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# NHGRI Community Engagement in Genomics Working Group

**Greta L. Goto, MBA and Maya Sabatello, LLB, PhD**

Co-Chairs, NHGRI Community Engagement in Genomics Working Group

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National Human Genome  
Research Institute

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# Mission

- The NHGRI Community Engagement in Genomics Working Group (CEGWG) was established in 2017 as a working group of the National Advisory Council for Human Genome Research. The goals of the working group are to facilitate NHGRI's understanding of community perspectives and needs about genomics, engage and educate diverse communities about genomics, and inform the leadership of NHGRI of issues relevant to its portfolio of genomics research and related programs.

<https://www.genome.gov/about-nhgri/National-Advisory-Council-for-Human-Genome-Research/Community-Engagement-in-Genomics-Working-Group>

# Goals

- Assess the gaps and needs of diverse communities related to genomics and genomic medicine.
- Develop programs and disseminating tools and resources to address identified gaps and needs.
- Provide input about NHGRI activities, particularly about their ability to reach all communities and to increase genomic literacy.
- Work in partnership with NHGRI to build relationships and trust with communities and to increase understanding of diverse communal views and priorities relevant to genomics.
- Identify potential areas of synergy or collaboration among communities, NHGRI, other National Institutes of Health institutes or centers and national and international organizations.

# Co-Chairs

**Greta L. Goto, M.B.A.**

Founding Member

Prader-Willi Syndrome Alaska Parent Group

**Maya Sabatello, LLB, Ph.D.**

Associate Professor of Medical Sciences

Co-Director, Precision Medicine: Ethics, Politics and Culture Project

Department of Medicine & Department of Medical Humanities and Ethics

Columbia University

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# Members

## **Rebecca Bakal, M.P.H.**

Program Manager, Health Equity and Assessment Research, Sinai Urban Health Institute

## **Kellan Baker, Ph.D.**

Executive Director, Whitman-Walker Institute

## **Gwen Darian**

Executive Vice President, Patient Advocacy and Engagement, National Patient Advocate Foundation

## **Gregory Diggs-Yang, Ph.D.**

Assistant Director, Stacey Nicholas Office of Diversity and Inclusion, University of California, Irvine

## **Brittany Hollister, Ph.D.**

Academic Program Specialist, University of Florida, Genetics Institute

## **Alma McCormick**

Executive Director, Messengers for Health, Crow Nation

## **Ella Greene-Moton**

Administrator, Community Based Organization Partners (CBOP) Community Ethics Review Board (CERB); Independent Contractor, Community-Academic Bridge

## **Alicia Santiago, Ph.D.**

Program Director, Directorate for STEM Education  
National Science Foundation

## **Ad Hoc:**

### **Michael Hahn**

Tribal Engagement Lead  
NIH *All of Us* Research Program

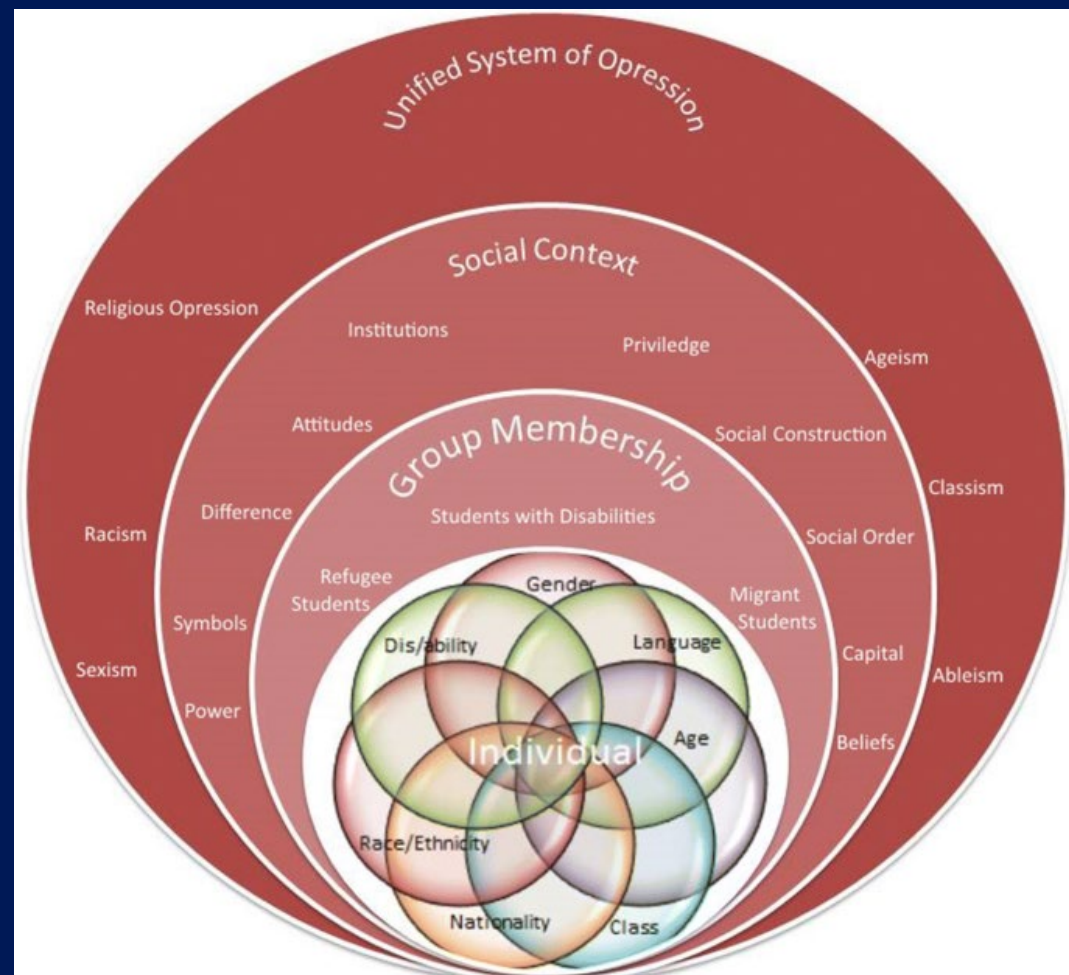
# Project One: Intersectionality and Trust

## *Working titles*

- The Need for an Intersectionality Framework in Precision Medicine Research
- Distrust in Genomic Medicine: The Need for an Intersectionality Lens

# Intersectionality Approach

- Multiple overlapping sociopolitical identities that are mutually constituted
- Systems of power & privilege influence lived experiences and create oppressed & marginalized populations
- Social justice



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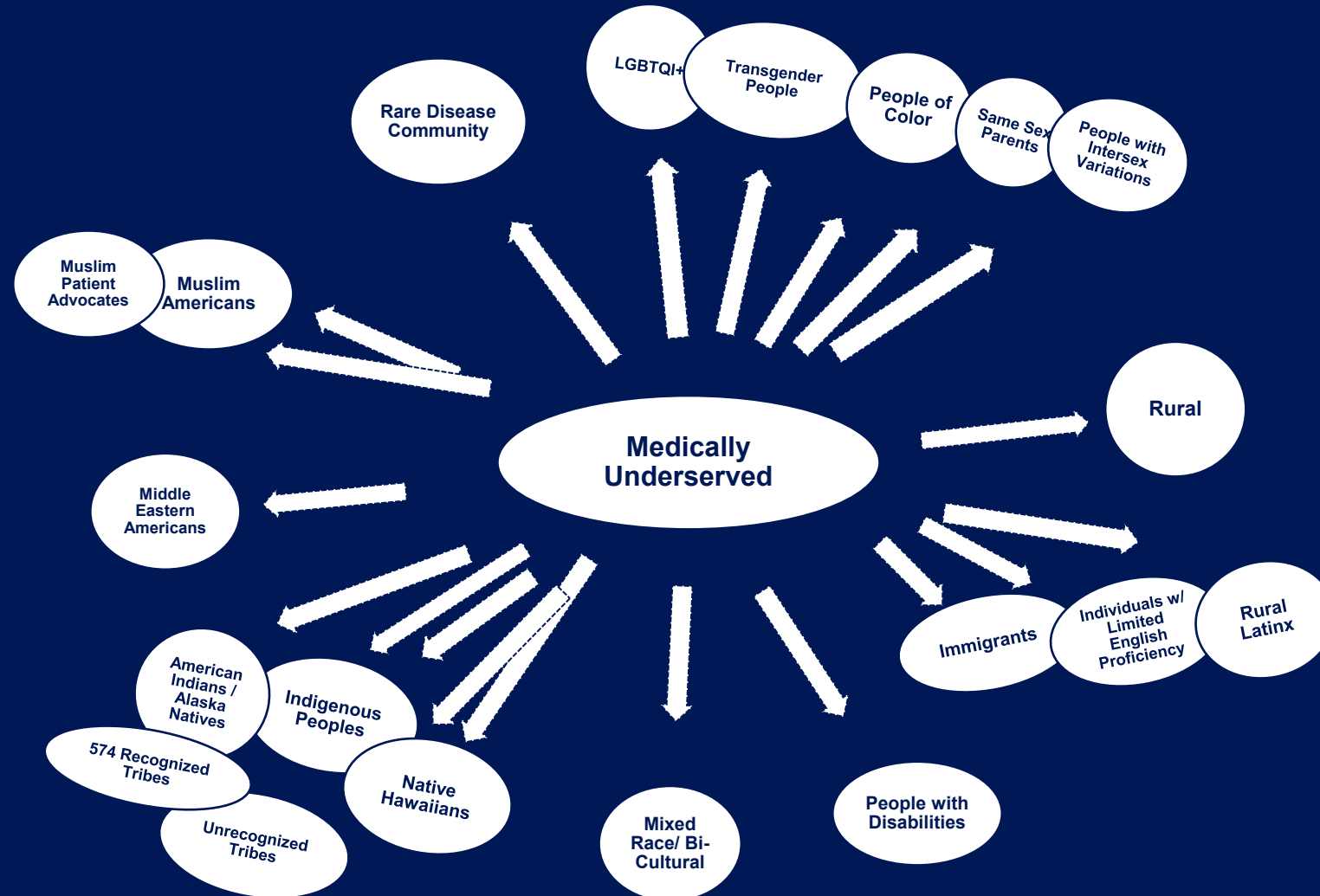
# Project Two: Community Outreach Concept Mapping

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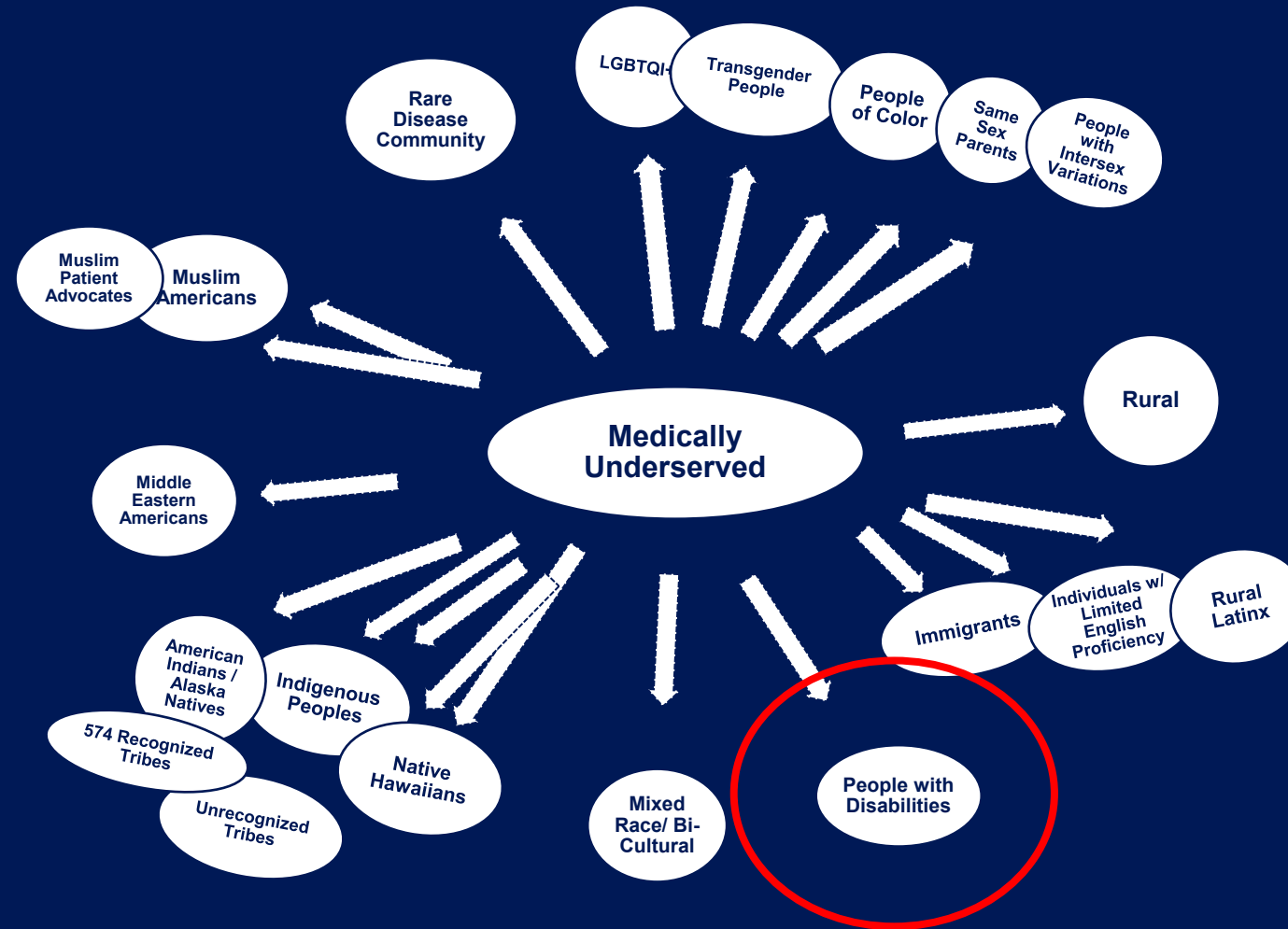
- One community that NHGRI should approach is \_\_\_\_\_.
- One sub-community that NHGRI should bring attention to is \_\_\_\_\_.
- One way that NHGRI can approach these communities is \_\_\_\_\_.



# Communities that NHGRI should approach include:

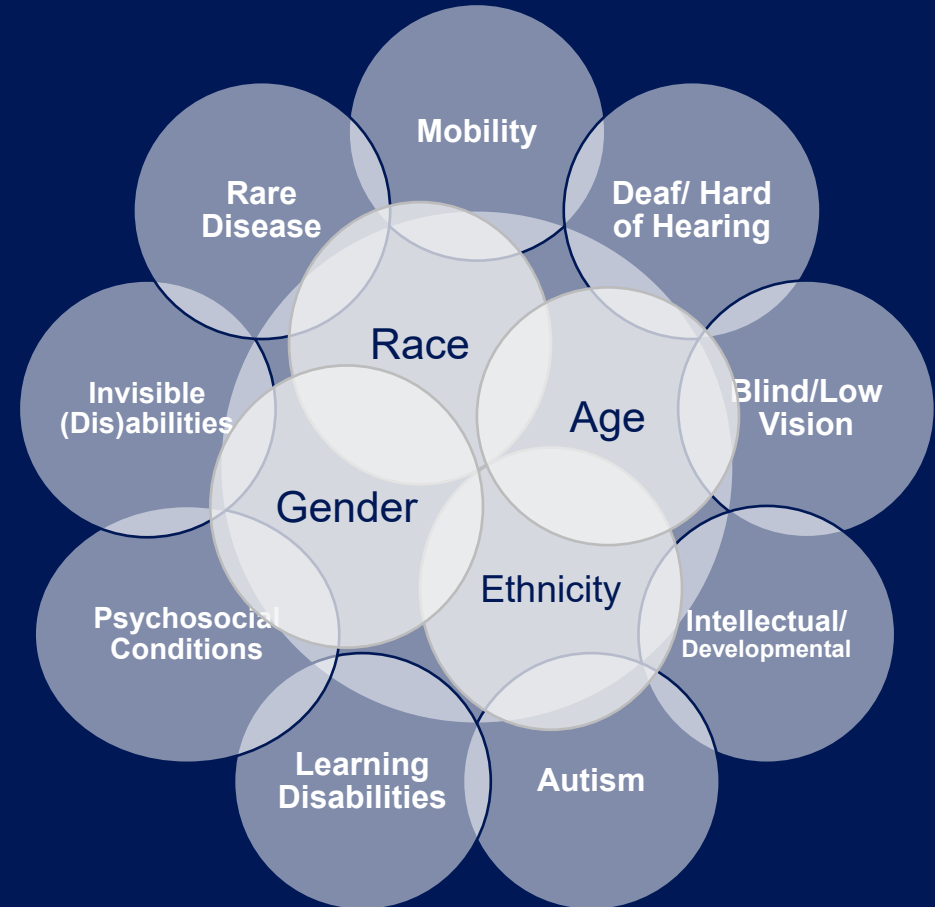


# Communities that NHGRI should approach are People who live with (Dis)abilities.

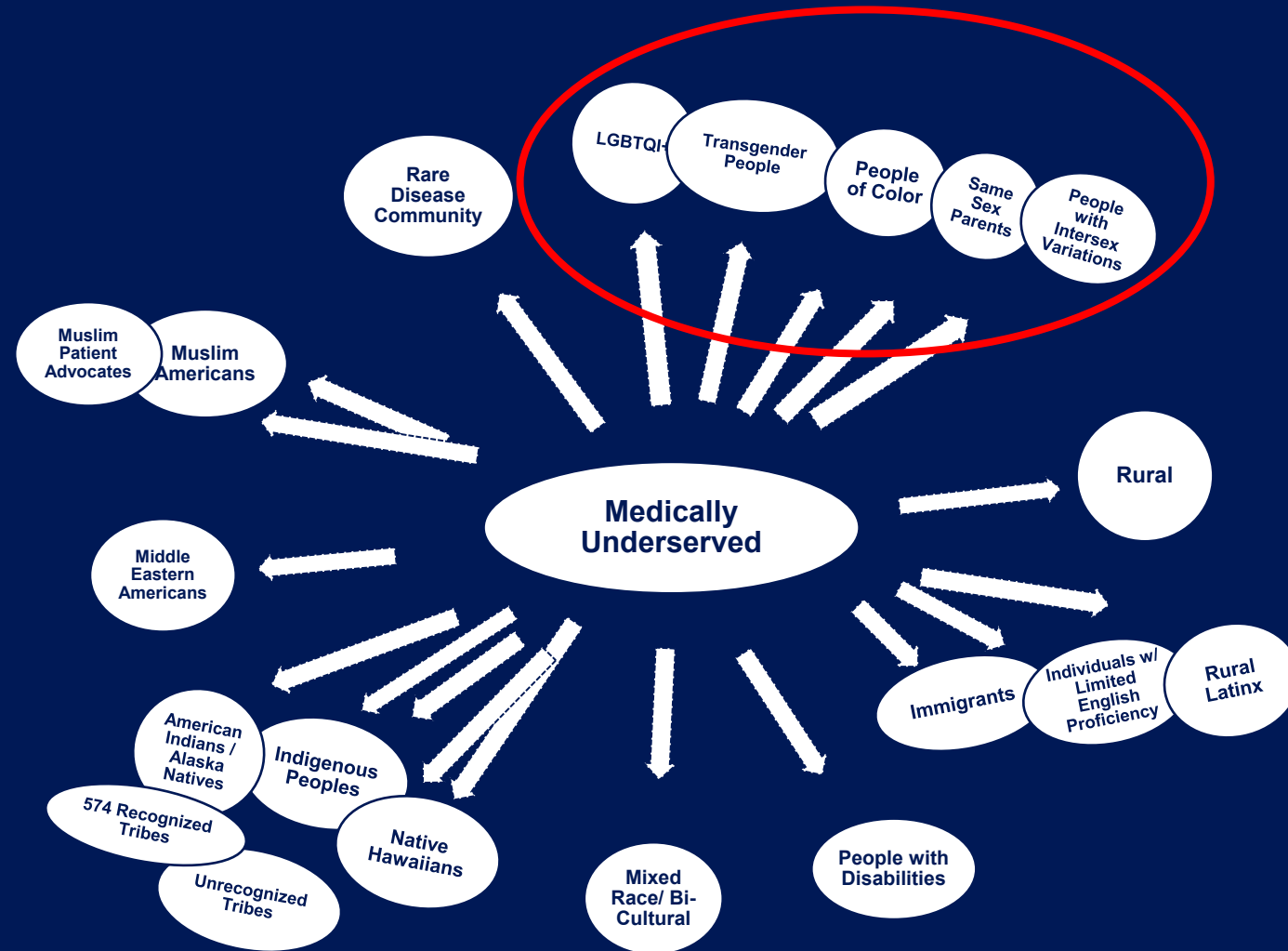


# People who live with (Dis)abilities example *(draft)*

- Approaches:
  - NHGRI
    - Inclusive Studies
    - (Dis)ability cultural competency
    - Training and workforce development
  - Researchers
    - Personal Contact
    - Connecting with the community outside of research or clinical settings

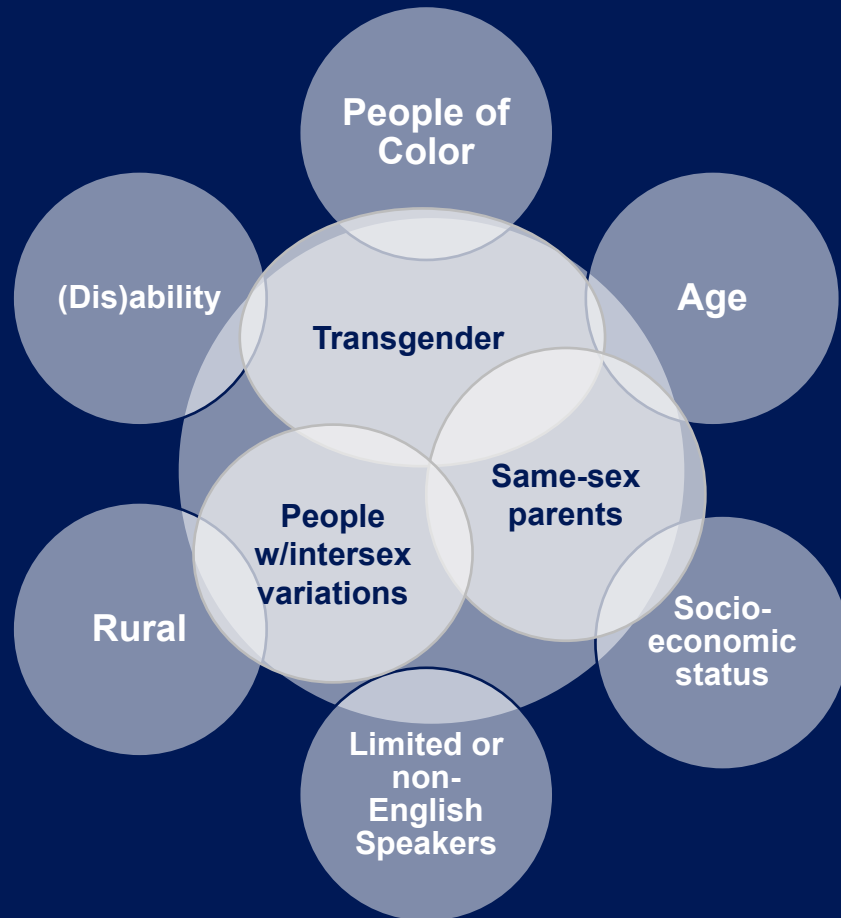


# A community that NHGRI should approach is LGBTQI+.



# LGBTQI+ example *(draft)*

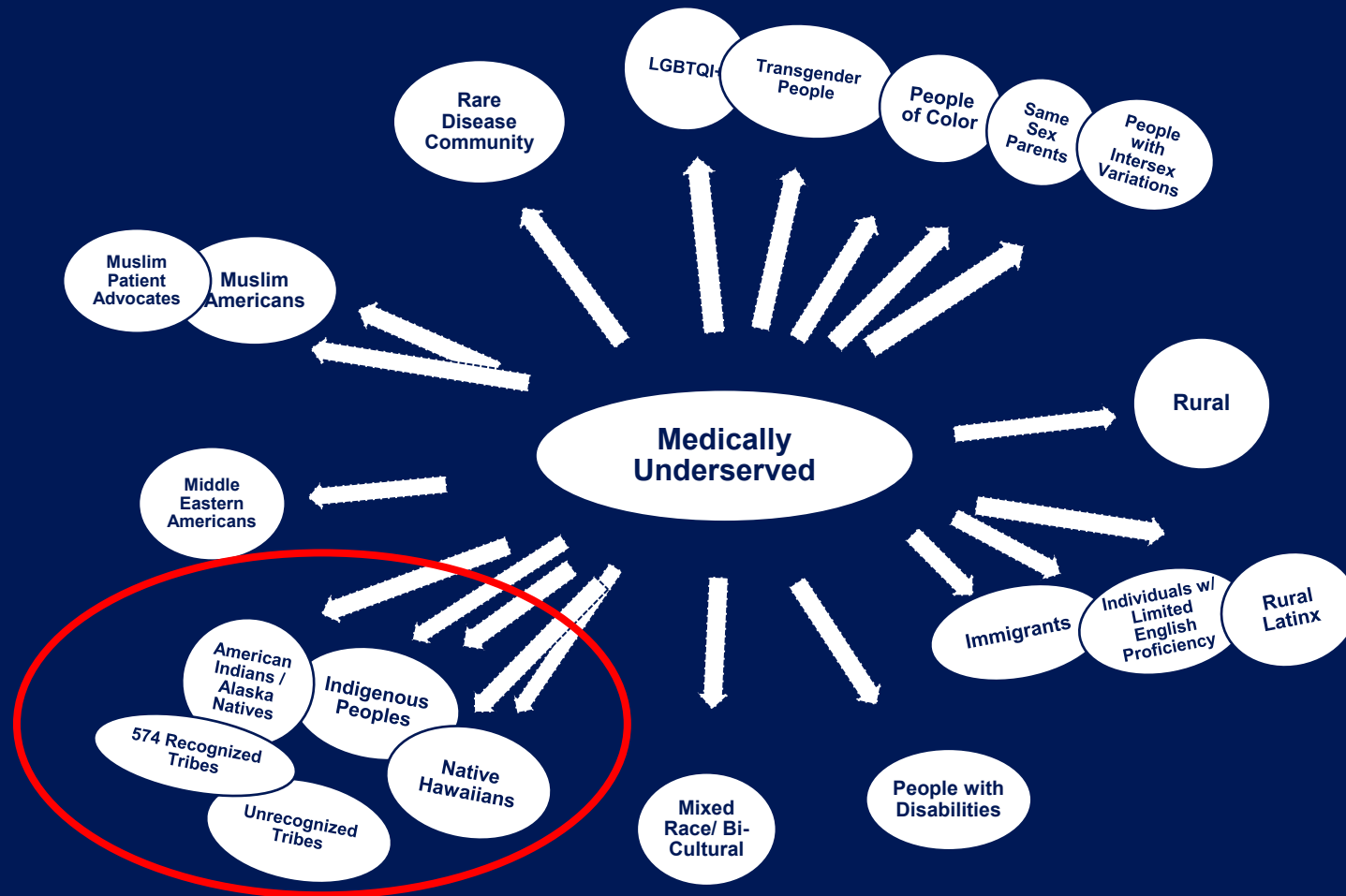
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- Approaches:

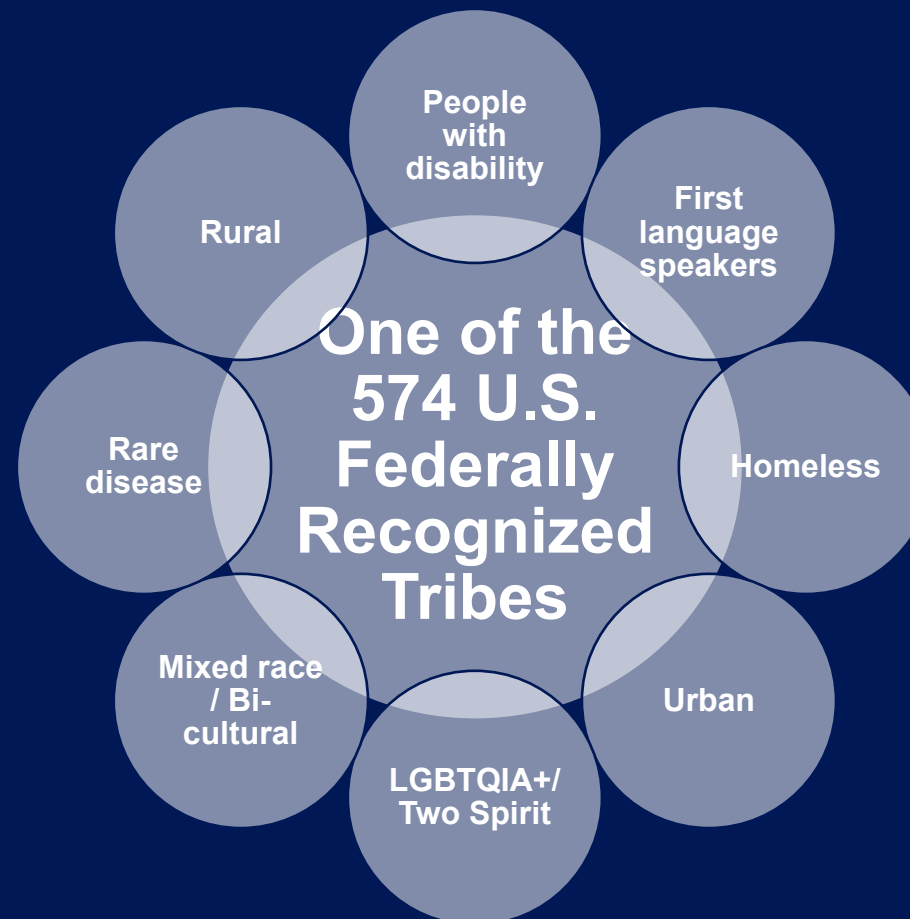
- Work with ISCC-PEG to develop and publish resources for [genome.gov](http://genome.gov)
- Host a symposium on LGBTQI+ issues in genomic research and medicine
- Push for the collection of sexual orientation, gender identity, and variations in sex characteristics (SOGISC) data on studies supported by NHGRI
- Require NHGRI-supported studies to include these populations or justify their exclusion

# A community that NHGRI should approach is the Indigenous community.



# Indigenous Communities example *(draft)*

- Approaches:
  - Researchers
    - Personal Contact (IHS or Tribal Clinic)
    - Identify Community Liaison
    - Community Liaison and researcher co-design and guides approach
    - Develop and nurture culturally appropriate relationship(s)



# Community Outreach & Collaboration

- Gwen Darien, Kellan Baker & Greta Goto – National Academies of Sciences, Engineering and Math: Workshop on Realizing the Potential of Genomics Across the Continuum of Precision Health Care
- Ella Greene-Moton – President-Elect of the American Public Health Association
- Maya Sabatello – American Society of Human Genetics Community Engagement Guidance & NHGRI Symposium on Disability and Genomics
- Kellen Baker & Maya Sabatello – NHGRI Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC-PEG) Project Group Co-Chairs



# Contact Information

## CEGWG Co-Chairs

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## CEGWG NHGRI Staff Liaisons

Christina Daulton – [christina.daulton@nih.gov](mailto:christina.daulton@nih.gov)

Belen Hurle - [bhurle@mail.nih.gov](mailto:bhurle@mail.nih.gov)

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# In Memorium

**Mary Jackson Scroggins**  
Founding Partner, Pinkie Hugs  
Co- Founder, In My Sister's Care



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