The Epidemiology of Autism Spectrum Disorder: Toward a More Inclusive World

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International Meeting for Autism Research (IMFAR)
4 May 2013
San Sebastián, Spain

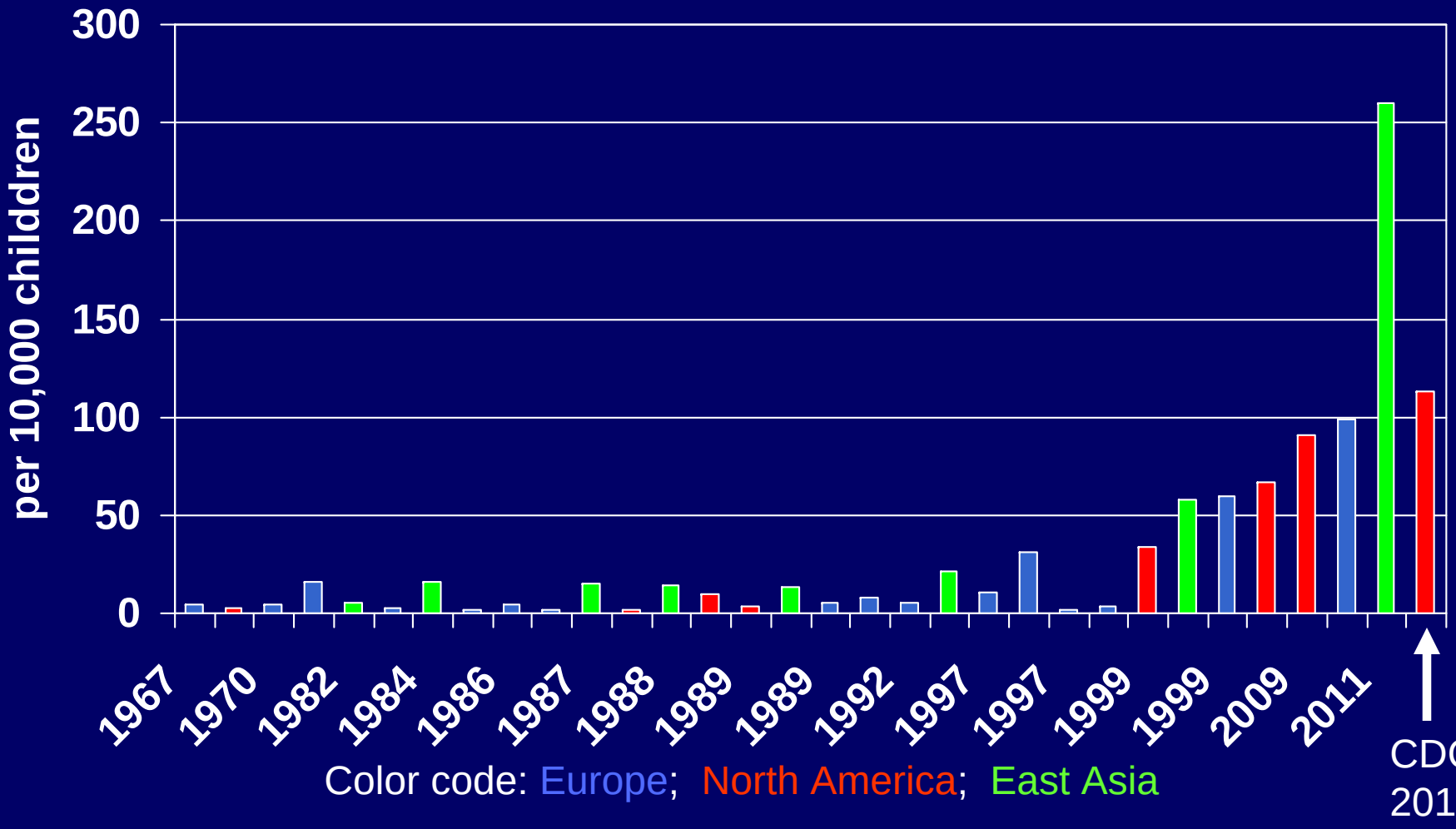
Population Health Sciences

Waisman Center
University of Wisconsin-Madison

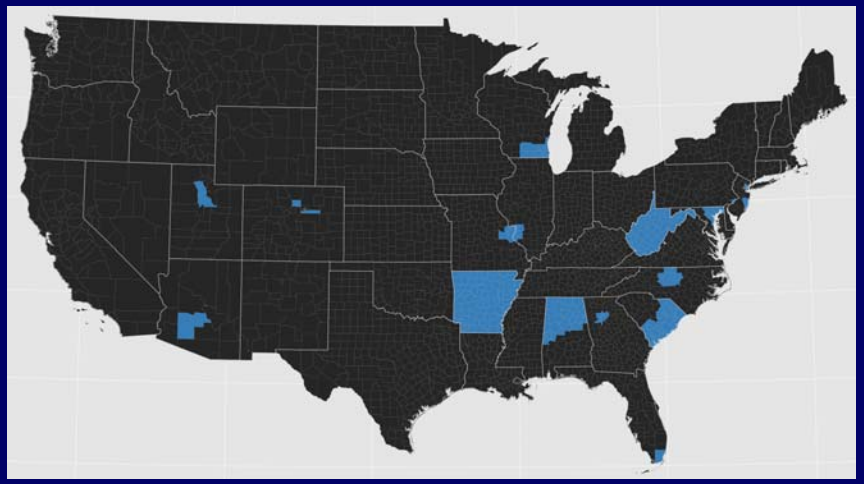
Epidemiology

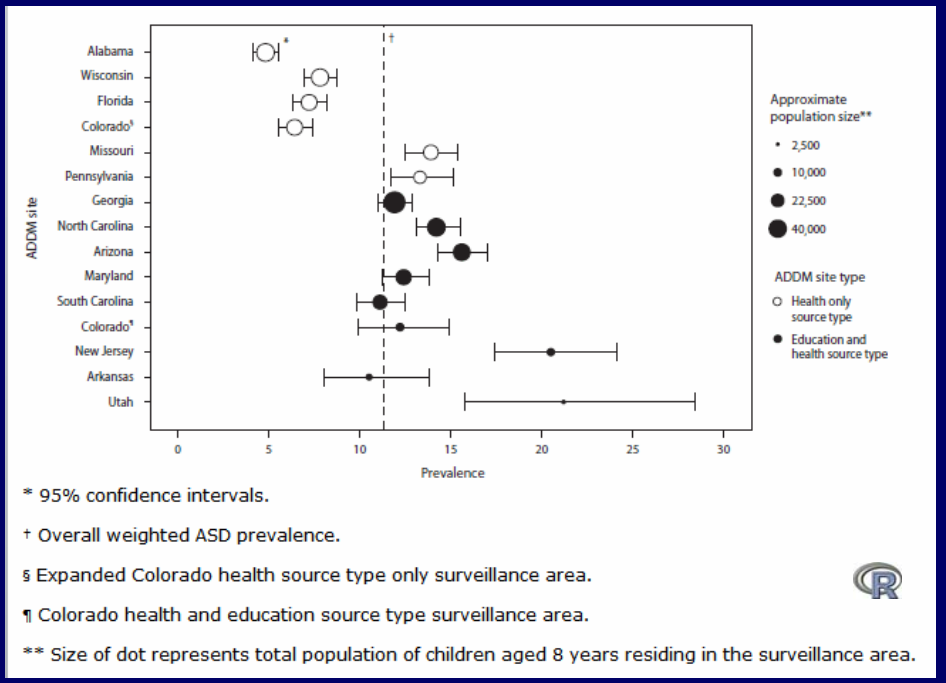
- The study of the frequency & distribution of diseases or other health outcomes in ***populations***
- A basis for determining
  - Prevalence, incidence and impacts
  - Service needs
  - Causes and risk factors
  - Natural history
  - Effectiveness & cost-effectiveness of treatments
  - Public health policy

The rising prevalence of autism based on epidemiologic studies over the past 50 years



Site-to-Site Variation in Prevalence: Will ≥2% be the new norm?



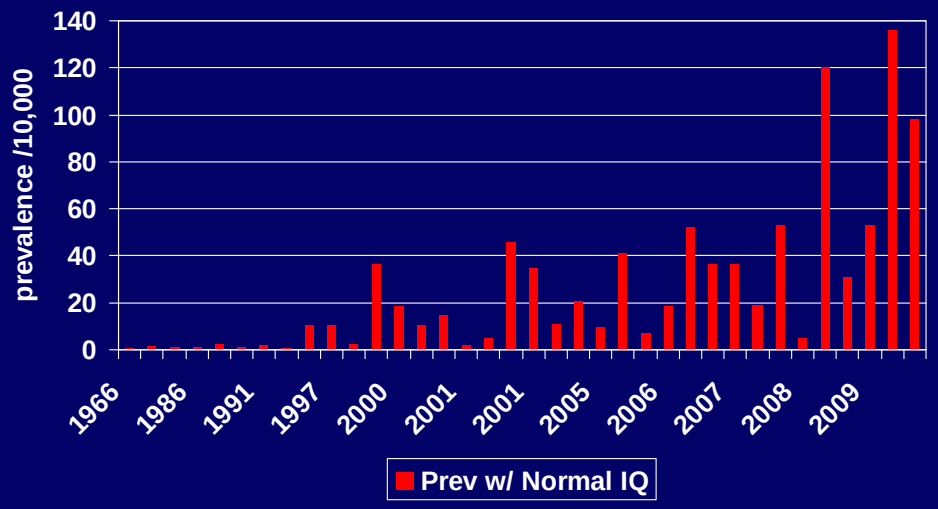


ADDM NET
Autism and Developmental Disabilities Monitoring Network

Centers of Disease Control and Prevention (CDC), Center on Birth Defects and Developmental Disabilities, *MMWR* 2012

http://www.cdc.gov/mmwr/pdf/ss/ss6103.pdf

Rise in Autism Prevalence Has Been More Pronounced for Those with ≥Average IQ



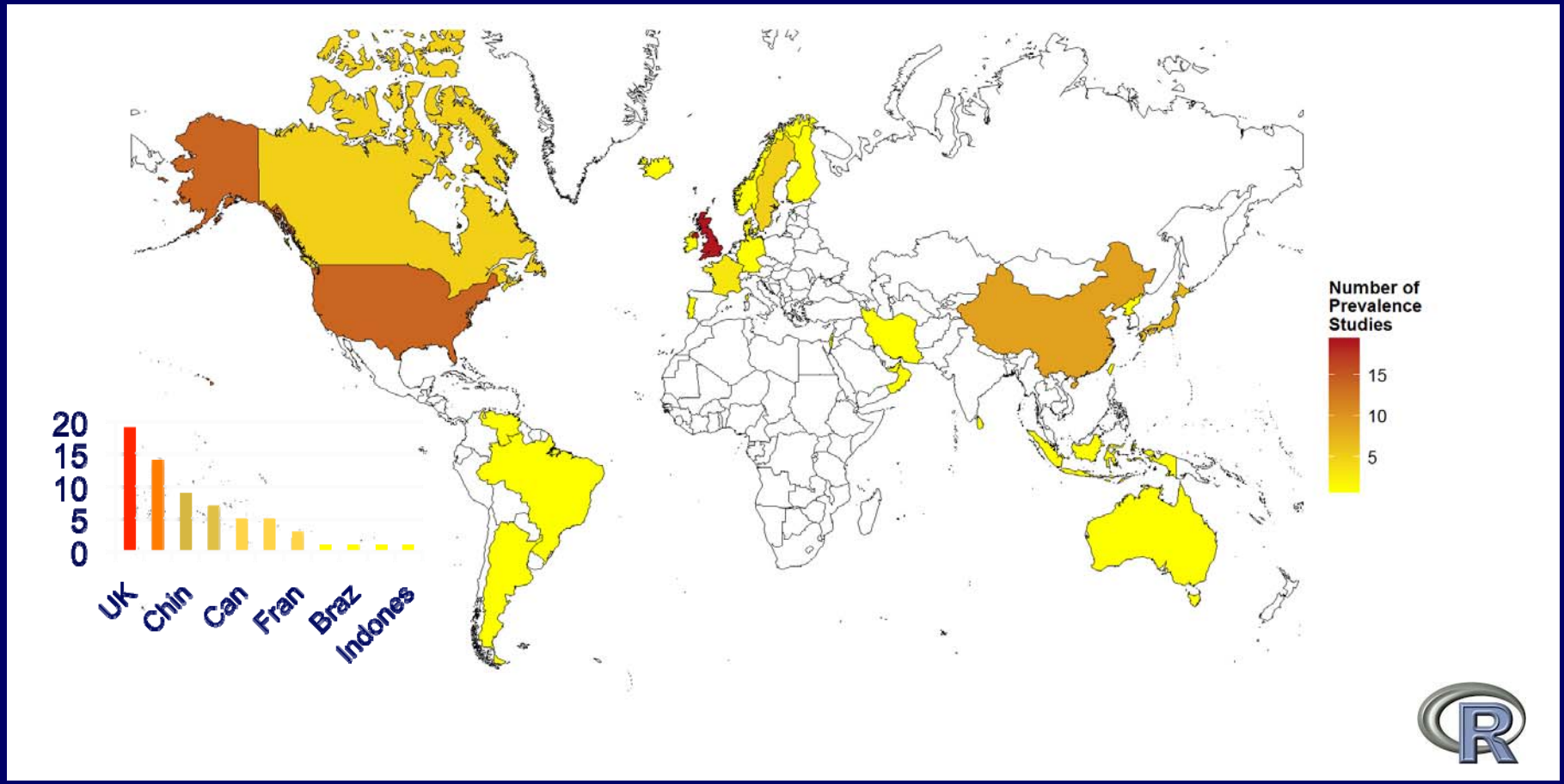
- Pre-2000, ~1/3 of children with autism identified in epidemiologic studies had IQs in normal range, versus ~2/3 post-2000.

Derived from: Elsabbagh M, Gauri D, Koh YJ, Young SK, Kauchali S, Marcin C, Montiel-Nava C, Patel V, Paula CS, Wang CY, Yasamy MT, Fombonne E, Global prevalence of autism and other pervasive developmental disorders, *Autism Research*, 2012; 5:160-79.

Other Developments in the Epidemiology of ASD

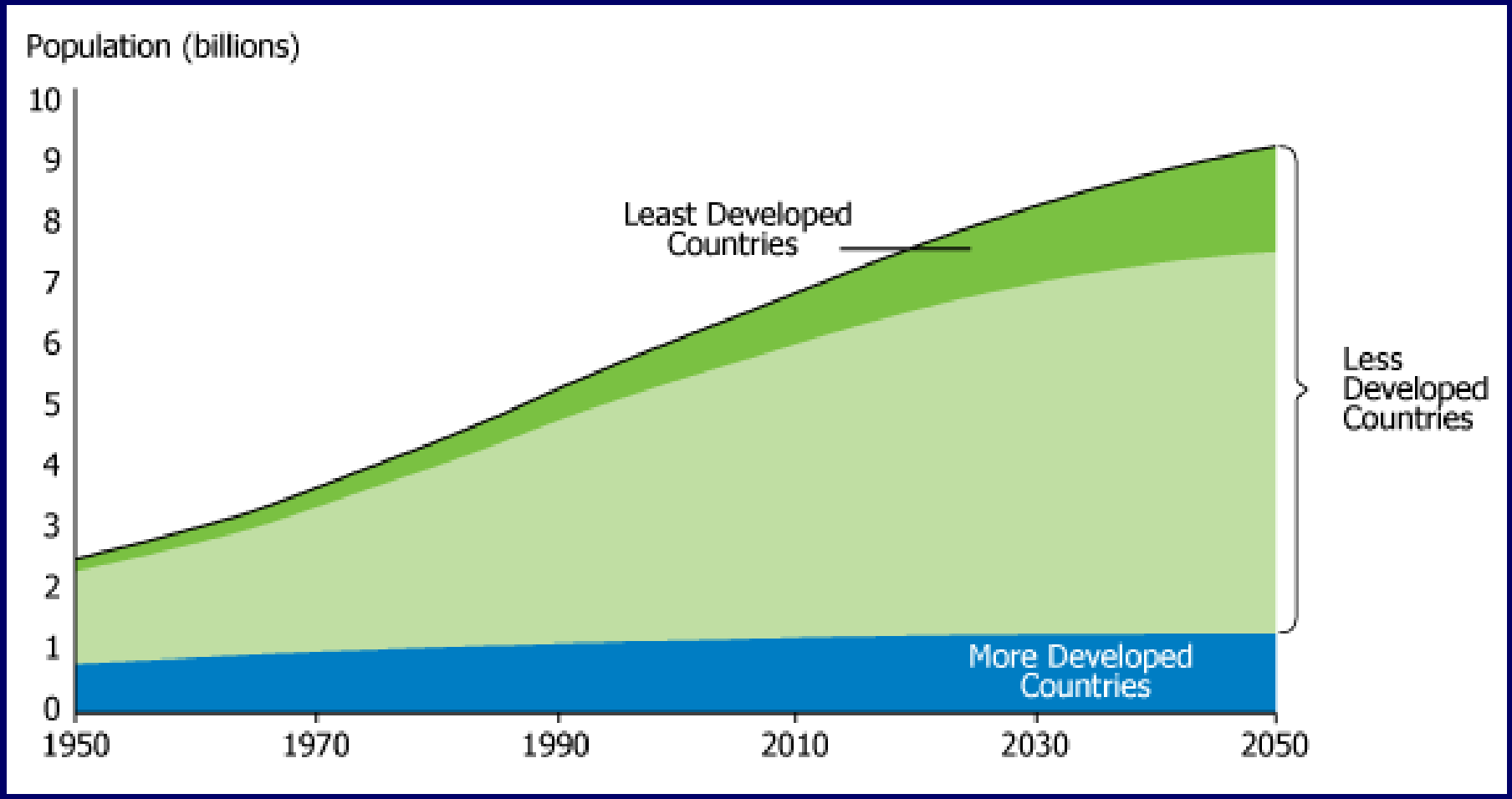
- Increased risk associated with maternal and paternal age
- Explosion of knowledge of specific gene mutations associated with autism
- Other prenatal and perinatal risk factors: preterm birth, low birth weight, folic acid, inter-pregnancy interval, …
- Potential effects of DSM-5 criteria on prevalence

Global Disparity in *the Number of Epidemiologic Studies* of Autism



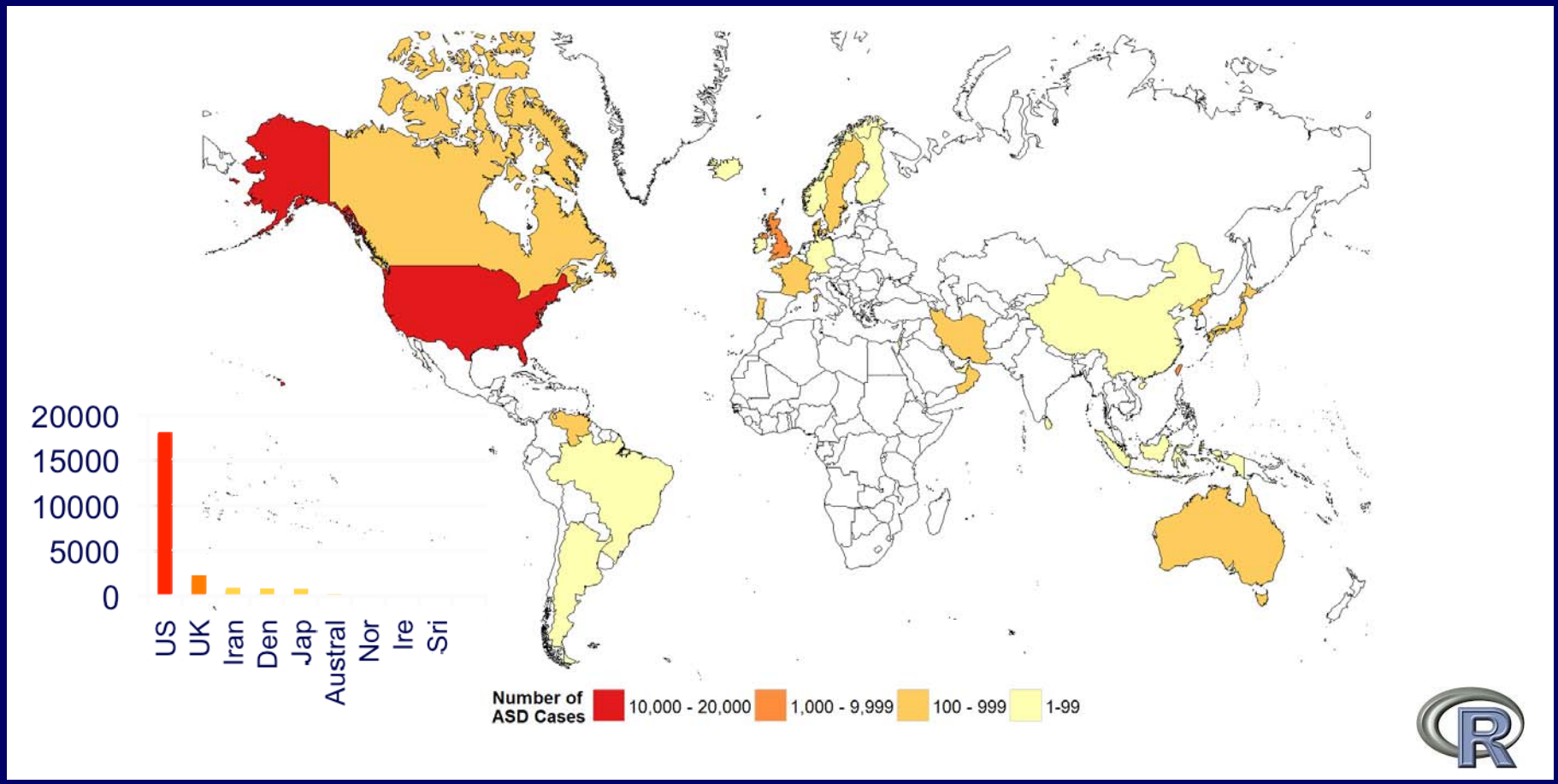
Based on studies reviewed in Elsabbagh M, et al, Global prevalence of autism and other pervasive developmental disorders, *Autism Research*, 2012; 5:160-79.

World Population is Mostly in Less Developed Countries, Where Nearly All Future Population Growth Will Occur



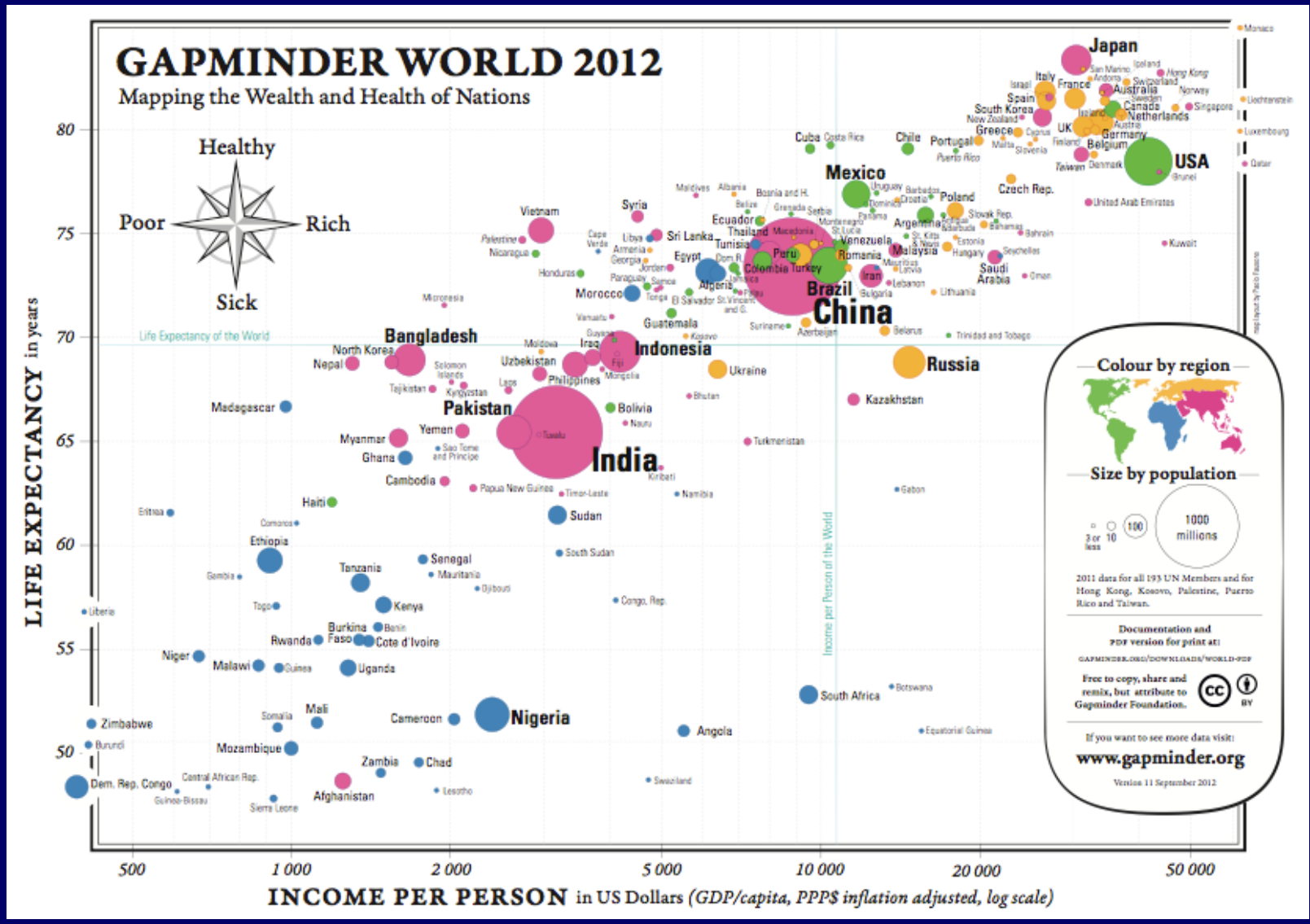
UN Population Division, World Population Prospects: The 2010 Revision, med var (2011).
http://www.prb.org/Publications/Datasheets/2012/world-population-data-sheet/fact-sheet-world-population.aspx

Global Disparity in the *Number of Epidemiologically Confirmed Autism Cases*



Based on studies reviewed in Elsabbagh M, et al, Global prevalence of autism and other pervasive developmental disorders, *Autism Research*, 2012; 5:160-79.

Global Economic and Health Disparity

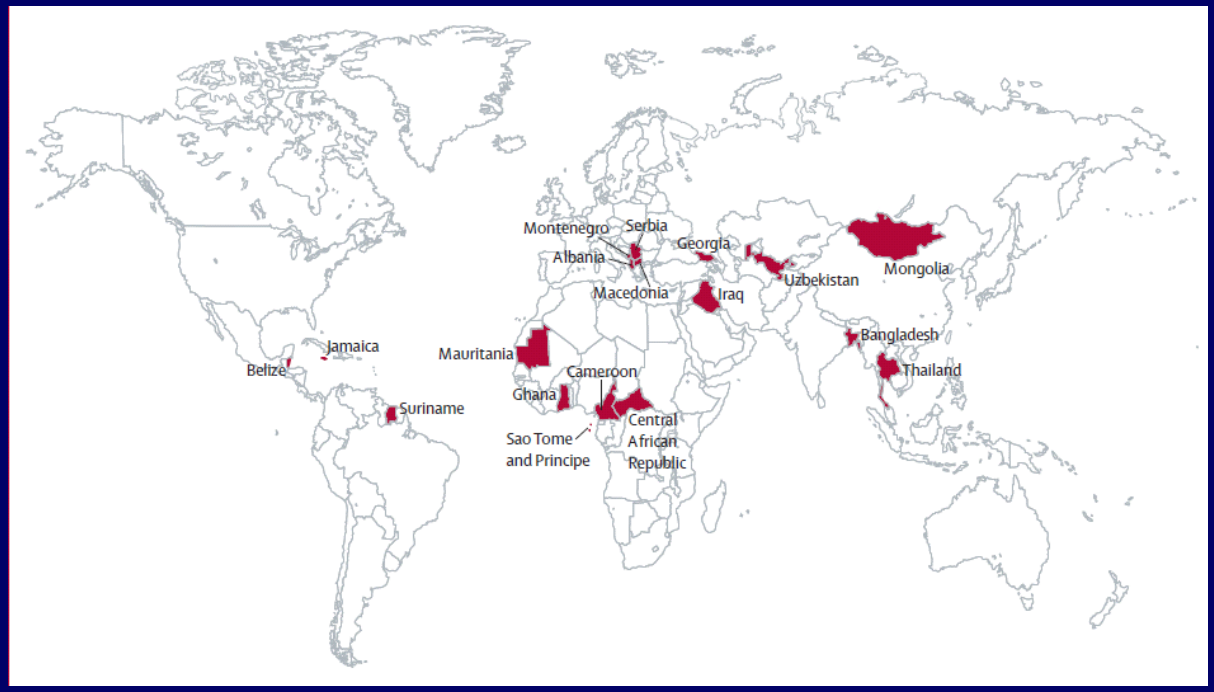


Major UNICEF screening surveys in 18 low and middle income countries found ~25% of children at high risk for disability, but no capacity for diagnostic assessments

Child disability screening, nutrition, and early learning in 18 countries with low and middle incomes: data from the third round of UNICEF's Multiple Indicator Cluster Survey (2005–06)

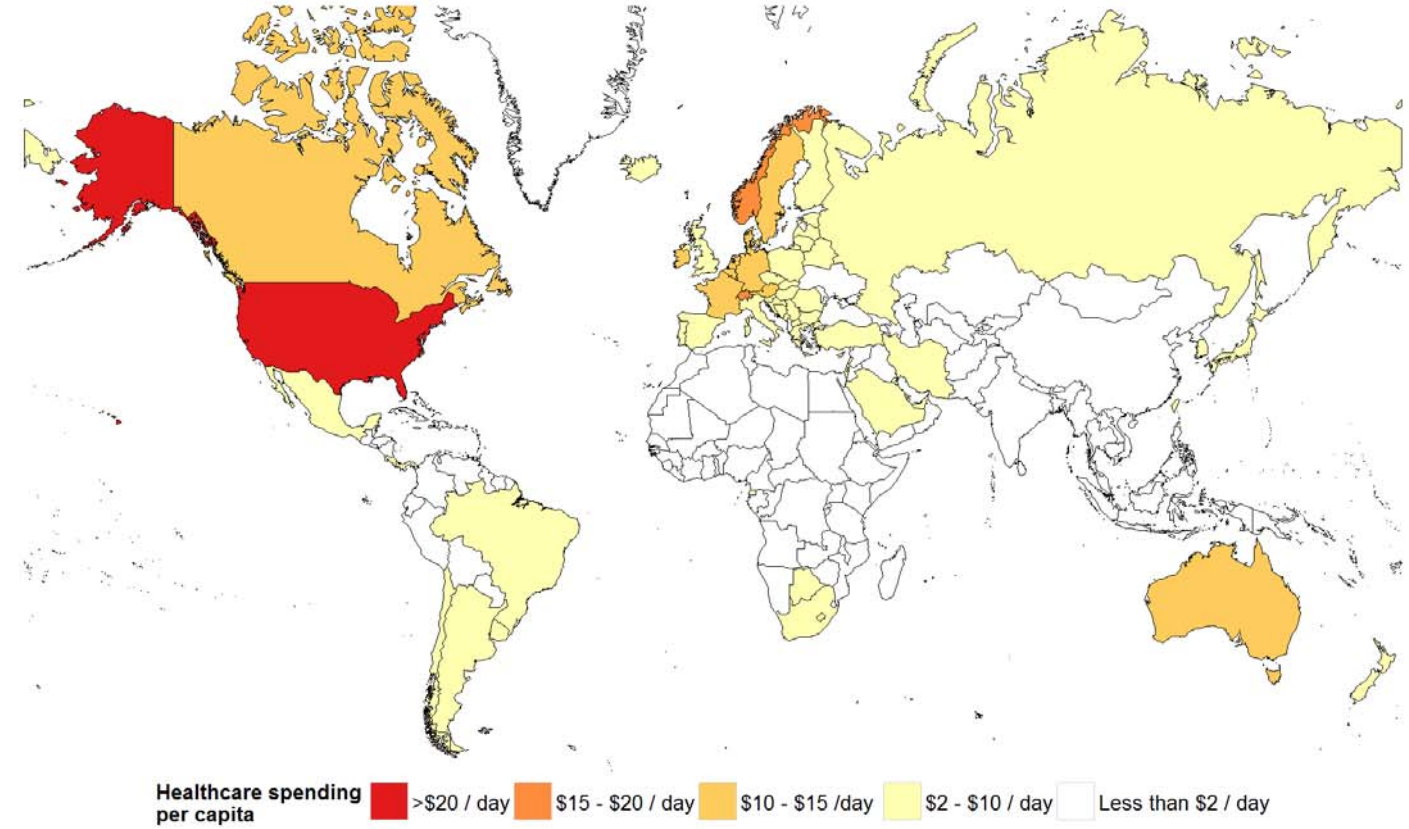
Carissa A Gottlieb, Matthew J Maenner, Claudia Cappa, Maureen S Durkin

Lancet 2009; 374: 1831–39



Global Disparity in Healthcare Expenditures:

Total per capita healthcare expenditure in most countries and for the vast majority of the world's population is <$500/year and well under $2/day.



The Cost of Autism Diagnosis in the US

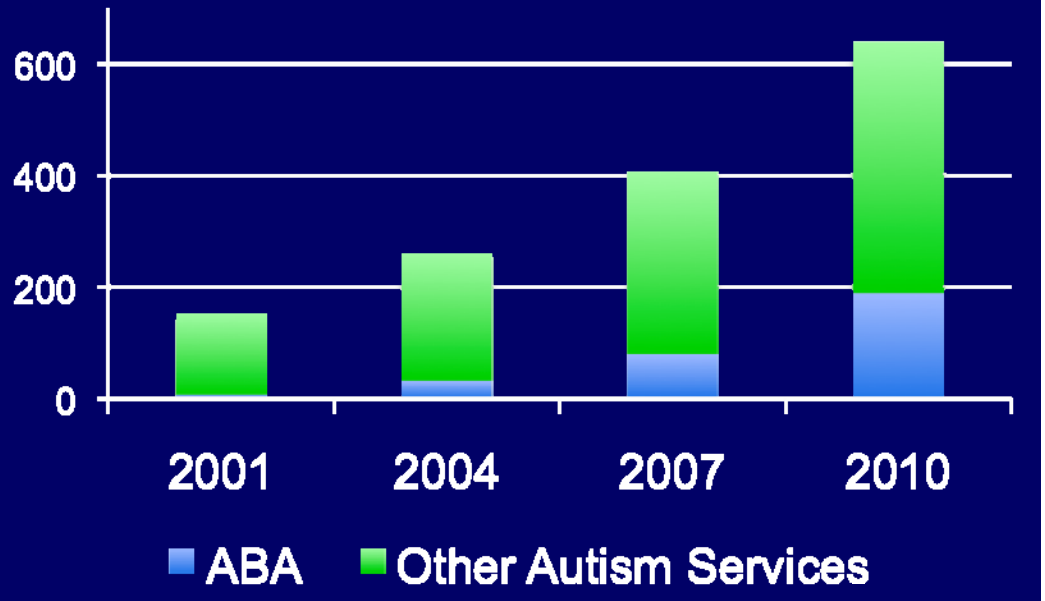
- “Our total evaluation cost just under $2000, including the ADOS and ADI-R. ___ has had several autism evaluations and they are usually at least $1000 involving at least 2 office visits …”
- “If you just want a diagnosis, you may be able to get one more quickly and less expensively with a less thorough evaluation. If you want a "gold standard" evaluation with an ADOS, it will cost more.”
- “Between the evaluation and the required follow-up meeting …, it was about $2800 for us.”
- “I just wanted the ADOS & ADI and several places quoted me $2400 minimum for the 2 tests done by grad students”

http://community.babycenter.com/post/a32453433/how_much_does_the_ados_cost

Increased Spending on Applied Behavior Analysis (ABA) and Other Autism Services in California

"Statewide, at least 75 firms, some with long waiting lists, offer ABA in a variety of styles. The cost -- often $50,000 a year or more for a single child"

--Alan Zarembo, *Los Angeles Times*



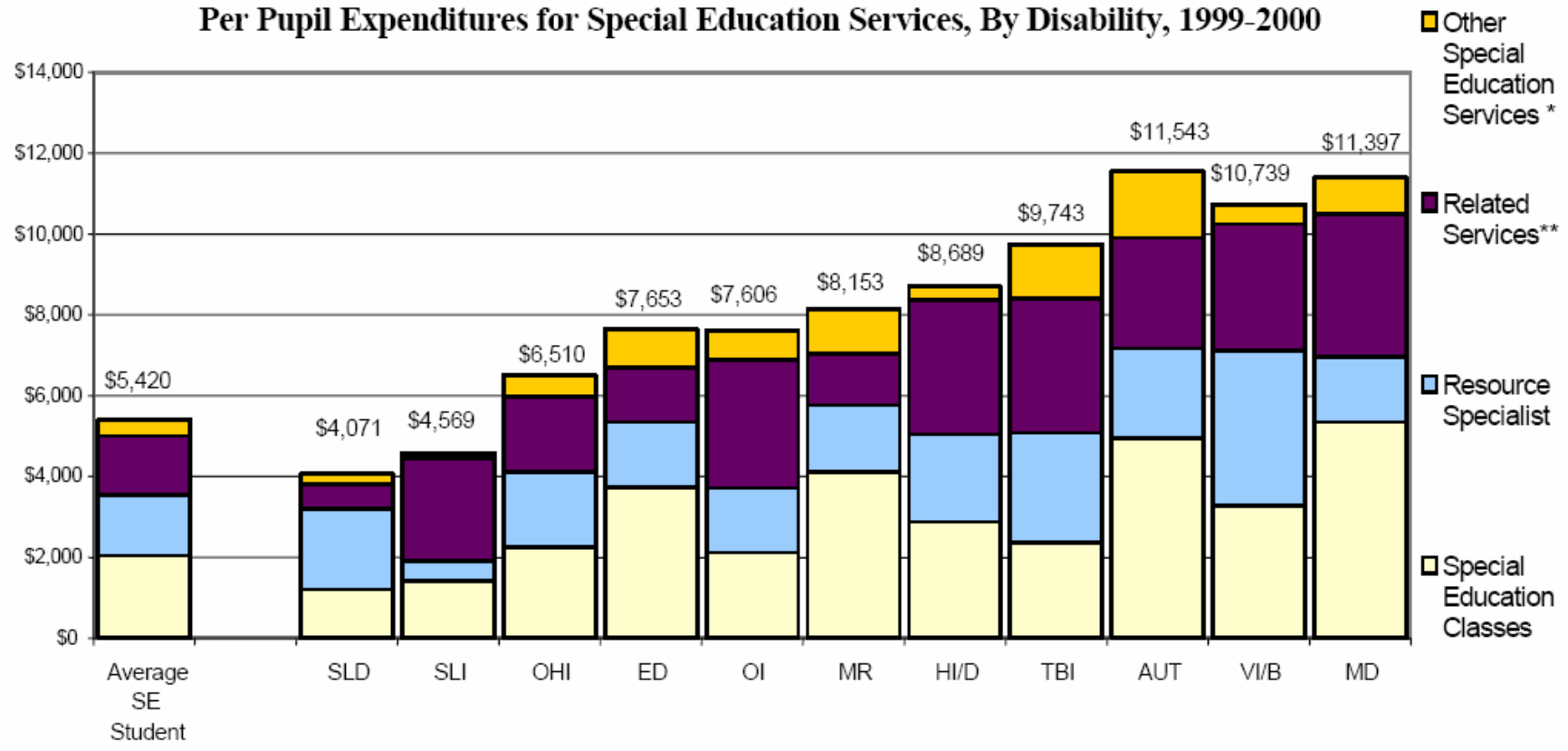
(In millions US$, Source: California Dept of Developmental Services)

http://www.latimes.com/news/local/autism/la-me-autism-day-three-html,0,3438178.htmlstory

Los Angeles Times

Autism: The Most Expensive Category of Special Education in the U.S.

Exhibit 4 reads: Students with autism (AUT) have the highest per pupil expenditures for special services ($11,543), and more of these expenditures are spent on special education classes than any of the three other types of expenditures.

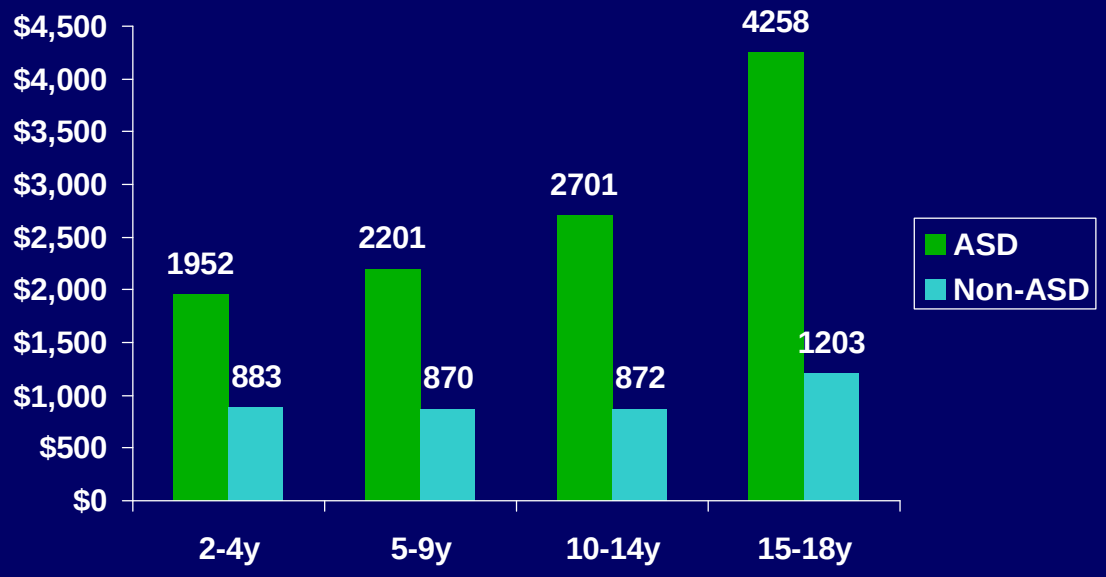


http://csef.air.org/publications/seep/national/final_seep_report_5.pdf

Cost of healthcare >3 times higher for children with autism vs. controls

A Comparison of Health Care Utilization and Costs of Children With and Without Autism Spectrum Disorders in a Large Group-Model Health Plan

Croen LA, et al, *Pediatrics*, 2006; 118(4):e1203-11



Mean annual member health-care costs by age, July 2003-June 2004.

Lifetime Costs of Autism in the US: $3.2 million per capita

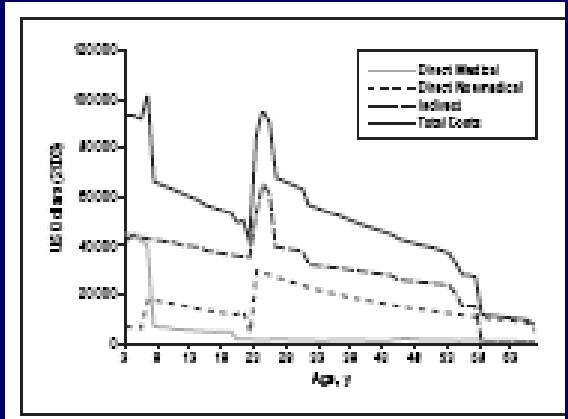


Figure 1. Age distribution of incremental societal costs of autism (present value).

"Although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood. The substantial costs resulting from adult care and lost productivity of both individuals with autism and their parents have important implications for those aging members of the baby boom generation approaching retirement. … physicians and other care professionals should consider recommending that parents of children with autism seek financial counseling to help plan for the transition to adulthood."

Ganz ML, The lifetime distribution of the incremental societal costs of autism. *Arch Pediatr Adolesc Med*. 2007; 161:343-9.

Does The Risk of Autism Increase With Family Income & Parental Education?

Brit. J. Psychiat. (1980), **137**, 410–417

Childhood Autism and Social Class: A Question of Selection?

By LORNA WING

But it remains true that a knowledgeable and determined parent of an autistic child is more likely to obtain an informed diagnosis.

WISCONSIN MEDICAL JOURNAL

Socioeconomic Disparity in the Prevalence of Autism Spectrum Disorder in Wisconsin

Matthew J. Maenner, BS; Carrie L. Arneson, MS; Maureen S. Durkin, PhD, DrPH

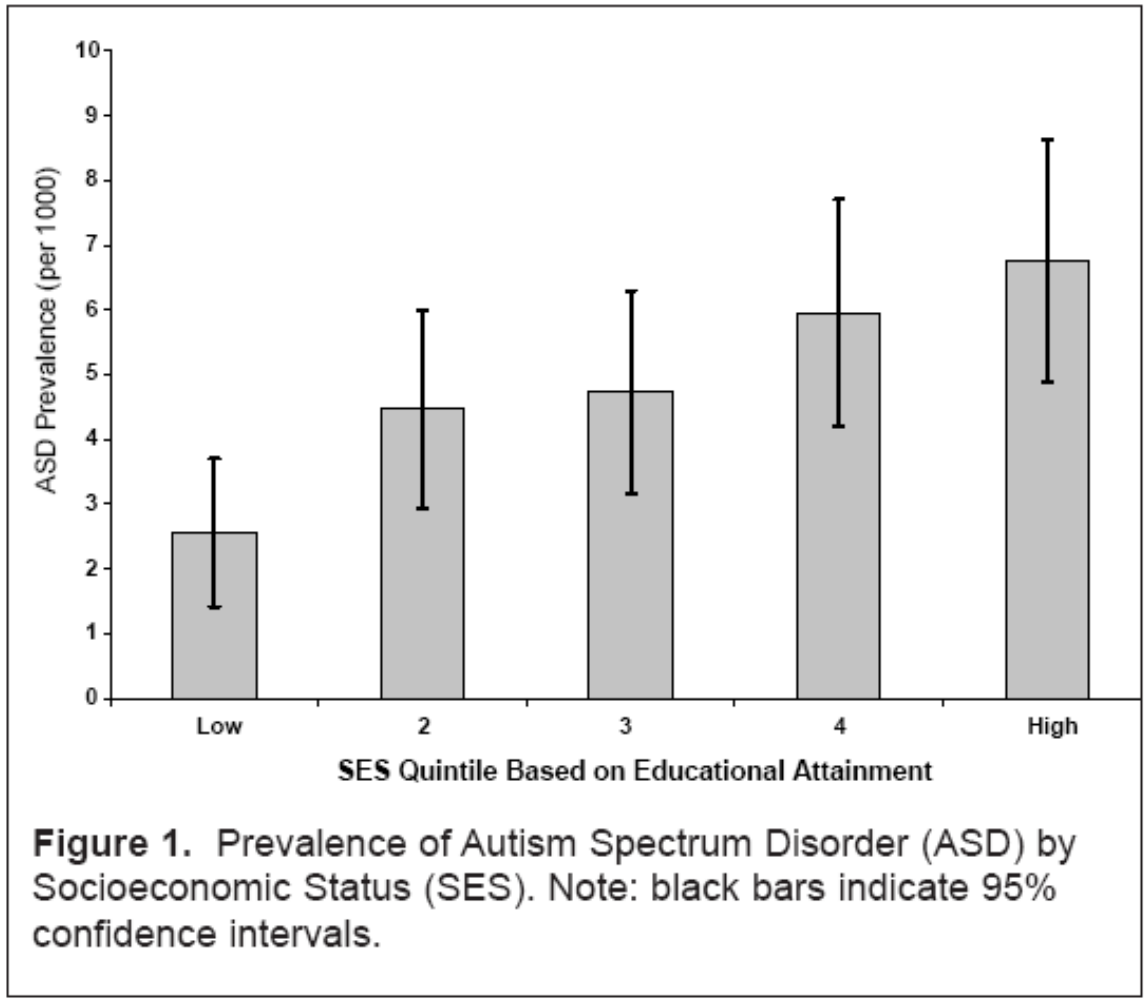
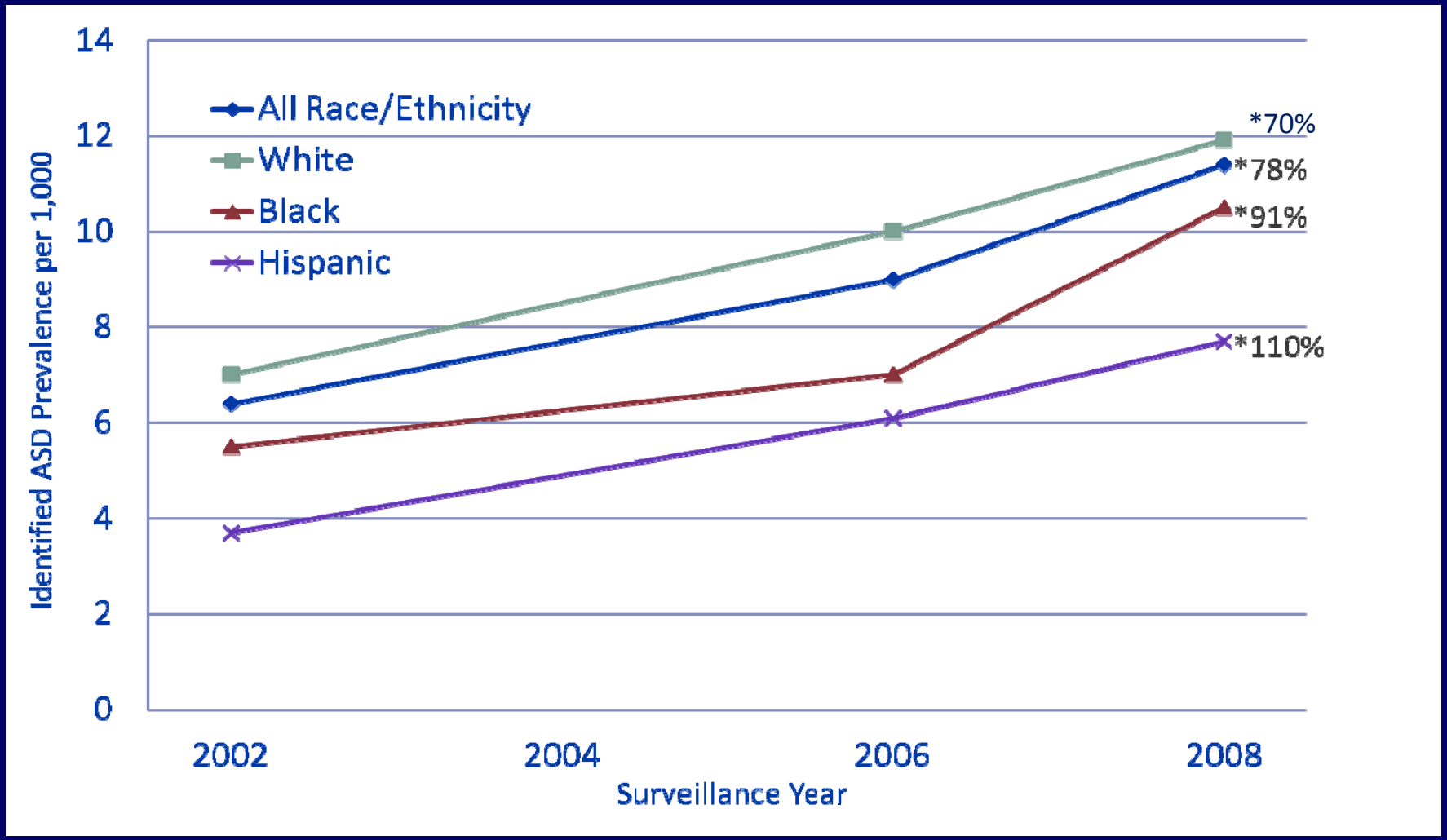


Figure 1. Prevalence of Autism Spectrum Disorder (ASD) by Socioeconomic Status (SES). Note: black bars indicate 95% confidence intervals.

- N = 181 cases, 36,989 children (age 8 years) under surveillance in 2002

WISADDS

Disparities in Autism Prevalence by Race/Ethnicity, US, (* Percent change in 13 sites completing both 2002 and 2008)



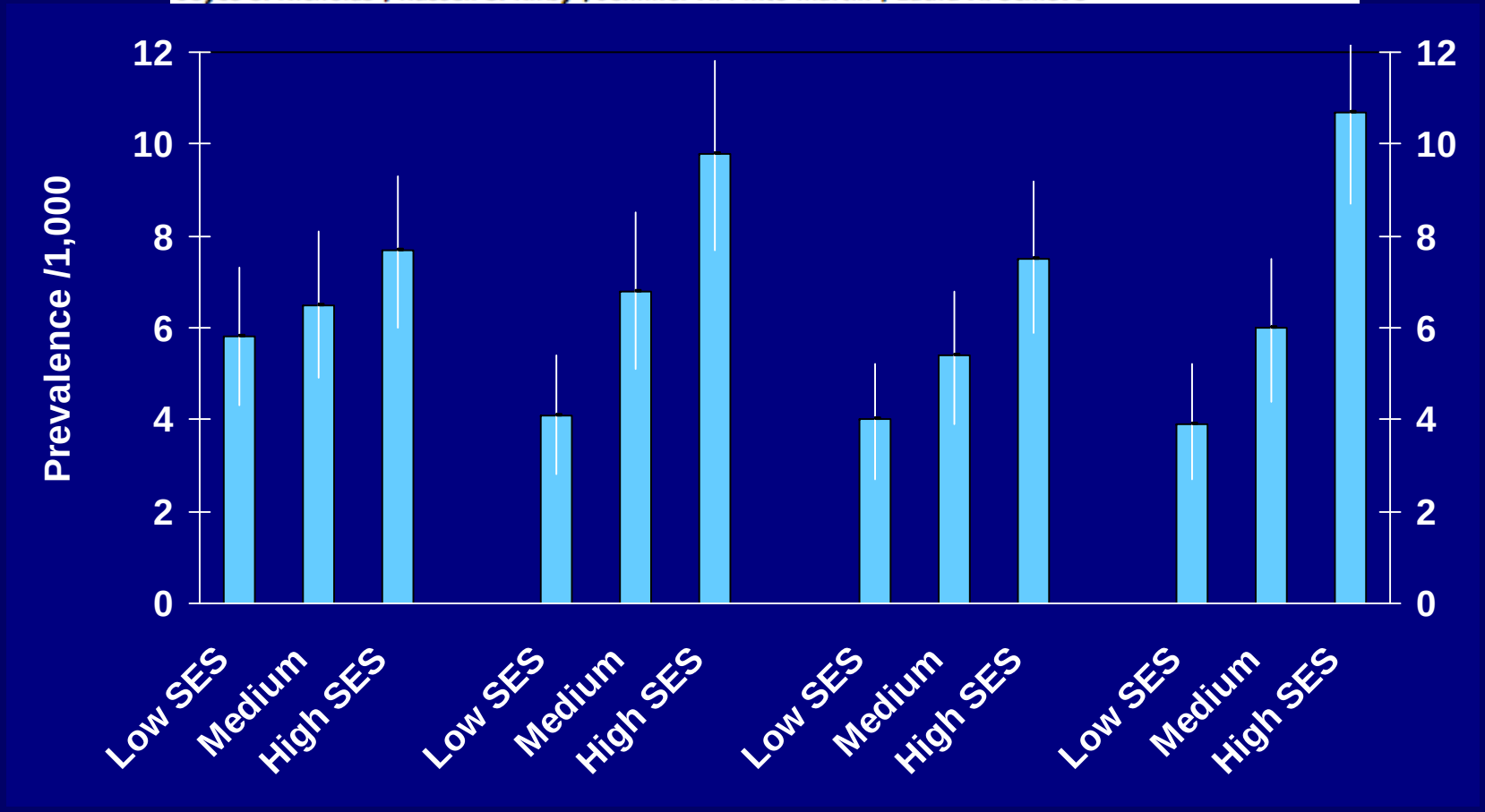
CDC ADDM Network, *MMWR*, 2012

http://www.cdc.gov/mmwr/pdf/ss/ss6103.pdf

Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study

PLoS One 2010

Maureen S. Durkin[1,2,3]*, Matthew J. Maenner[1,3], F. John Meaney[4], Susan E. Levy[5], Carolyn DiGuiseppi[6], Joyce S. Nicholas[7], Russell S. Kirby[8], Jennifer A. Pinto-Martin[9], Laura A. Schieve[10]



Based on ADDM data from 12 U.S. states, population of 557,689 8-year-old children in 2002, including 3,680 with ASD.
SES = Socioeconomic Status

Implications of ASD-SES Gradient

- If the SES gradient is due only to ascertainment bias:
  - there are significant SES disparities in access to diagnostic and other services for children with autism in communities across the US
  - current estimates of autism prevalence are inaccurate, with children of low and medium SES being under-identified and underserved relative to those with high SES
- The apparent difference in ASD prevalence by race/ethnicity is due largely to confounding by SES

SES and Clinician Bias:

In addition to biased ascertainment resulting from those with higher SES having greater access to diagnostic services, as suggested by Wing, it is possible that bias on the part of clinicians might contribute to ascertainment bias. Cuccuro et al. found that clinicians were more likely to assign autism diagnoses to vignettes of high SES vs. low SES children, all else equal.

Cuccuro ML, et al Professional perceptions of children with developmental difficulties: the influence of race and socioeconomic status. *J Autism Devel Disorders*, 1996; 26(4):461-9.

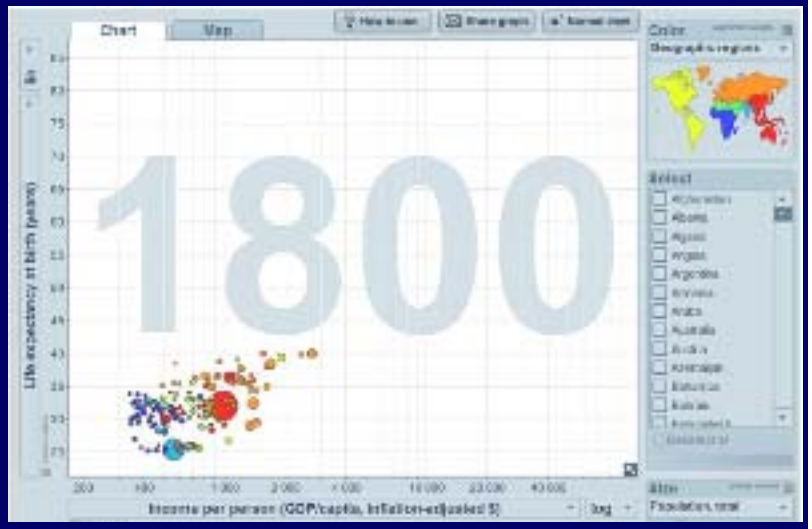
Explaining SES & Ethnic Inequalities in Access to ASD Diagnosis & Treatment in the US

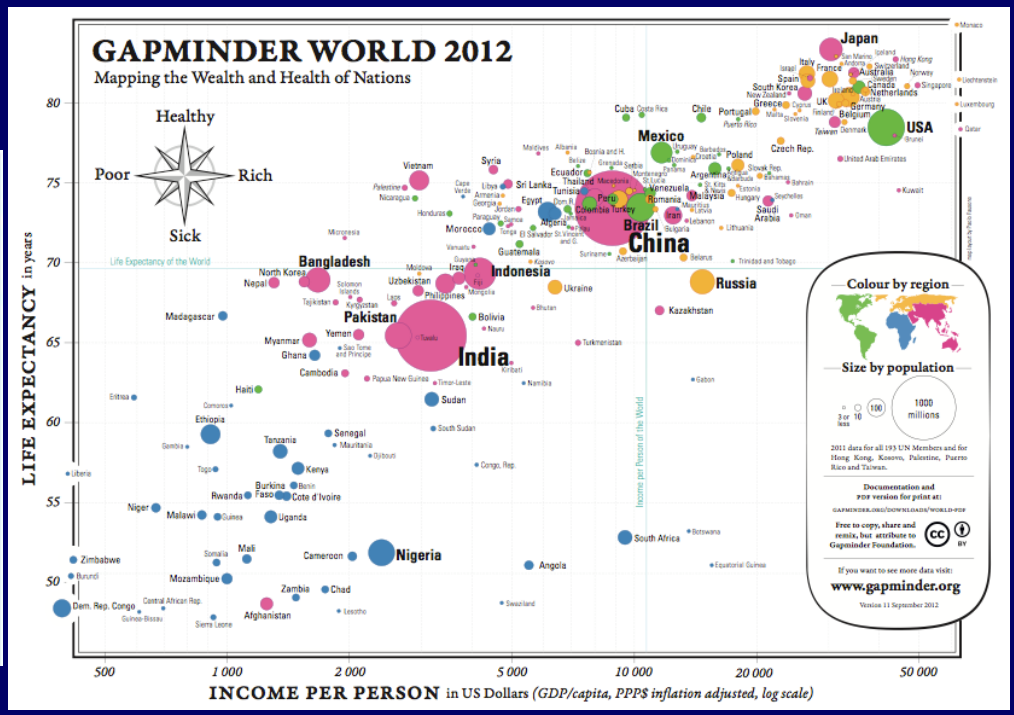
- Higher levels of resources ⟶ greater access to new technologies
  - Access to ABA required formal ASD diagnosis before age 8 years
- Treatments that are more difficult to access ⟶ greater inequalities
  - Among children with ASD, white children were >2 times likely to receive ABA than Latino children

Sandra Magaña, PhD, MSW

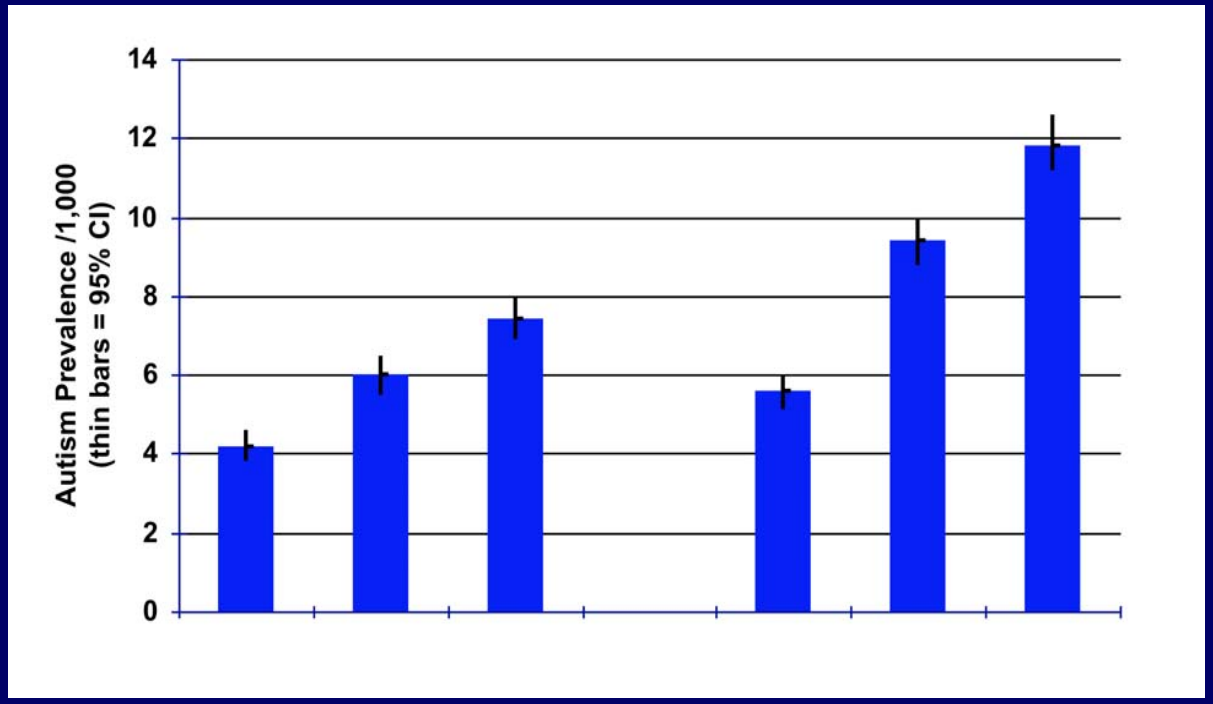
Magaña S, Lopez K, Aguinaga A, Morton H, Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities*, 2013; 51(3):(in press)

Increasing Health Disparities with Advances in Health Technologies





Increasing SES Disparity in Autism Prevalence in the US Despite More Screening & Awareness



ADDM Network, IMFAR 2012 Poster

Evidence from Sweden that the ASD-SES association in the US might be due to disparities in access to services

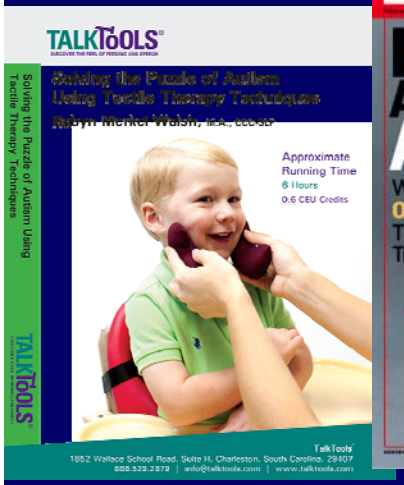
Parental Socioeconomic Status and Risk of Offspring Autism Spectrum Disorders in a Swedish Population-Based Study

Dheeraj Rai, M.B.B.S., MRCPsych, Glyn Lewis, FRCPsych, Ph.D., Michael Lundberg, M.P.H., Ricardo Araya, MRCPsych, Ph.D., Anna Svensson, M.Sc., Ph.D., Christina Dalman, M.D., Ph.D., Peter Carpenter, M.B.Ch.B., FRCPsych, Cecilia Magnusson, M.D., Ph.D.

	All Autism Spectrum Disorders		
Parental Socioeconomic Status at Time of Child's Birth	Cases/Controls 4,709/46,489	Crude OR (95% CI)	Adjusted OR[a] (95% CI)
Household disposable income (individualized)			
Quintile 1 (Lowest)	847/8,151	1.2 (1.1–1.4)	1.3 (1.2–1.5)
Quintile 2	1,121/9,447	1.4 (1.3–1.6)	1.4 (1.3–1.6)
Quintile 3	1,051/9,710	1.3 (1.2–1.4)	1.3 (1.2–1.5)
Quintile 4	878/9,574	1.1 (1.0–1.2)	1.1 (1.0–1.2)
Quintile 5 (highest)	812/9,607	1.0 (Ref)	1.0 (Ref)

JOURNAL OF THE AMERICAN ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY
VOLUME 51 NUMBER 5 MAY 2012

Media Images of Autism



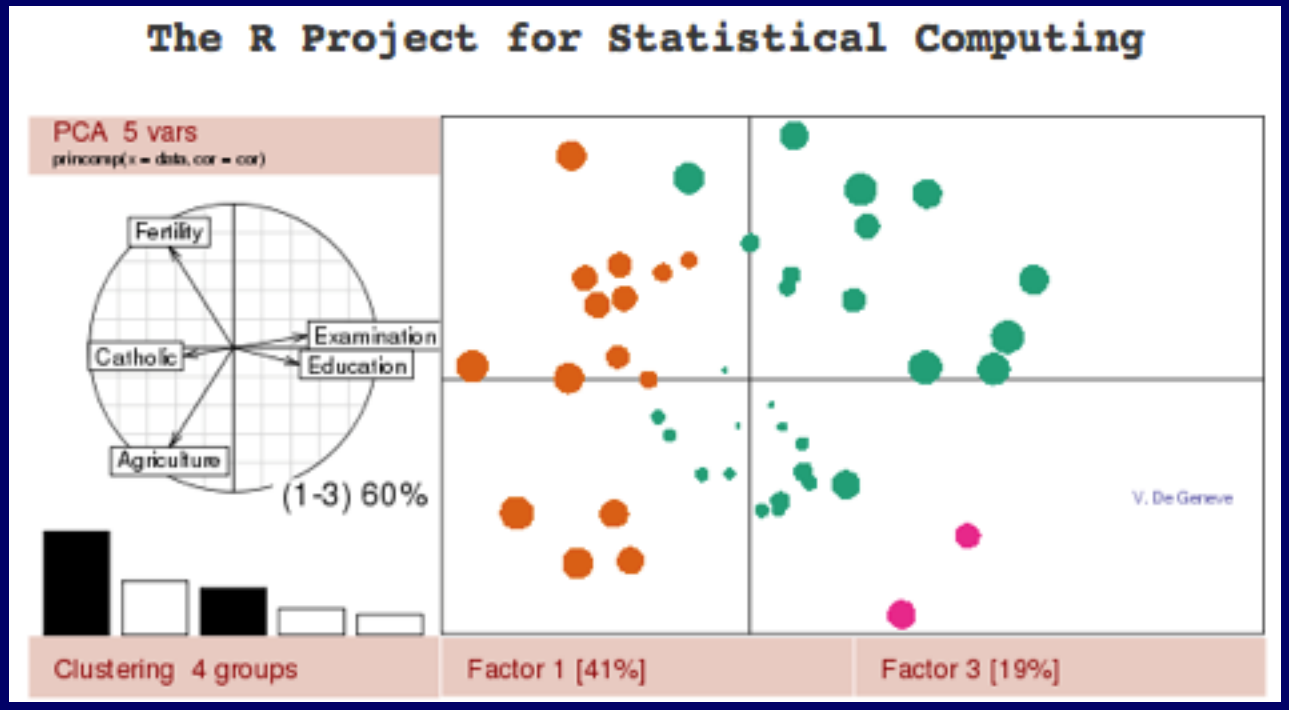
INSAR
Cultural Diversity Committee

- Provide a forum for professional development, information sharing, & collaboration among those interested in racial/ethnic/ cultural/SES diversity in autism
- Promote inclusion & diversity in autism research
- Travel awards & ↑ feeling of belonging for IMFAR attendees from less-represented countries

- Tamara Daley, PhD

- Marshalyn Yeargin-Allsopp, MD

A Model for Free & Open Global Collaboration



- R is a free software environment for statistical computing and graphics.

The licenses for most software and other practical works are designed to take away your freedom to share and change the works. By contrast, our General Public Licenses are intended to guarantee your freedom to share and change all versions of a program--to make sure it remains free software for all its users.

http://www.r-project.org

Free & Open

DisabilityMeasures.org

Free & Open Disability Measurement Tools

Our goal is to improve the global accessibility of open-access measurement tools for assessment, screening, and research concerning individuals with disabilities. We're building a clearinghouse for freely available measurement tools and a collaborative platform to promote their dissemination.

One of the barriers to research on disability, particularly in low-resource settings, is the lack of free and high-quality screening tools and instruments. Typically, proprietary measures are available under a license that requires a payment each time the measure is used. These licenses can become prohibitively expensive, and they limit our ability to share information and work together.

We want to provide an alternative to the proprietary model of licensing measurement tools. This website will serve as a centralized location for promoting and disseminating freely-available measures of disability.

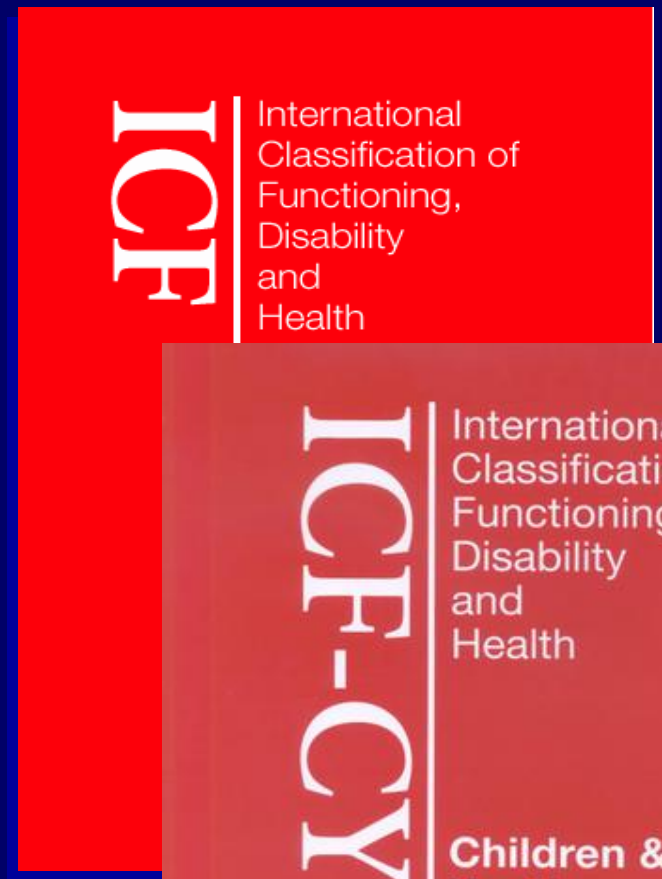
- **To recommend a measure for inclusion here, please fill out this form.**
- Anyone can contribute, and we're happy to acknowledge your collaboration.
- We want to be objective about quality; measures should be supported by peer-reviewed articles or reputable technical reports.
- Unless you are the author and ask us to host the measure on DisabiltyMeasures.org, we will provide a description of the measure and a link to the 'official' website created by its authors.

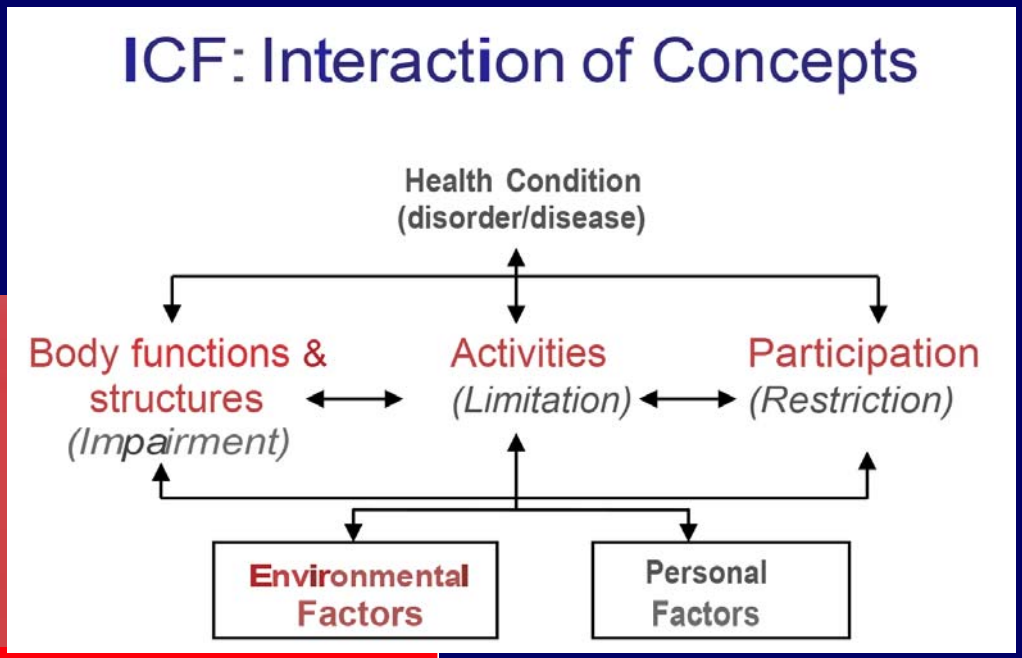
http://www.disabilitymeasures.org

Created by Matthew Maenner, PhD

Examples of Developmental Disability Screening & Assessment Tools that are/might be Freely Available

- Waisman Activities of Daily Living scale (W-ADL) -- Maenner et al 2012 (www.waisman.wisc.edu/family/WADL)
- Vocational Index (for ASD) – Taylor and Seltzer 2011
- Ten Questions screen (TQ) -- Belmont 1984, Zaman, et al 1990, Durkin et al 1995 (www.DisabilityMeasures.org)
- 23Q (adaptation of TQ to include autism) -- Kakooza-Mwesige et al 2013 (http://aut.sagepub.com/content/early/2013/03/26/1362361313475848.abstract)
- Neurodevelopmental Screening Test (NDST) – INCLEN (www.inclen.org)
- Gross Motor Functional Classification Scale (GMFCS) --Palisano et al 1997 (http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.pdf)
- M-CHAT -- Robins et al 1999 (https://www.m-chat.org/)
- PROMIS, & NIH Toolbox - www.nihpromis.org , www.nihtoolbox.org





"the lives of individuals with disability are limited not so much by their specific type of disability as by the social interpretation of that disability", … stigma, & other environmental barriers.
-- Nora Groce 1999

Barrier-Free Technology Enhances Participation of People with Physical and Sensory Disabilities

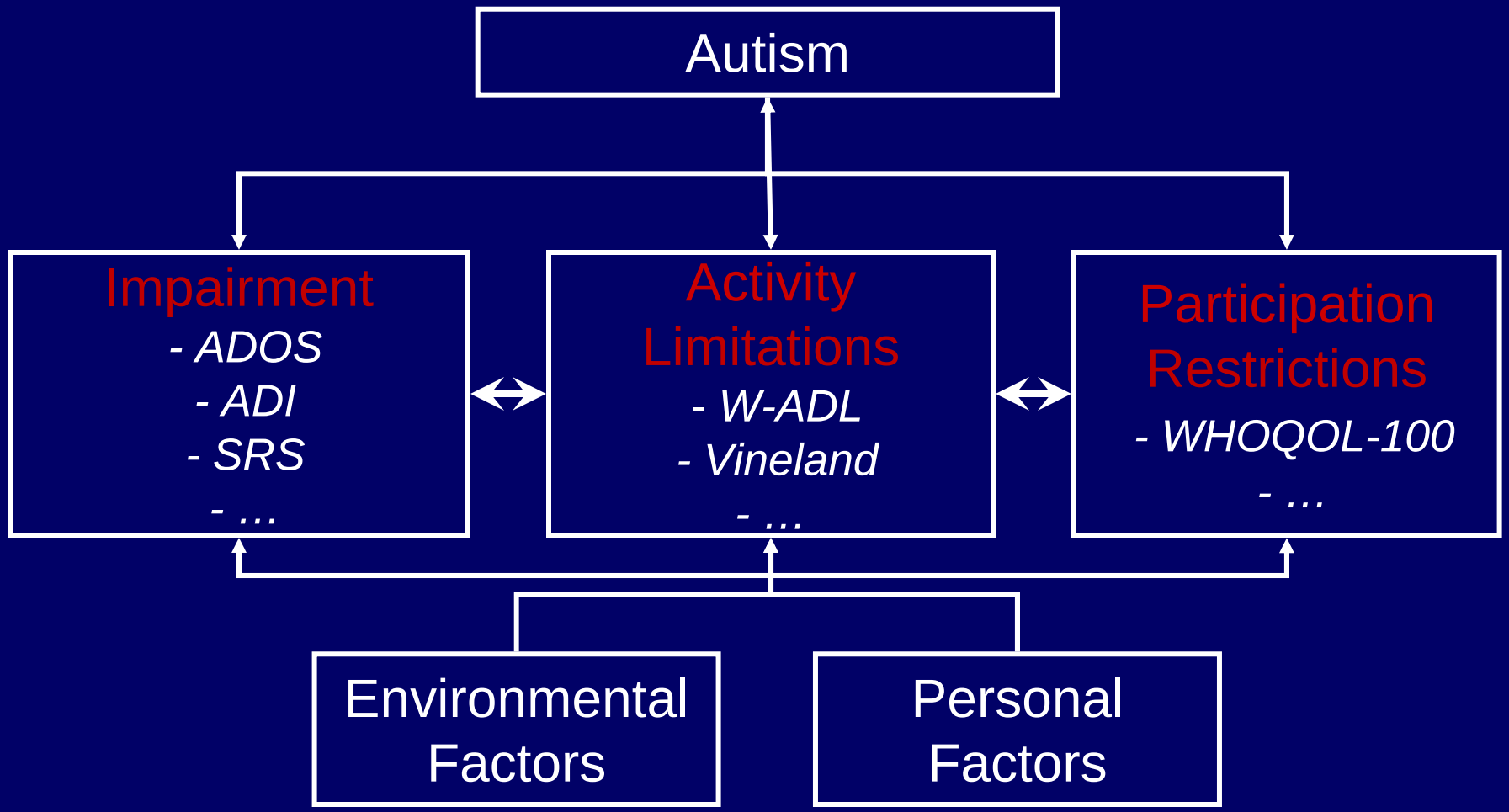
Power wheelchair with augmented communication device

Hand-held wireless device sends text messages to hearing aids

TRACE CENTER
UNIVERSITY OF WISCONSIN-MADISON

Barrier-Free Technology Coming of Age
http://trace.wisc.edu/

Measurement of ICF Dimensions



Social integration in global mental health: what is it and how can it be measured?

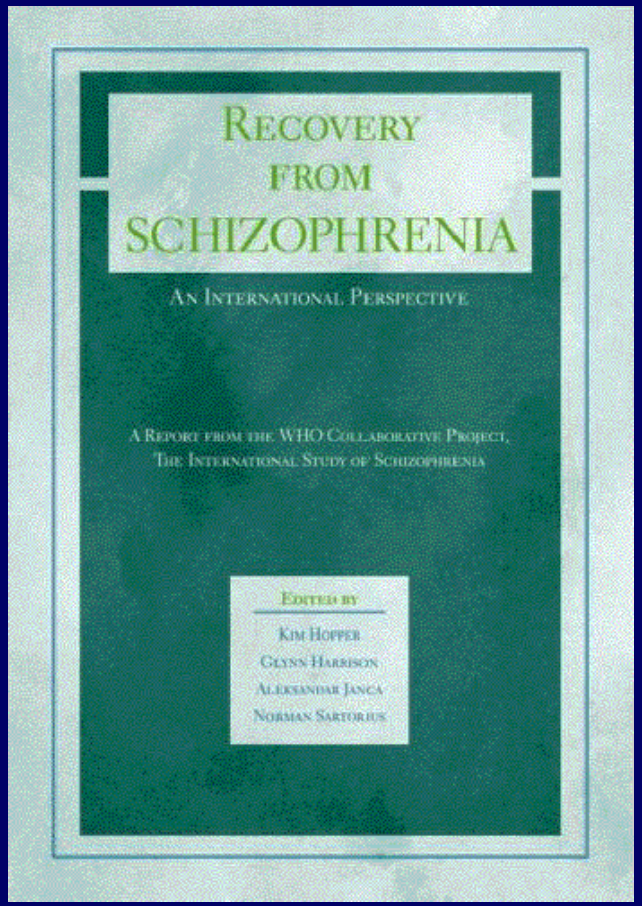
Epidemiology and Psychiatric Sciences, page 1 of 9.

J. N. Baumgartner[1,2]* and E. Susser[1,3]

- Need for cross-culturally applicable measures of “active participation in community and civic life”
- Capabilities approach (Sen): not just functioning (activities and achievements) but whether people have freedoms (opportunities & environments necessary to function as they wish)

WHO Coordinated International Study on the Course and Outcome of Schizophrenia

- "… extraordinary … finding that subjects in the developing world were generally better off than their counterparts in the developed world."
- More likely to marry, be included in family and social life.



Oxford University Press, 2007

http://ssrd.rfmh.org/who/isos/index.html

The New York Times

By GARETH COOK
Published: November 29, 2012

The Autism Advantage

Building a More Inclusive Work Force

Investing in Helping Adults With Autism

"People with autism are no different from anyone else – they want a job, a home and friends."

http://dk.specialisterne.com/om-specialisterne/specialist-people-foundation/

U.N. Conventions on the Rights of the Child (CRC) and on the Rights of Persons with Disabilities (CRPD)

- CRC Art 23, Sec 1: “A mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self reliance and facilitate the child’s active participation in the community.”

- CRPD Art 27: “…Recognize the right of persons with disabilities to work...”
- Paradigm Shift: Persons with disabilities not viewed as *objects* of charity, medical treatment or social protection, but as *subjects* with rights.

Conclusion

- With the convergence of ideas & technologies, such as the ICF, the CRPD, the capabilities approach to human development, inclusive schools and workforce, free and open tools to allow global collaboration, and barrier-free technologies, we can look forward to a more inclusive world for people with autism and other developmental disabilities.
- Epidemiologic research needs to be expanded to include low and middle income communities and greater attention to the functional and participation dimensions of ASD.

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