

THE GURU PROGRAM: “NO ELSI ABOUT US WITHOUT US”

Leslie Francis, University of Utah
Aubrey Mansfield, University of Utah
Maya Sabatello, Columbia University
Jim Tabery, University of Utah

A BIT OF BACKGROUND: NHGRI'S ELSI AND DIVERSITY ACTION PLAN PROGRAMS

- The ELSI (Ethical, Legal, and Social Implications) Program
 - Created in 1990 as a core element of Human Genome Project funding, aimed at identifying, analyzing, and addressing how the information obtained from the Human Genome Project should be responsibly accessed and used.



Image source: NHGRI

A BIT OF BACKGROUND: NHGRI'S ELSI AND DIVERSITY ACTION PLAN PROGRAMS

- The Diversity Action Plan (DAP) Program
 - Created in 2002 to increase diversity among the pool of scientists and scholars studying genomics and ELSI
 - NHGRI currently hosts over a dozen DAP programs spread out across the United States
 - The University of Utah's GURU Program was the first DAP ever to focus on disability



Image source: NHGRI

THE GURU PROGRAM: WHY?

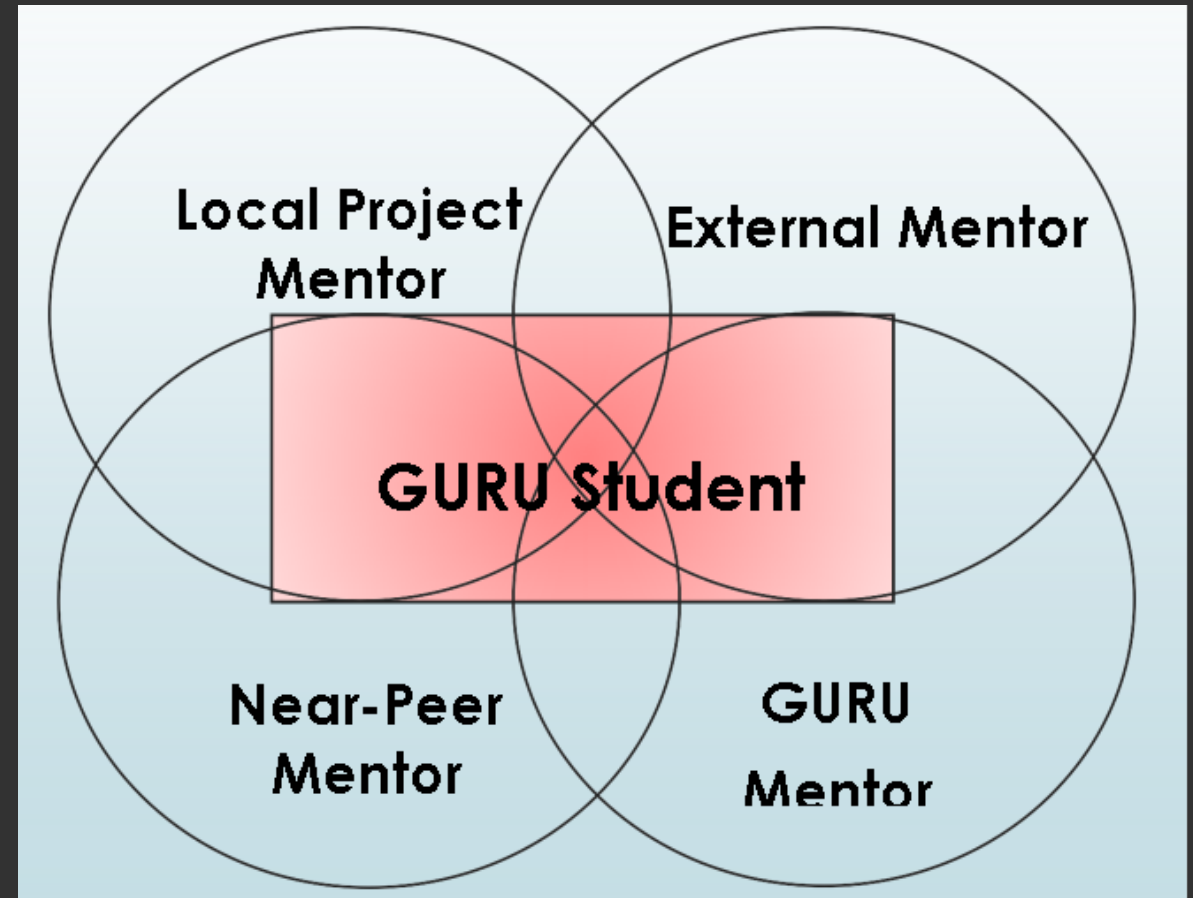


Uceer
Utah Center for Excellence
in ELSI Research

- Utah Center for Excellence in ELSI Research (UCEER), created in 2016, has historically focused on prenatal and newborn genetic screening and testing.
- Disability community principle: “Nothing about us without us.”
- Result: Graduate and Undergraduate Researchers of UCEER (GURU) Program, created in 2018
- Hope: No ELSI about us without us.

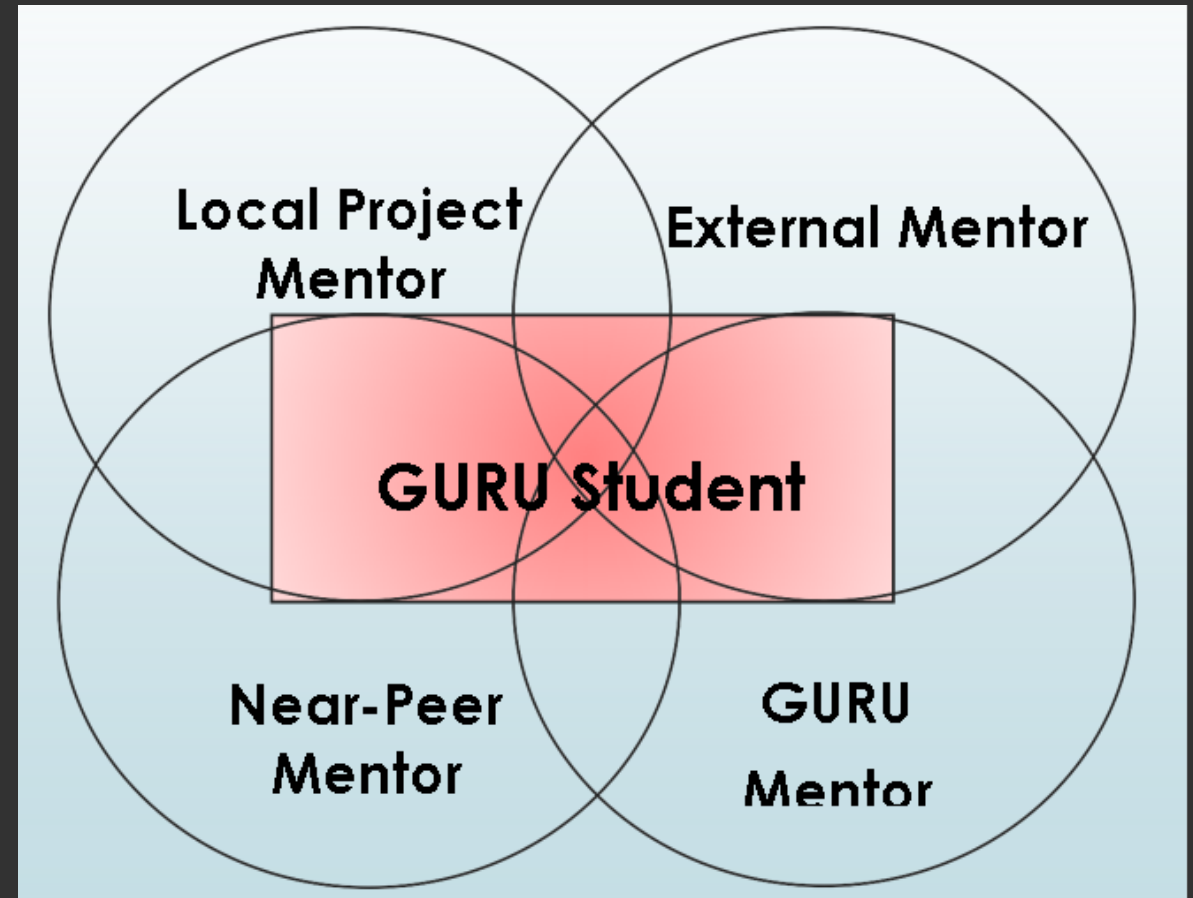
THE GURU PROGRAM: WHAT?

- The Mentorship Network
 - Local (i.e. Univ. of Utah) project mentor
 - External mentor
 - Near-peer mentor
 - GURU mentor



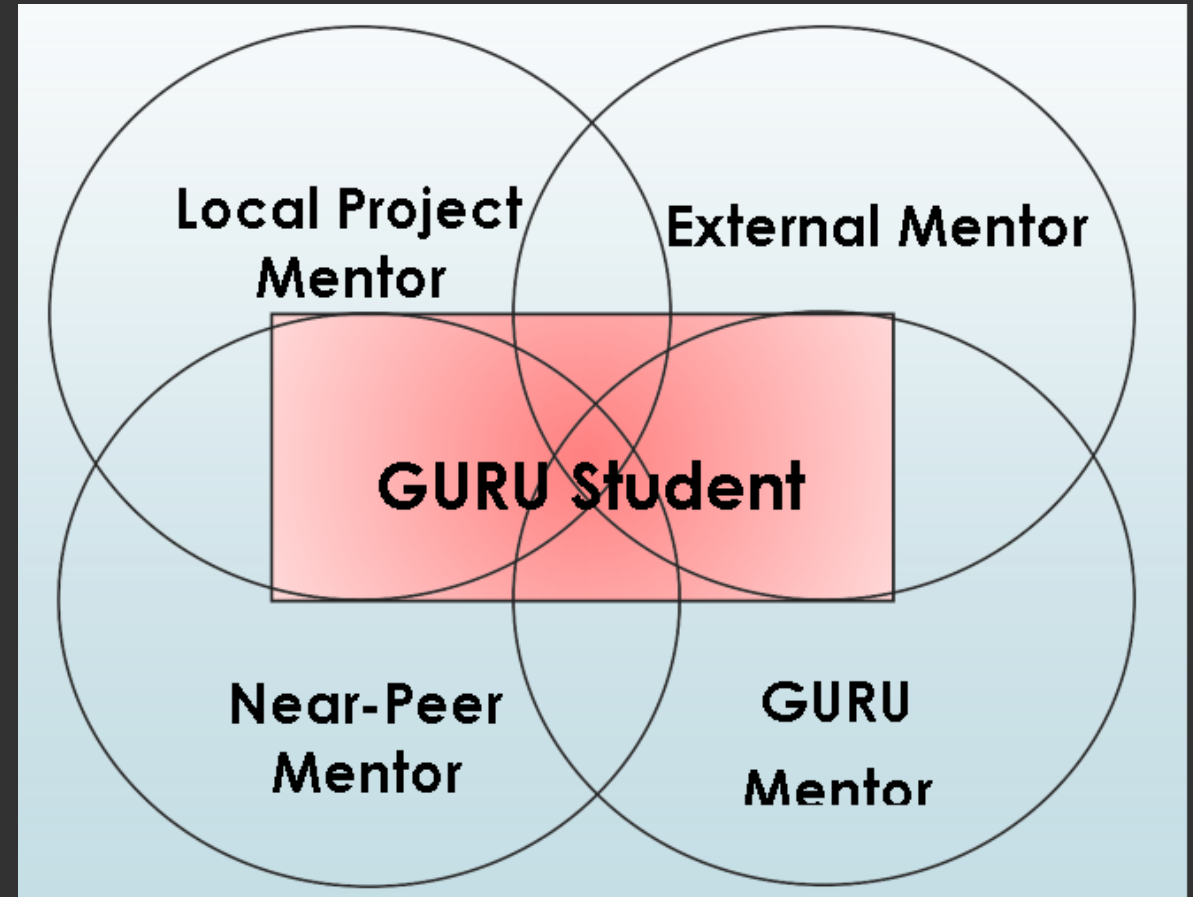
THE GURU PROGRAM: WHAT?

- Also
 - Curricular resources (e.g., ELSI course offerings, training in the responsible conduct of research)
 - Research resources (e.g., funds for conference travel/presentation, funds for conducting own research)
 - Membership in the UCEER Mentored RAs community



THE GURU PROGRAM: WHAT?

- Participants
 - 4 students/year (15 students since 2018-2019)
 - Placement: genetic counseling program, medical school, graduate school, private industry (genetics/genealogy company), academic position, research administration



THE GURU PROGRAM: WHO?



• **Maya Sabatello LLB, PhD:** Associate Professor at Columbia University, specializing in law, bioethics, and disability, particularly with issues revolving around precision medicine research. Maya has been one of the *External Mentors* in the GURU Program since its inception.

THE GURU PROGRAM: WHO?



- **Aubrey Mansfield:** Graduate student at the University of Utah, earning her master's degree in recreational therapy. Aubrey joined the program as one of the *GURU Students* in 2021-2022 and has returned to participate in 2022-2023.

THE GURU PROGRAM: WHO?



- **Leslie Francis JD, PhD:** Distinguished professor of law and philosophy at the University of Utah, specializing in privacy/confidentiality, bioethics, and disability, particularly with issues revolving around health care. Leslie has been a *Local Project Mentor* working with GURU students every year that the program has existed.

THE GURU PROGRAM: WHO?



- **Jim Tabery PhD MA:** Professor of philosophy at the University of Utah, specializing in bioethics as well as the history and philosophy of science, with a particular focus on genetics. Jim has been one of the PIs for the GURU Program and the *GURU Mentor* from the very beginning.

THE GURU PROGRAM: A CONVERSATION ABOUT SUCCESSES, LESSONS, AND CHALLENGES

(1) Mentor-Mentee Matching and the GURU Experience

What attracted you to the program, and what have you gotten out of participating?

What makes somebody a well-matched mentor in a program like this?

What does it mean to have the same disability, or have the same research interest? Does matching matter?

How does it work to be involved as an abled mentor?



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THE GURU PROGRAM: A CONVERSATION ABOUT SUCCESSES, LESSONS, AND CHALLENGES



(2) Structural Ableism in the Academic and Research Environments



Where does a program like GURU bump into structural ableism in the academic/research environment, which challenges its anti-ableist agenda?



THE GURU PROGRAM: A CONVERSATION ABOUT SUCCESSES, LESSONS, AND CHALLENGES

(3) Identity and Privacy

How do we balance the priority placed on incorporating the perspective of people who have experience living with disability against one-dimensionally reducing participants to a single characteristic?

Does a program like GURU which centralizes around disability make it harder to be cognizant of issues of intersectionality, or harder on participants who don't see disability as central to their identity?

How should a program that revolves around disability protect the privacy of those students who do not wish to have their disability status known?



THANK YOU



**We look forward to hearing
from and learning from you!**

