments. In response, Autism Speaks launched the Global Autism Public Health Initiative (GAPH) - a comprehensive and coordinated strategy to increase autism awareness, collect data for public health planning, and build capacity for services and research by facilitating collaboration, building on local efforts.



INSAR International Society for Autism Research

Who?

Anyone willing to travel and interact with international experts willing to share their expertise. GAPH relies on guidance from international experts willing to share their expertise in evidence-based science and considering innovative approaches to diagnosing and delivering that information.

What?

Volunteer researchers are rewarded with opportunities that can make an immediate difference in the lives of individuals and families from autism communities around the world. GAPH is custom-made to meet the specific needs of local communities with full consideration for cultural sensitivity and significance.

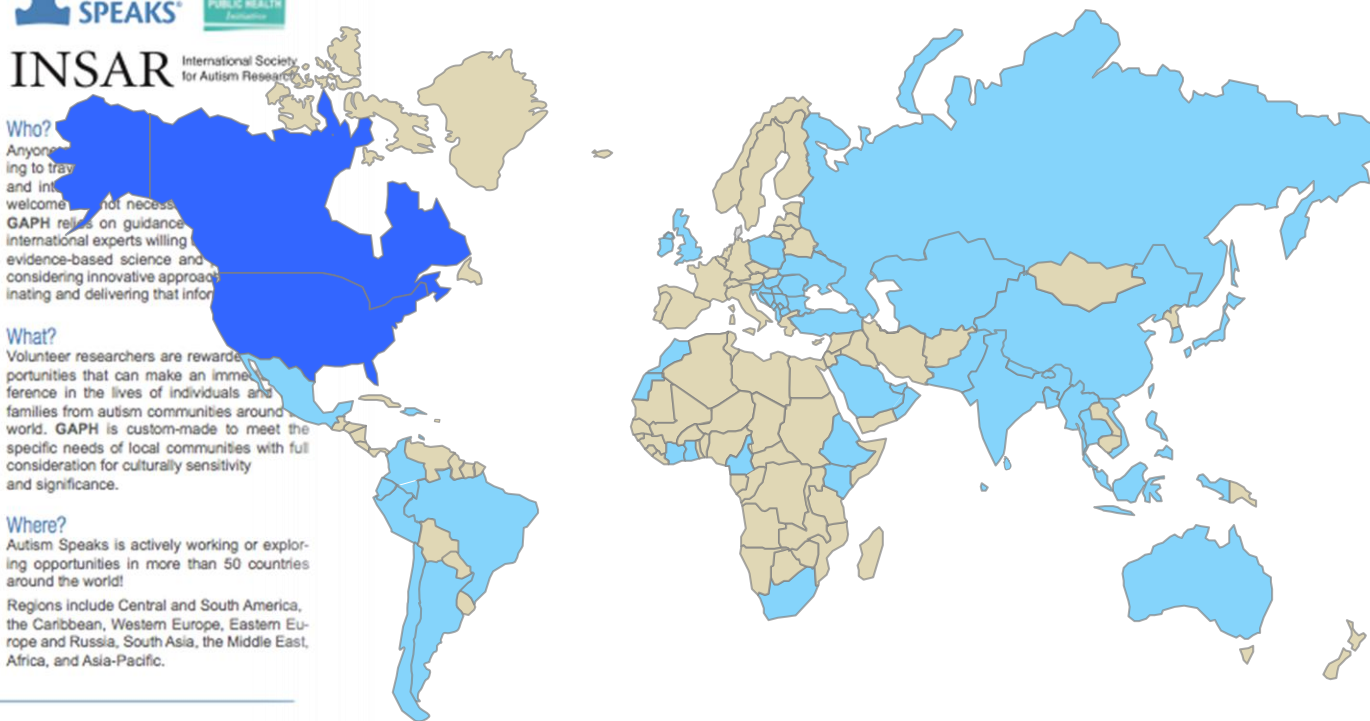
Where?

Autism Speaks is actively working or exploring opportunities in more than 50 countries around the world!

Regions include Central and South America, the Caribbean, Western Europe, Eastern Europe and Russia, South Asia, the Middle East, Africa, and Asia-Pacific.

When?

Today! If you are interested in learning more about this exciting new program please visit: AutismSpeaks.org/global



Partners in More Than 70 Countries Worldwide

Global Autism Awareness & Advocacy



United Nations

A/RES/62/139



General Assembly

Distr.: General
21 January 2008

Sixty-second session
Agenda item 66 (a)

Resolution adopted by the General Assembly on 18 December 2007

[on the report of the Third Committee (A/62/435)]

62/139. World Autism Awareness Day

United Nations

A/67/L.33



General Assembly

Distr.: Limited
5 December 2012

Original: English

Sixty-seventh session
Agenda item 127

**Addressing the socioeconomic needs of individuals,
families and societies affected by autism spectrum
disorders and other developmental disorders**

Afghanistan, Albania, Algeria, Angola, Azerbaijan, Bangladesh, Belarus, Benin, Bosnia and Herzegovina, Brazil, Bulgaria, Chile, Cyprus, Costa Rica, Dominican Republic, Ecuador, Eritrea, Georgia, Guyana, Haiti, Honduras, Iran (Islamic Republic of), Israel, Jordan, Kenya, Madagascar, Maldives, Nigeria, Panama, Peru, Philippines, Saint Kitts and Nevis, Saudi Arabia, Sri Lanka, Suriname, Tajikistan, Timor-Leste, Turkey, Ukraine and United States of America:
draft resolution

**Addressing the socioeconomic needs of individuals, families
and societies affected by autism spectrum disorders (ASD),
developmental disorders (DD) and associated disabilities**



**World Health
Organization**

**SIXTY-SEVENTH WORLD HEALTH ASSEMBLY
Provisional agenda item 13.4**

**A67/17
21 March 2014**

**Comprehensive and coordinated efforts for the
management of autism spectrum disorders**

Global Autism Awareness & Advocacy



Advocacy Leadership Network 2016 (ALN): Accomplished advocates from 45 countries





**TOGETHER, we can build a better
TOMORROW!**

THANK YOU!

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