

Overview of ELSI

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**Ethical, Legal and Social Implications of Autism Research
Workshop
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Genesis of “ELSI”



genome.gov
National Human Genome Research Institute
National Institutes of Health

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-
-

[Home](#) > [Research Funding](#) > [DER Funded Programs](#) > **ELSI Research Program**

- DER Funded Programs**
- Centers of Excellence in Genomic Science
- DER Program Staff
- ELSI Research Program

ELSI Research Program

The Ethical, Legal and Social Implications (ELSI) Research Program

ELSI Research Program : [ELSI Planning and Evaluation History](#) : [ELSI Abstracts and Activities Database](#) : [ELSI Grant Publications and Products](#) : [ELSI Program Reports](#)

See Also:
[Grants Home](#)
[Office of Policy,](#)

genomics.energy.gov Human Genome Project Information · Genomic Science Program · DOE Microbial Genomics · home



Human Genome Project Information

- About the HGP
- Ethical / Legal Issues
- Medicine
- Education
- Gene Gateway
- Research Archive
- Sequence Databases
- Landmark Papers
- Sequence Insights
- Related Projects

Ethical, Legal, and Social Issues Research

Lessons learned

- Privacy, discrimination
- Psychosocial impact of genetic testing
- Attitudes towards and uptake of genetic testing
- Community engagement

ELSI issues: Research

- Informed consent
- Privacy and confidentiality
- Data sharing and use
- Recruitment and diversity
- Fair distribution of benefits



ELSI issues: Health care

- Fairness in and access to services
- Effectiveness and cost-effectiveness
- Informed consent
- Communication
- Health disparities



ELSI issues: Societal

- Concepts of risk and benefit
- Distinction between research and clinical practice
- Concepts of health and disease
- Implications for reductionism, determinism, free will, individual responsibility
- Understanding of relationships among humans and between humans and non-humans



ELSI issues: Legal, regulatory & policy

- Intellectual property
- Regulation of genetic testing
- Ownership and liability of biobanked samples
- Impact of genetic non-discrimination legislation
- Use of genetics in non-medical settings



Criteria for ethical research

- Scientific or social value

- Scientific validity
- Fair subject selection
- Favorable risk:benefit ratio

- Independent review

- Informed consent
- Respect for potential and enrolled participants

- *Emanuel et al. 2000 JAMA 283:2701*

Independent review

- Current review based on:
 - Recognition of conflict of interest
 - Power differential
- IRBs formed to mitigate conflict of interest
- Relationship between researchers and participants has changed
 - Funding
 - Research design
 - Access to research materials and data
 - Ownership

Independent review

- ASD vs ADHD funding and COI
 - 31% of articles on ADHD vs 6% on autism in PubMed had a disclosed COI
 - 10% for-profit funders of ADHD research vs 1% of autism research

Scientific or social value

- What are the benefits of the research?
- Who decides what constitutes benefit?

neurotypical Normal is a cycle
on a washing machine.

What is the standard that identifies one person as whole and capable and another as disabled and broken?

neurodiversity.com

Neurotypical Issues

See also: Abuse Bullying Psychological Defense Mechanisms
Discrimination Sociopathology

Offering a mix of humorous and drop-dead serious examinations of states of mind often characterized as "normal."

Scientific or social value

- Oxytocin study
 - Enhancement
 - Medicalization of normal behavior
- Prenatal genetic testing
 - Prenatal genetic counseling patients indicated desire to use prenatal testing for:
 - 75% for “mental retardation”
 - 13% for “superior intelligence”
 - *Hathaway et al. 2009*

FEBRUARY 12, 2009

CURRENTS

A Baby, Please. Blond, Freckles -- Hold the Colic

Laboratory Techniques That Screen for Diseases in Embryos Are Now Being Offered to Create Designer Children

By GAUTAM NAIK

Unnatural Selection | How to increase the chances of having a green-eyed, blond-haired daughter

Embryos



A woman's eggs are fertilized with sperm in a lab, creating several embryos.

Embryos identified with markers



A single cell is removed from each embryo, and then tested for biomarkers associated with the female gender, green eyes and blond hair.



Only embryos with the biomarkers for the required traits are placed in the woman's womb.



The procedure virtually guarantees that the child will be female and increases the probability it will have green eyes and blond hair.



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Measures of Intelligence - Sample Report

[» view all sample reports](#)

[Preliminary Research report](#) on 1 reported marker.

Example Data

About Measures of Intelligence

Though genetics clearly plays a role, the relative significance of nature and nurture in determining a person's intelligence is highly controversial. Even the nature of intelligence and the validity of tools used to measure it are subject to great debate. While some aspects of intelligence – such as mathematical ability – lend themselves to standardized testing, others are much more difficult to quantify. Recent studies estimate that in early childhood about 25 - 40% of individual variation in measurable intelligence can be attributed to genetics. In adults, this number increases to about 80%.



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- IQ (intelligence quotient)
- EQ (emotional quotient)
- Athletic Abilities
- Character
- Health
- Environmental Sensitivity
- Artistic Creativity
- Addiction Susceptibility

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(1) Character

- 1 Optimism Gene
- 2 Risk Taking Gene
- 3 Sociable Gene
- 5 Persistence Gene
- 6 Shyness Gene
- 8 Composure Gene
9. Split Personality Gene
- 11 Depression Gene
- 12 Impulsive Gene
- 13 Attentiveness/Focused Gene
- 15 Mould-ability/Adaptability Gene

(2) Intelligence (IQ)

- 19 Creative Gene
- 21 Analytical/Thinking Gene
- 23 Comprehension Gene
- 25 Memory Gene
- 26 Intelligence Gene

(3) Emotion (EQ)

- 28 Affectionate Gene
- 29 Faithfulness/Loyalty Gene
- 30 Passion/Enthusiasm Gene
- 31 Propensity for Teenage Romance Gene
- 34 Sensitivity/Sentimentality Gene

(4) Artistic Gene

- 35 Performing Gene
- 37 Musical Gene
- 38 Drawing Gene
- 40 Dancing Gene
- 42 Linguistic/Literature Gene

(5) Sport

- 44 Endurance Gene
- 46 Explosive Power Gene
- 49 Technique/Skill Gene

(6) Environment

- 49 Sensitivity to Second-Hand Smoke Gene
- 51 Insensitivity to Second-Hand Smoke Gene

(7) Health

- 51 Myopia Gene
- 55 Obesity Gene
- 57 General Wellness Gene

(8) Addiction

- 59 General Addiction/Obsession (Internet, Games, TV)
- 61 Self Detoxifying Gene
- 63 Alcoholism Gene
- 65 Smoking Gene
- 67 Anti Intoxication Gene
- 68 Alcohol Intoxication Gene

Question 1

- What is needed to heighten awareness of ELSI issues, and approaches to address those issues, in the autism research community?

Developing methods to integrate community values into research

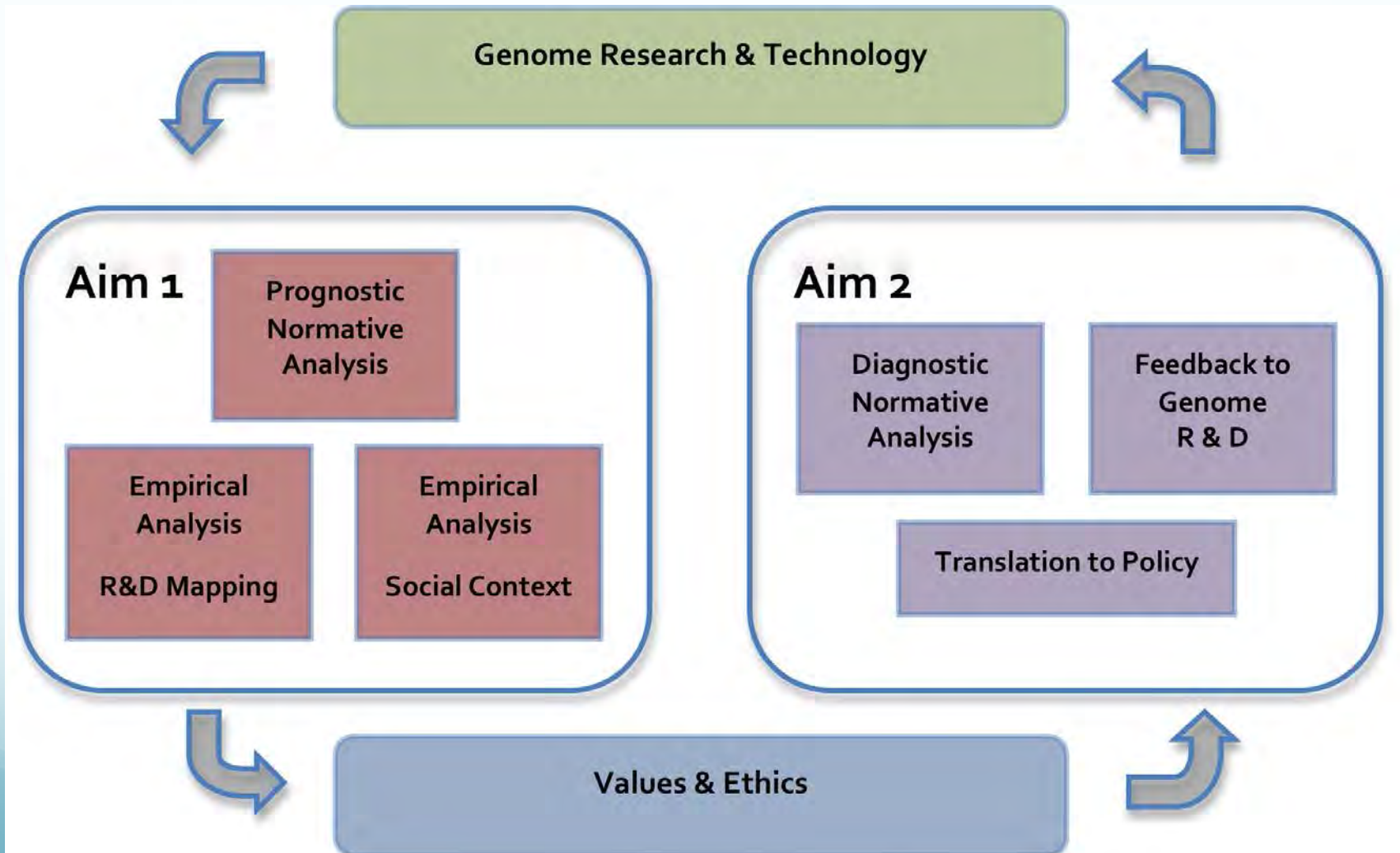
Question 2

- What ELSI issues in autism require targeted research?

Assessing perceptions of benefit from research

Evaluating ethical and scientific impact of changing relationship between researchers, participants and autism community on research

CIRGE Research Program



INVEST model

