

# AUTISM, HISTORY, AND THE COMMUNICATION OF SCIENTIFIC FINDINGS IN ERAS OF UNCERTAINTY AND CONTROVERSY

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# Why Autism, Risk Communication & Ethics?

- There are few studies and papers examining Risk communication & ethical issues unique to ASDs
- Areas of need include:
  - ▣ The communication of environmental, genetic, and GxE risks to diverse stakeholders
  - ▣ communicating potential harms from autism research to parents, patients, and the public
  - ▣ Autism & culturally sensitive genetic counseling
  - ▣ the communication of genetic test results and their uncertainty

# History, Ethics, and Risk Communication

- Historical controversies in autism demand research in this area
  - ▣ Debates over autism etiology have raged for more than sixty years
  - ▣ These debates and controversies have shaped the behavior of all stakeholders, both historically and present day
  - ▣ Recent debates about autism and vaccination have polarized many ASD stakeholders

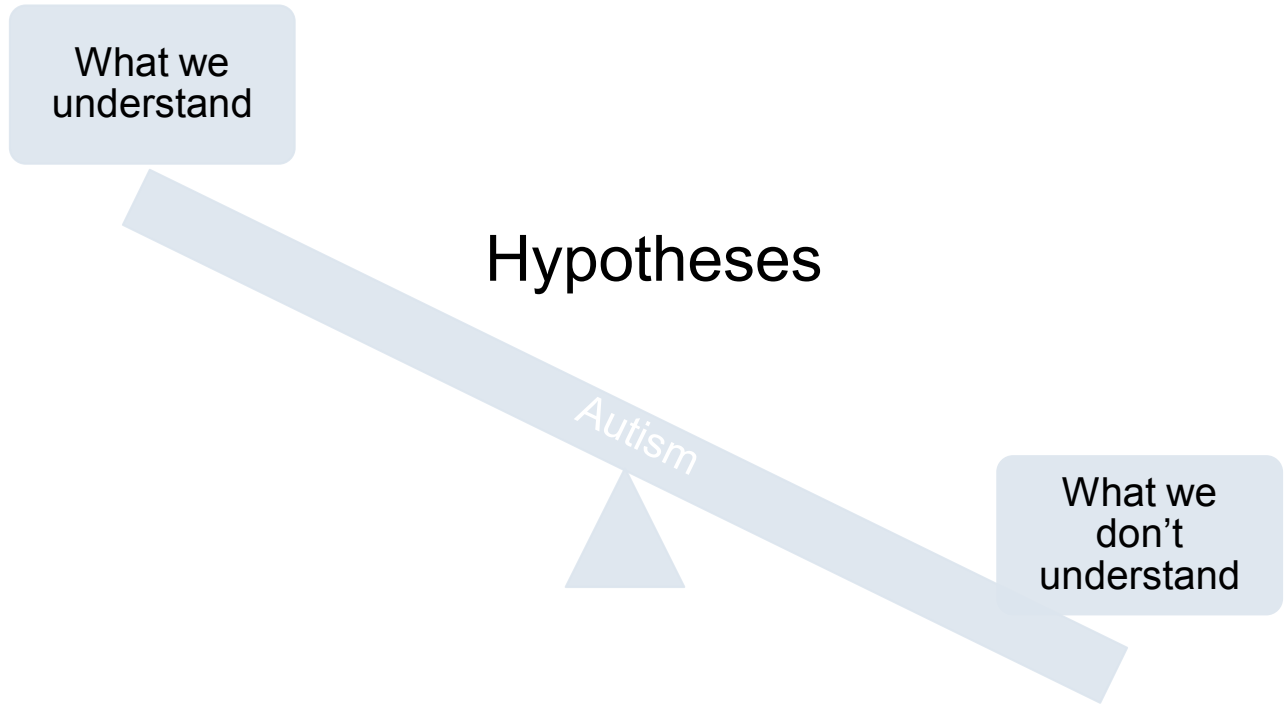
# Autism and Risk Communication Failures



+ Mothers =

**AUTISM**

# Challenges of Autism Risk Communication



# Risk Communication Challenges

- Environmental Risk Factors
  - Uncertainty of evidence
  - Causal contribution
  - Avoidability
  - Responsibility
  - Risks and benefits
  - Stigma
  - Guilt

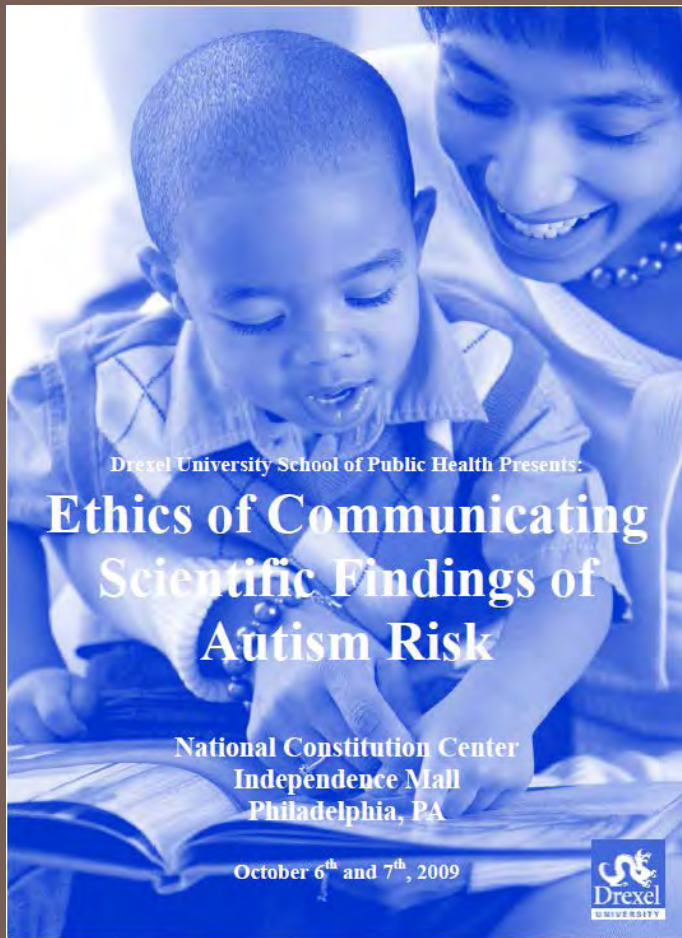
# Risk Communication Challenges

- Genetic Risk Factors
  - Determinism
  - identity
  - Early detection and treatment?
  - Eugenics
  - Genetic counseling
  - Clinical relevance?
    - Rare variant, large risk
  - Stigma



# Risk Communication Challenges

- **Complex Causation → G x E**
  - ▣ In addition to environmental and genetic challenges...
    - Numeracy
    - Not 1, but 2 or more causes
    - Communicating attributable risks



Drexel University School of Public Health Presents:

# Ethics of Communicating Scientific Findings of Autism Risk

National Constitution Center  
Independence Mall  
Philadelphia, PA

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MEETING  
FUNDED BY  
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SPEAKS

# Stakeholder Participation

- Susan Axelrod, MA, Pennsylvania Department of Education
- Evon L. Bergey, MSW, LCSW, Magellan Health Services Newtown Care Management Center
- Laura Bono, SafeMinds & National Autism Association
- Louis Z. Cooper, MD, College of Physicians and Surgeons of Columbia University & National Network for Immunization Information
- Bernard Courtieu, DVM, MBA, IntegraGen
- Lisa A. Croen, PhD, Kaiser Permanente
- Geraldine Dawson, PhD, University of North Carolina at Chapel Hill & Autism Speaks
- Peter Doehring, PhD, Children's Hospital of Philadelphia
- Baruch Fischhoff, Howard Heinz University & Carnegie Mellon University
- Lynn Goldman, MD, MPH, John Hopkins University Bloomberg School of Public Health
- Richard Grinker, PhD, George Washington University
- Lee Grossman, CDC, NIH, and IACC
- Vidya Bhushan Gupta, MD, MPH, New York Medical College & AAP
- Irva Hertz-Picciotto, MA, PhD, MPH, University of California, Davis
- Michael F. Huerta, PhD, National Institute of Mental Health & NIH
- Rebecca Landa, PhD, CCC-SLP, John Hopkins University School of Medicine & Kennedy Krieger's Center for Autism and Related Disorders
- Paul Law, MD, MPH, Kennedy Krieger Institute & John Hopkins University School of Medicine
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- Karin Lee, National Institute of Mental Health & NIH
- Susan E. Levy, MD, Children's Hospital of Philadelphia PA-CADDRE
- Laura Line, MS, National Nursing Centers Consortium
- Erin Lopes Bak, MPH, PA-CADDRE & Early Autism Longitudinal Investigation
- Robert McKeown, PhD, FACE, University of South Carolina Arnold School of Public Health
- Cathy Melfi, Maternity Care Coalition in Philadelphia
- Lori Nelsen-Luneburg, PhD
- Craig J. Newschaffer, Drexel University School of Public Health
- Dennis M. O'Brien, PA House of Representatives
- Holly Peay, MS, CGC, National Coalition for Health Professional Education in Genetics
- Jennifer A. Pinto-Martin, PhD, MPH, University of Pennsylvania & CADDRE
- Glenn F. Rall, PhD, Fox Chase Cancer Center
- Scott Michael Robertson, Autistic Self Advocacy Network & ASCEND
- Michelle Rowe, PhD, Kinney Center for Autism Education & Saint Joseph's University
- Jean R. Rutenberg, The Center for Autism in Philadelphia
- Daniel Salmon, PhD, MPH, National Vaccine Program Office & John Hopkins University Bloomberg School of Public Health
- Maiken Scott, WHYYPH Philadelphia
- Marjorie Shulbank, Maryland State Dept. of Education
- Alison Singer, MBA, Autism Science Foundation
- Christopher Stodgell, PhD, University of Rochester School of Medicine
- Peter Szatmari, MD, MSc, McMaster University & Child Studies
- Holly Tabor, PhD, University of Washington School of Medicine & Treuman Katz Center for Pediatric Medicine
- Sholom Wacholder, PhD, National Cancer Institute
- Claudia Wallis, TIME Magazine & Columbia University
- Marshayn Yeargin, MD, CDC
- Michael Yudell, PhD, MPH, Drexel University School of Public Health

# Clinicians & Service Providers

- Require risk communication by professional organizations as part of continuing education requirements
- Develop risk communication “tool kits” for distribution to providers through various channels
- Improve content and resources supporting these efforts by emphasizing communication styles that “meet families where they are”
- Train professionals on how to best communicate risk information in the face of scientific uncertainty
- Prepare professionals to address emerging risk factors as they move into the public consciousness
- Establish a centralized resource, which compiles up-to-date evidence related to autism risk factors and is “vetted” by a broad range of stakeholders.
- Address the glaring need for families to understand more complex ideas about risk by including access to understandable information in the centralized resource

# Researchers & the Media

- Train autism scientists to handle the media by having them work closely with university press officers
- Develop a media tool kit for scientists to assist in dealing with the mainstream press
- Develop clear guidelines for reporting preliminary findings
- Support graduate training in risk communication with a particular focus on performing it accurately & ethically
- Include a separate allowance in grant awards for the funding of the dissemination of research findings

# Tailoring Risk Messages

- Present information on websites in an accurate, clear manner that conveys respect and encourages affected individuals and their families to explore their questions with trusted professionals
- Provide opportunities for voicing opinions, sharing feelings, offering different points of view, and asking questions either through webinars, town hall meetings, or social networks
- Provide a mechanism for direct one-on-one contact when possible
- Assist in improving the public's understanding of new findings by providing clear accurate interpretations, answering questions with accurate information, and allowing researchers the opportunity to post directly in articles or blogs.

# Dissemination of Research Results

- Develop protocols and approaches for the evaluation and possible return of results for autism studies including returning aggregate results when more appropriate
- Consider the clinical validity and utility of possible results as well as what they will possibly used for by recipients before their return
- Avoid the creation or amplification of therapeutic misconception in the return of results when addressing the purpose of research with participants
- Create guidelines for return of results in autism research by involving multiple stakeholders in the autism community, including affected individuals, their families, and advocacy groups. This could include the establishment of a national autism ethics advisory board
- Perform research into how study participants actually interpret and use research results to fill the lack of empirical data in this area

# Themes in Autism Risk Communication

- Uncertainty (in the face of certainty)
  - ▣ Communication of scientific findings, return of results
- Risk salience (prioritizing risk)
- Controversy
  - ▣ Vulnerable populations
- Blame (from parents to clinicians to science and medicine)
  - ▣ vulnerable populations, return of results
- Distrust
  - ▣ Access & barriers to care, culturally sensitive
- Health disparities
  - ▣ Justice, vulnerable populations, access & barriers to care