



**CENTER FOR HEALTH  
POLICY RESEARCH**

# Disaggregation Nation

# UCLA Center for Health Policy Research

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# Navigating and Improving State Data Systems

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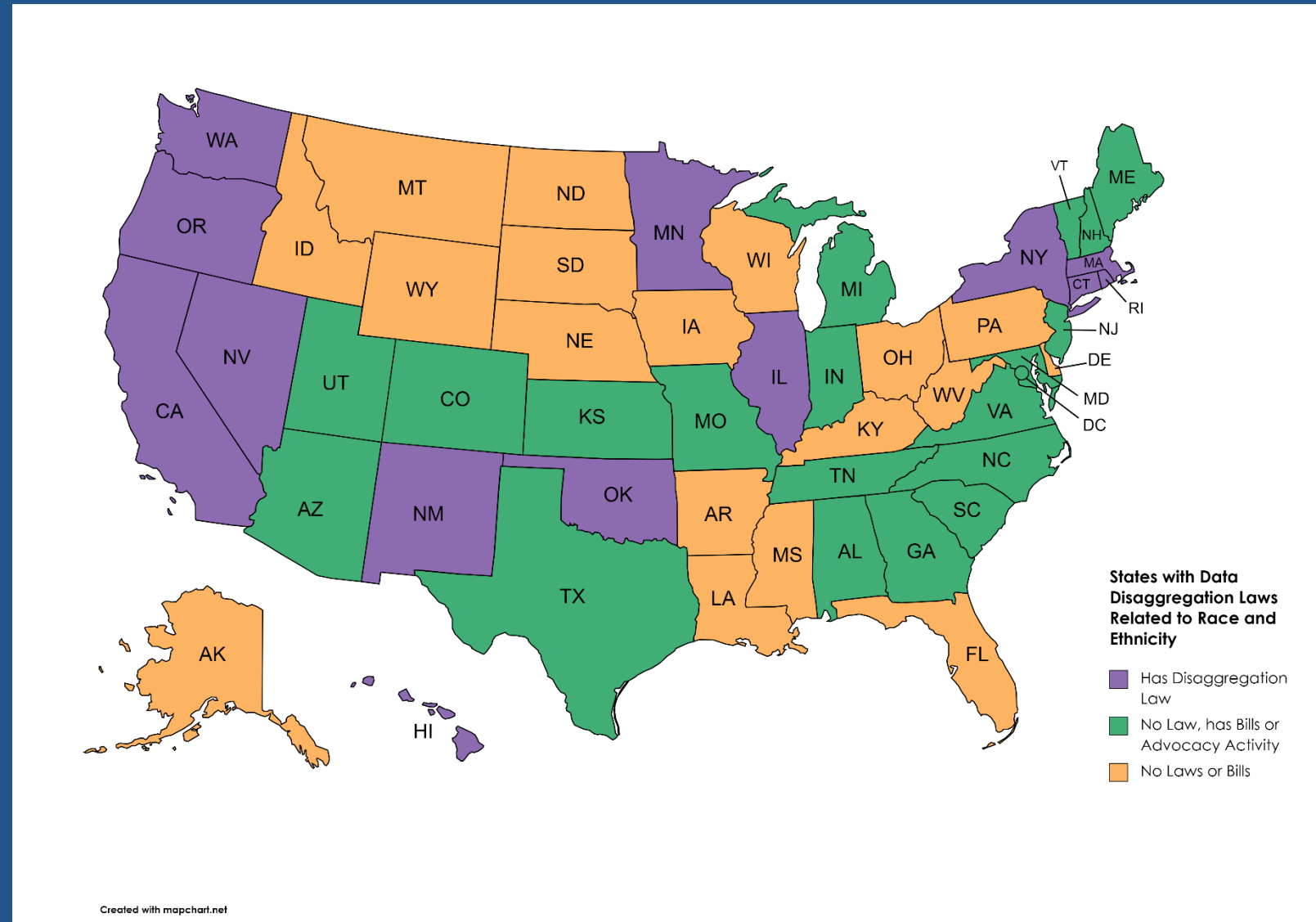
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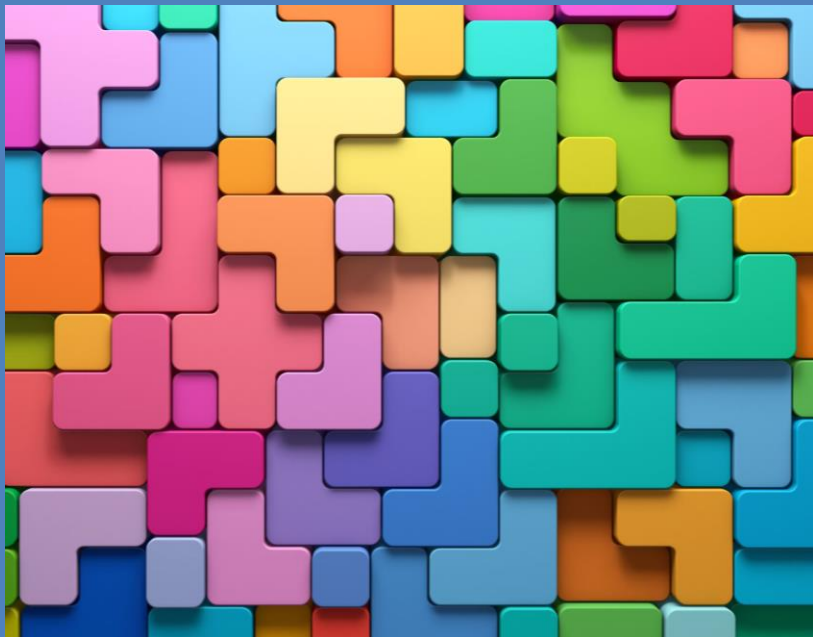
# THE STATE OF DATA DISAGGREGATION

# The State of Data Disaggregation

- 13 states have laws
- 19 states have bills or advocacy activities but no laws
- 18 states have no laws or bills



# Summary: State Data Disaggregation Laws



- **13 states:** require data disaggregation of race and ethnicity data beyond federal standards
- **4 state laws were** passed in 2023: HI, IL, MA, NV
  - *CA law vetoed: disaggregation for Latino and Mesoamerican Indigenous groups*
- **CT, MA, OR and WA** have the most expansive laws

# Which Groups Have To Be Disaggregated?

State	American Indian or Alaska Native	Asian	Black or African American	Hispanic or Latino	Middle Eastern or North African	Native Hawaiian or Pacific Islander	White
California		X	X			X	
Connecticut	X	X	X	X	X	X	X
Hawaii		X				X	
Illinois					X		
Massachusetts		X	X	X		X	X
Minnesota	X	X	X	X		X	
Nevada					X		
New Mexico	X						
New York		X				X	
Oklahoma	X						
Oregon	X	X	X	X	X	X	X
Rhode Island		X					
Washington		X	X	X	X	X	X

# Does Law Name Specific Groups?

## Names Specific Groups

- California
- Connecticut
- Hawaii
- Illinois
- Massachusetts
- Nevada
- New Mexico
- New York
- Oregon
- Rhode Island
- Washington

## Most Populous Groups

- Minnesota (Karen community)
- New York

## Not Specified

- New Mexico
- Oklahoma
- Washington (student data)



# How Broadly Does the Law Apply?

## Single Agency

- California
- Minnesota
- Oklahoma
- Rhode Island

## Multiple Agencies

- California
- Connecticut
- New Mexico
- Oregon
- Washington

## All Agencies

- Hawaii
- Illinois
- Massachusetts
- Nevada
- New York

# Legislative Language and Implementation

## Responsibility

- Specifies entity tasked with developing standards?
- With carrying out collection and reporting?

## Reporting

- Requires reporting on progress to legislature or public?
- Progress on implementation and/or data collection?

## Mandates Use

- Does the law mandate use of disaggregated data?
- Available to the public?

# Funding and Implementation

- Is funding provided?
- Is funding available from elsewhere?
- Enforcement
  - Often not mandated due to cost
- Examples
  - Massachusetts
  - Oregon
  - Minnesota



# EXAMPLES TO SHARE?

# STATE AND LOCAL LAWS

# Using Local Law to Implement and Extend State Law

- In 2015, the California legislature passed AB 959 (Chui), The Lesbian, Gay, Bisexual, and Transgender Disparities Reduction Act, which adds Section 8310.8 of the Government Code to direct 4 specific state departments to collect voluntary self-identification information pertaining to sexual orientation and gender identity
- In 2016, the San Francisco Board of Supervisors passed Ordinance 159-16, which amended the City's Administrative Code to require covered City departments to collect and analyze data concerning sexual orientation and gender identity (SOGI) of the clients they serve

# Comparison of State and Local Laws

## State of California

- Deadline for compliance: July 1, 2018
- Identifies 4 covered state departments
- Requires covered departments to report collected data and methods used to collect data to the Legislature, except:
  - Personally identifiable data, which is protected from disclosure, or statistically unreliable estimates
  - Where guidelines for demographic data categories are defined by a federal program or survey
  - Where survey data is collected by third parties and not solely-funded by the covered department
- Outlines legitimate uses of the data collected

## City and County of San Francisco

- Begin Collection by: July 1, 2017
- Identifies 6 covered entities (offices and departments)
  - Includes entity contractors and grantees with award amounts exceeding \$50,000
- Tasks the SF Dept of Public Health with developing and maintaining standards
- Requires entities to have plans to protect data privacy
- Requires annual reports on compliance submitted to City Administrator
- Mandates use of SOGI data to examine disparities
- Requires covered departments to develop action plans to address reported disparities

# SOGI Data Collection: Covered Entities

## State of California

- California Department of Health Care Services
- California Department of Public Health
- California Department of Social Services
- California Department of Aging

## City and County of San Francisco

- San Francisco Department of Public Health
- The Mayor's Office of Housing and Community Development
- San Francisco Department of Children, Youth, and Their Families
- San Francisco Department of Human Services and Aging
- San Francisco Department of Homelessness and Supportive Housing



# San Francisco Human Services Agency

## CalFresh

**SF Food Bank**  
2 contracts; 4,436 clients

## Disability & Aging Services

<b>Homebridge</b> 1 contract; 910 clients
<b>Homerise</b> 2 contracts; 190 clients
<b>Mercy Housing CA</b> 4 contracts; 318 clients
<b>Steppingstone</b> 1 contract; 12 clients
<b>Tenderloin NDC</b> 4 contracts; 701 clients

## Family & Children Services

<b>Family Bldrs by Adoption</b> 1 contract; 229 clients
<b>Family Support Svcs</b> 2 contracts; 66 clients
<b>First Place for Youth</b> 1 contract; 289 clients
<b>Homeless Prenatal Prog</b> 1 contract; 51 clients

## Economic Support & Self-Sufficiency Programs

<b>Adobe Services:</b> 1 contract; 42 clients
<b>Arriba Juntos-IAL:</b> 4 contracts; 496 clients
<b>Bay Area Legal Aid:</b> 1 contract; 912 clients
<b>Catholic Charities:</b> 1 contract; 42 clients
<b>Episcopal Comm Svcs:</b> 1 contract; 22 clients
<b>Goodwill Industries:</b> 1 contract; 8 clients
<b>Homerise:</b> 1 contract; 87 clients
<b>Casa de las Madres:</b> 1 contract; 161 clients
<b>SF Clean City Coalitn:</b> 1 contract; 10 clients
<b>Young Comm Devel:</b> 2 contracts; 145 clients

# Setting Standards for Data Collection

- Difference between California and San Francisco laws
  - California: No entity is named as responsible for developing an overall standard for how SOGI data should be collected
  - San Francisco: The San Francisco Department of Public Health is responsible for developing and maintain standards
    - Ability to grant partial or full data collection waivers
      - Clear guidelines and process for evaluating waiver applications to prevent misuse of waivers to avoid data collection
      - If DPH standards prevent entity from meeting state or federal reporting requirements

# Accountability: Assessing Compliance

- San Francisco requires that annual compliance reports address progress in implementing SOGI data collection, including:
  - Efforts to update data storage systems to ensure they are capable of storing and protecting SOGI data of clients
  - Efforts to revise data collection forms to enter compliance
  - Plans to instruct and educate staff and contractors on new requirements

# Barriers to Implementation: Reporting Standards

- Differences in reporting and collection standards across federal, state, and local entities
  - Department of Public Health must report to the U.S. Centers for Disease Control and Prevention
  - Department of Homelessness and Supportive Housing must report to the U.S. Department of Housing and Urban Development

# Barriers to Implementation: Infrastructure

- Revisions to legal agreements with contractors and grantees
- Revision of data collection instruments
  - Paper forms, including language translations
  - Programming for electronic surveys
- Deficiencies in IT and data storage systems
  - Lack of interoperability across areas/divisions/programs
  - Reliance on statewide or consortium computing systems that entities do not control
    - Change in state law reduced the impact of this for San Francisco

# Barriers to Implementation: Staff Training

- Data is often collected through face-to-face interactions with staff and support personnel
- Data collection can be sensitive and respondents/clients may not want to disclose information
  - Staff need to understand:
    - Why data is being collected
    - Why respondents may not want to disclose
    - Culturally sensitive ways to present the need for data collection and ways to respond to respondent/client questions

# Barriers to Implementation: Cost

- Developing new infrastructure and training can lead to substantial upfront costs
  - Creating new interoperable computing systems
  - Revisions to legal contracts, surveys, and forms
  - Developing training materials, training staff, keeping staff training current
- Once created, these changes may lower overall costs and/or lower the costs of implementing future changes

# Accountability: Achieving Service Equity

- In San Francisco, covered entities are required to include in their annual compliance report an assessment of services provided and a plan to address inequities identified:
  - Analyses using new SOGI measures that describe existing service provision by SOGI characteristics
  - Identify areas in which SOGI populations are underrepresented or underserved relative to need
  - Outline steps that will be taken to address inequities in service provision



# Lessons Learned for Data Collection

- State and local laws that compliment each other can enable implementation
- Key issues that should be addressed to enable implementation:
  - Standards for data collection: who determines?
  - Maintaining respondent privacy
  - Assessing and enforcing accountability
    - Regular, publicly available reports
    - Methodology used to collect data
    - Barriers to implementation and plans for addressing them
    - Dates and/or benchmarks for assessing compliance
    - Reporting of data collected in aggregate to assess quality
- Guidance need not be provided in law if law outlines entity responsible for developing guidance and sets clear expectations for that agency

# Lessons Learned on Data Use

- Data should be collected for a purpose: improving service delivery to underserved communities
  - Protections should be in place to prevent the use of this data to harm or to identify individuals within marginalized communities
- Laws that mandate reporting of disparities are ok, but mandating that government entities use this data to develop action plans to improve services is better

# LEGAL RESOURCES FOR DISAGGREGATION EFFORTS

# Legal Authority for Public Health Data Collection

- State and local health departments primarily responsible
- Health care providers duty to report
- Federal government supports and collects data

**FIGURE 3: UNDERSTANDING STATUTES, RULES, & POLICIES**

	Statute*	Rule**	Policy
Who	Adopted by a legislative body (state legislature or U.S. Congress) and signed by the executive (governor or president)	Adopted by a state or federal agency acting within the bounds of its statutory authority after notice to the public and opportunity for public comment	Adopted by a state or federal agency, consistent with law or rule, without the requirement for public notice and comment
Effect	Legally binding	Often fills in details of legislation; legally binding once adopted	Explains an agency’s interpretation of their rule or policy. May or may not bind the agency or regulated individuals; depends on the substance of the policy, the authority in which it is issued, and the jurisdiction

\* Also known as law, Act, enacted legislation, legislation

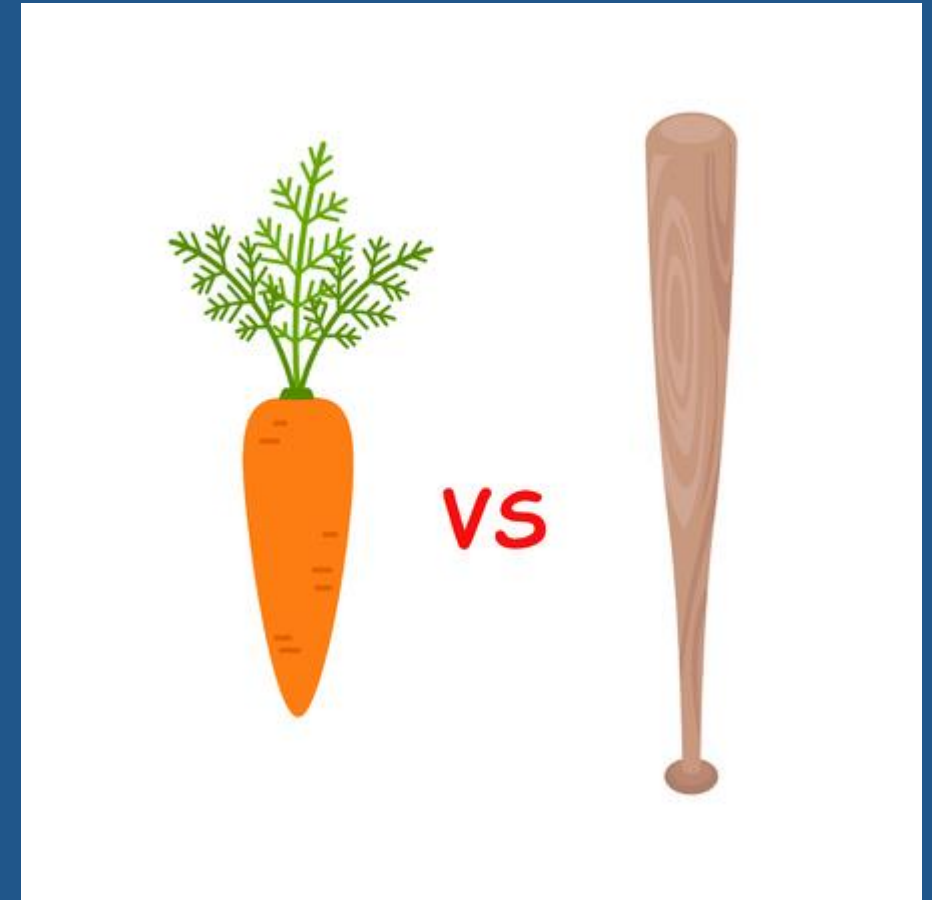
\*\* Also known as regulation

# Network for Public Health Law

- **networkforphl.org**
  - Understanding and navigating legal issues
  - Manage disclosure risk
  - Checklist of the legal, policy and ethical considerations for data collection, access and sharing
  - Tools to build data sharing agreements

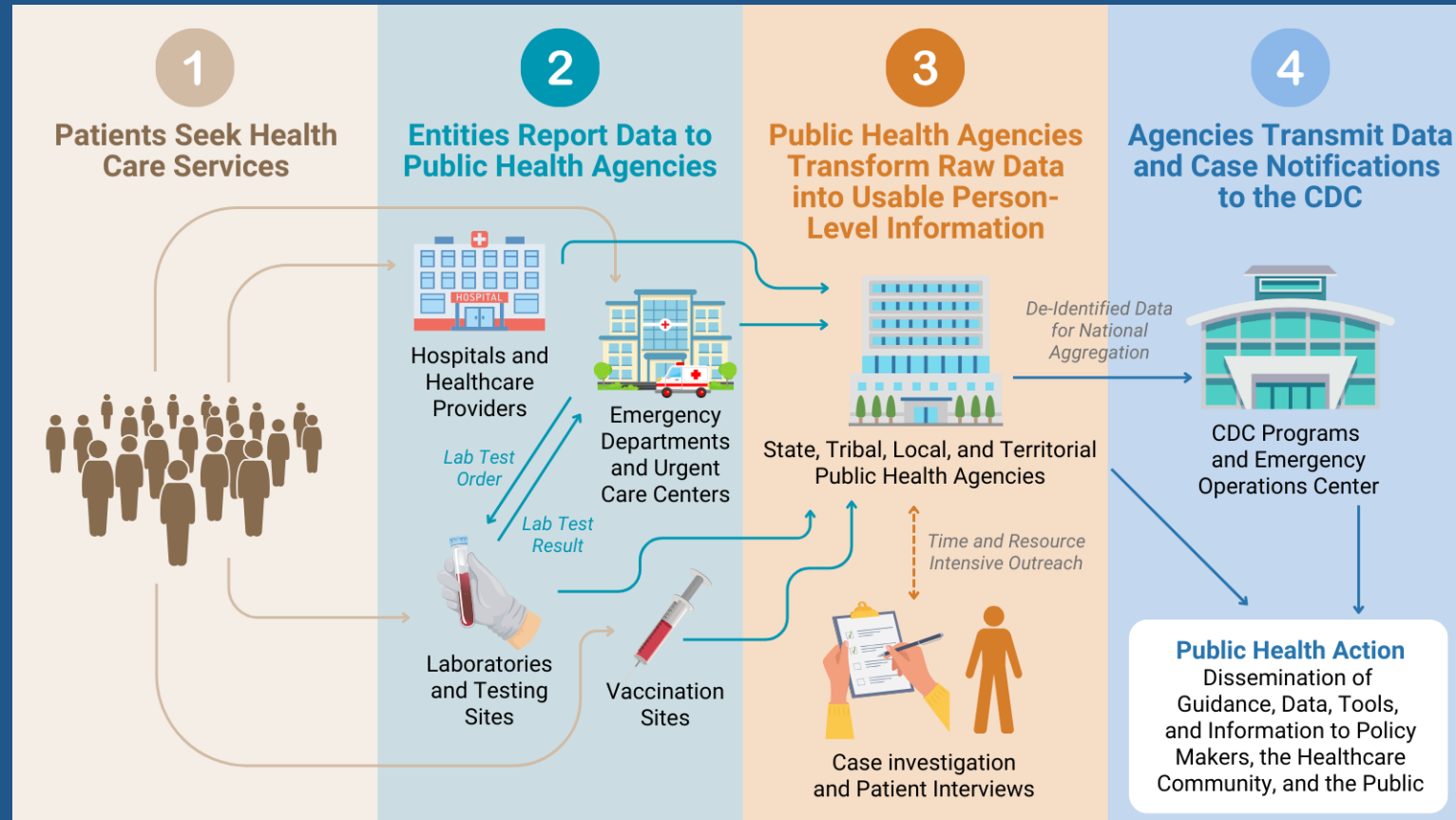
# Network for Public Health Law

- They offer technical assistance
  - Help advise legal teams
  - Contact Information:  
[networkforphl.org/connect-with-us](http://networkforphl.org/connect-with-us)

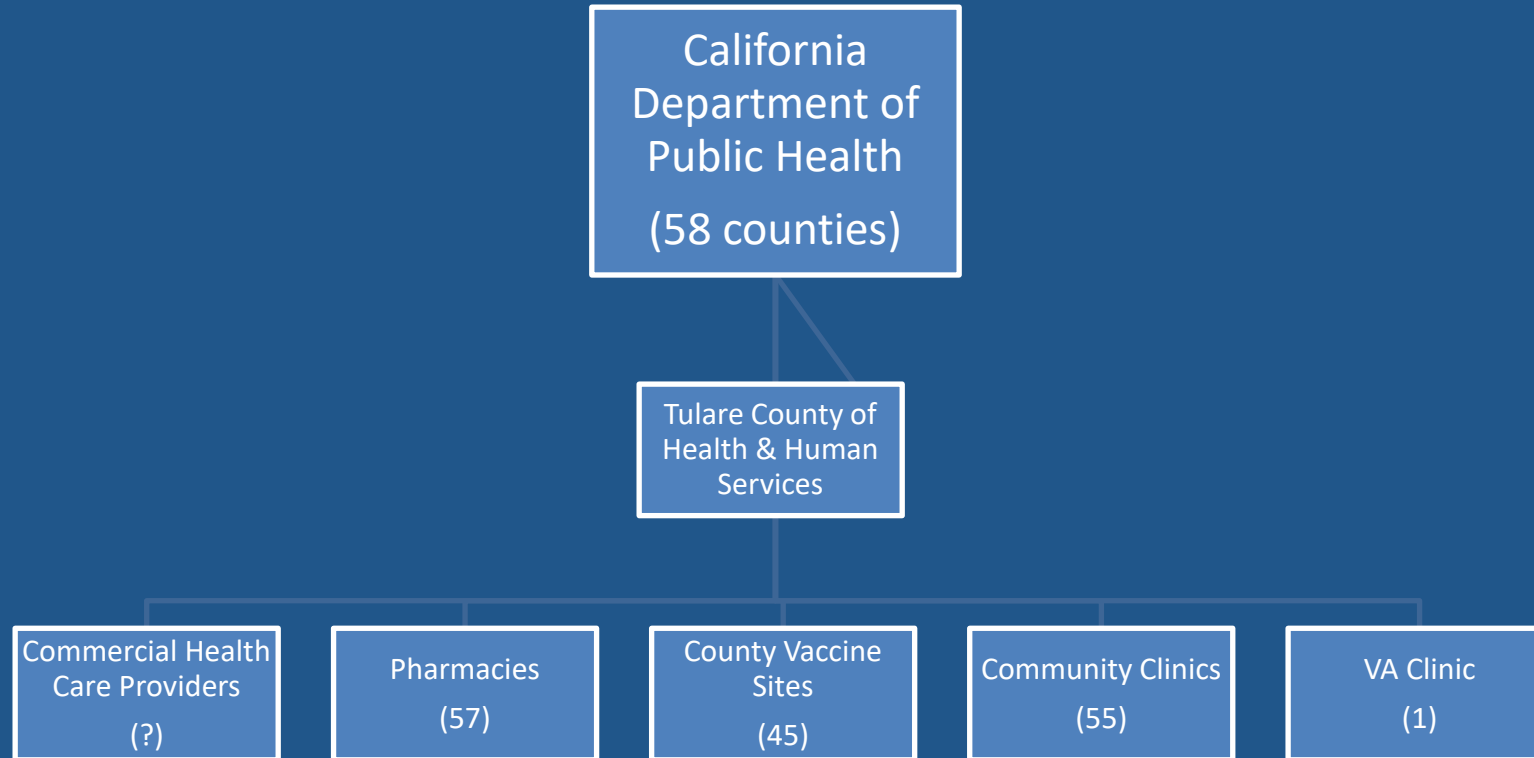


# WHAT DOES A STATE DATA ECOSYSTEM LOOK LIKE?



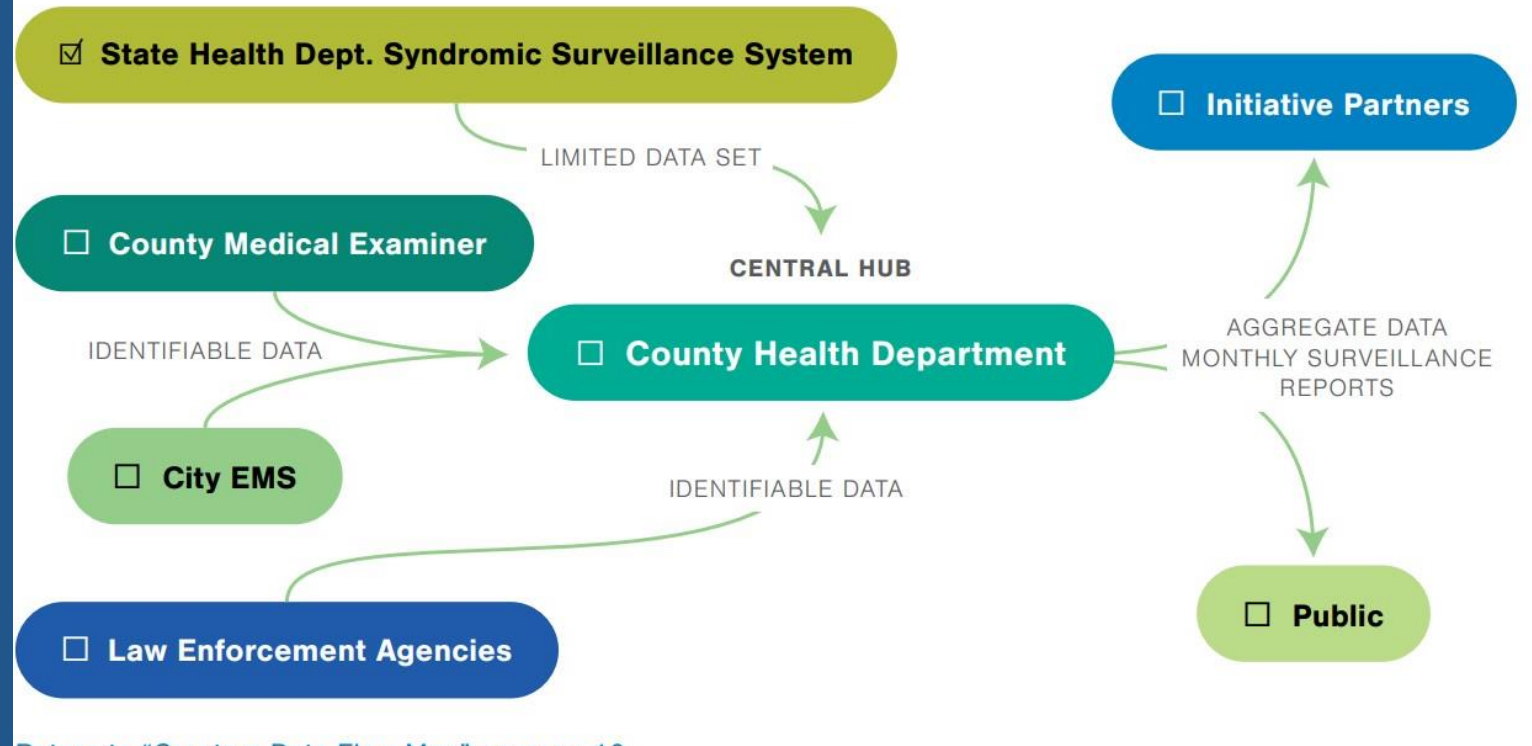


# Health Data Eco-System



158+?

### Data Flow Map (Pathways to Yes Step 3)



Source: Pathways to Yes, NPHL.

# Functional Integrated Data System (IDS)

- Governance
- Legal Issues & Data Security
- Data Management & Analytics
- Political & Economic Stability

Source: The IDS Approach\_Fantuzzo et al. 2017\_9.13.17.docx (upenn.edu)

# Governance

- Full government leadership support to build and use an IDS approach to social problem solving in government.
- A governance process in place to develop and manage all the basic functions of IDS operations; this involves overseeing the people, regulations, policies, & procedures of the IDS.
- A community of relevant stakeholders that agrees that building and using an IDS is the right thing to do.

# Legal Issues & Data Security

- Written ethical and legal agreements in place that authorize the use of the IDS on a routine basis.
- Adequate technology and trained personnel to integrate cross-sector administrative data at an individual level efficiently for all IDS inquiry projects while keeping individual records private and secure.

# Data Management & Analytics

- Trained data managers and data analysts who have access to relevant data elements across sectors that are of sufficient quality to use appropriate statistical methods to conduct high-priority IDS inquiry projects that generate the actionable intelligence to affect the mission of the IDS.
- Research and policy experts who can translate the findings from IDS inquiry projects into useful actionable intelligence to enhance policy and practice.

# Political & Economic Stability

- Effective means to communicate the value of what has been learned from IDS inquiry to relevant stakeholders by showing them how IDS use has resulted in increased understanding of an important social problem and how it has enabled government to improve policies and services while keeping personal data private and secure, thus demonstrating fidelity to the IDS mission, vision, and values.
- Political and economic support to sustain IDS inquiry on all relevant high-priority projects.
- Sustainability across time.



# Agency Needs for Implementation

- Staffing
- System support
- System security
- Training
- Organizational support for technology
- System compatibility
- Standards and confidentiality
- Funding
- Data issues
- Users

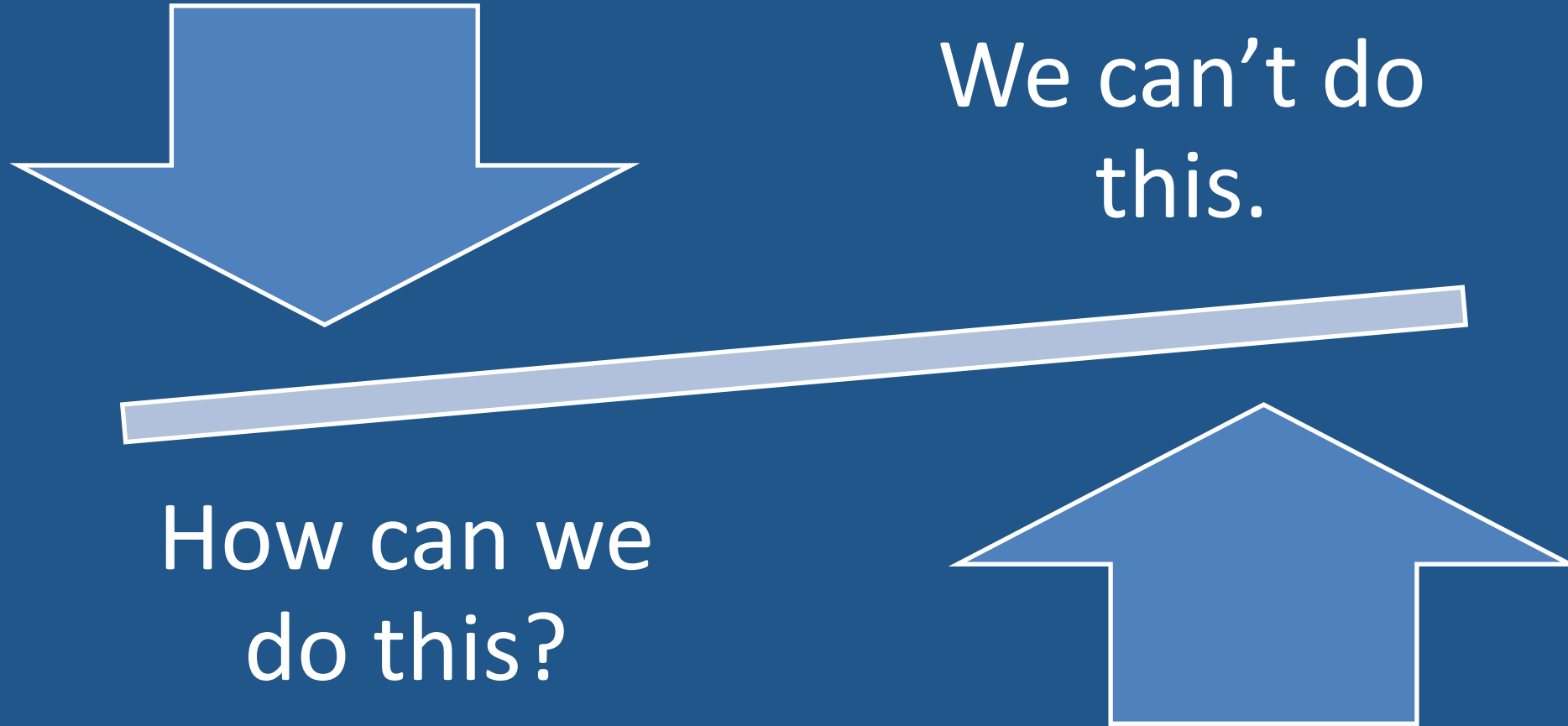
# Identify the Key Players

- Top Down Approach (Care about collecting data)
  - Legislative and Executive Branch
  - State Health Agency
- Bottom-Up Approach (Care about using data)
  - Community Clinics
  - Local Healthcare Providers
  - County or City Health Department

# Find the Lever

- Departmental authority
  - Who produces guidelines?
  - Who provides funding and resources?
  - Who enforces rules?
- Data champions among the staff
  - Who advocates internally?
  - Who shares data success stories?

# Flip This Lever



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# Implementation Challenges, Solutions and Community Roles