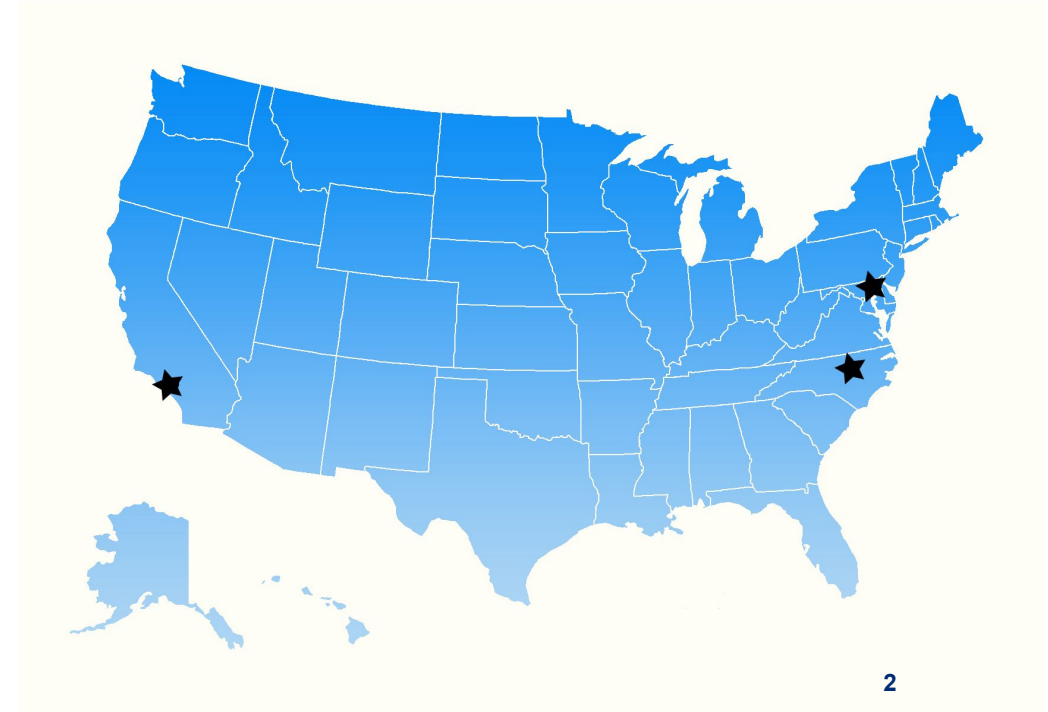# About NHeLP

- National non-profit law firm committed to improving health care access and quality for underserved individuals and families
- Offices: CA, DC, NC
- Join our mailing list at www.healthlaw.org
- Follow us on Facebook & Twitter @nhelp_org and @marayoudelman

NHeLP's Demographic Data Partners

DREDF

Disability Rights Education & Defense Fund

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

MAP

movement advancement project ▶

race forward

Who counts depends on who is counted.

N. S. Reed, et al., "Disability and COVID-19: Who Counts Depends on Who Is Counted," *Lancet Public Health*, vol. 5, no. 8 (2020): e423.

Opportunities

- Ensuring compassionate, appropriate individual care
- Shaping & planning institutional programs and services
- Improving understanding of disparities at a state or national level
- Establish and Evaluate Policy
- Program management, service, analysis, research, and other useful activities

Concerns

- Use of demographic data should be limited to purpose for which it is collected
- Improper use undermines public trust and exposes underserved groups to further discrimination and inequitable treatment
- Demographic information can accidentally or unintentionally fall into the hands of third party data miners or allow for re-identification of individual subjects
- Without transparency and clarity in how demographic information will be used, data collection can generate skepticism or mistrust in systems that are actually meant to improve health care quality and prevent historical discrimination

Concerns contd.

- Missteps or misuses render demographic data more harmful than helpful and work against the purpose of improving health care access and outcomes across all populations
- HIPAA only applicable to certain actors and in regard to data collected in health arena
  - "Big Data" often mines way beyond health data – health & fitness apps, social media, etc.
  - "Big Data" can also sell to health providers which can use it to make incorrect ass
- Potential for re-identification if a data snooper combines datasets so can identify individuals
  - Have to be extra careful with smaller numbers of individuals
  - Have to be careful when merging different data sets
  - umptions and false correlation

Recommendations

- Collect comprehensive demographic data
- Fund research on the best ways to solicit accurate answers to demographic data collection questions
- Train staff to appropriately ask demographic data questions
- Develop privacy protections beyond HIPAA, particularly for entities that collect, store, analyze and sell health-related Big Data
- Ensure that existing nondiscrimination protections apply to the consequences that can arise of Big Data entities or those they sell to misuse the data
- Hold insurers and other HIPAA-covered health entities accountable for their use of Big Data by making them responsible for outreach & public education on Big Data and how it an be distinguished from demographic data

Resources

- [Demographic Data Collection in Medicaid & CHIP: CMS Authority to Collect Race & Ethnicity Data](#), NHeLP

- [The Constitutionality of Demographic Data Collection](#), NHeLP

- Data Privacy Series:
  - [Administrative Data: Providing Information to Advance Autonomy and Drive Equality](#), Movement Advancement Project
  - [Striking the Balance: Approaches to Racial Equitable Data Collection that Protect Privacy in Health](#), Race Forward
  - [This Data Not That Data: Big Data, Privacy, and the Impact on People with Disabilities](#), Disability Rights Education and Defense Fund
  - [Data and Discrimination: Improving Data Privacy for Low-Income Older Adults in Managed Care](#), Justice in Aging

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