



NATIONAL ASSOCIATION OF
CHRONIC DISEASE DIRECTORS

Promoting Health. Preventing Disease.

NACDD Chronic Disease Directors Forum

August 1, 2019

Agenda

- Welcome and Zoom Overview
- Speaker introductions
- Learning Module: Natalie Burke
- Chronic Disease Director remarks: Laurie Schneider, Colorado
- Q and A, Discussion
- Data Management Plans: Dr. Lawrence Barker
- Updates and Announcements

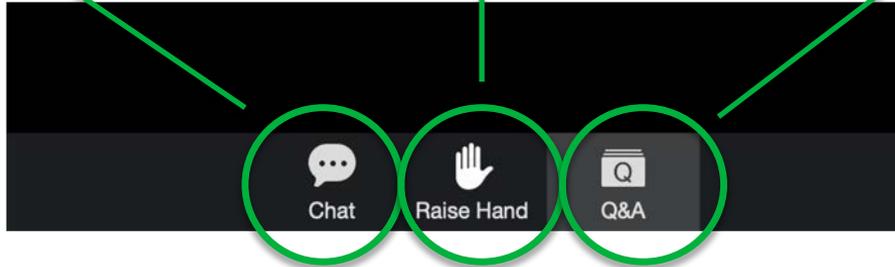


Zoom overview

Use the “Chat” function to send messages to panelists.

Use the “Raise hand” function during Q and A/discussion if you would like to ask a question verbally rather than in the Q and A box. We can then unmute you to ask your question.

Use “Q and A” to ask questions during the webinar. Q and A is set so questions may be viewed by all meeting participants, and other attendees may comment on/ respond to questions.



Zoom overview & link to slides

- Under view options at the top of your Zoom window, select “Full screen” or “Fit to window.”
- For help during the webinar, send a chat to the panelists and we will help.
- Slides available here:
https://www.chronicdisease.org/page/CDDF_First_Thursday

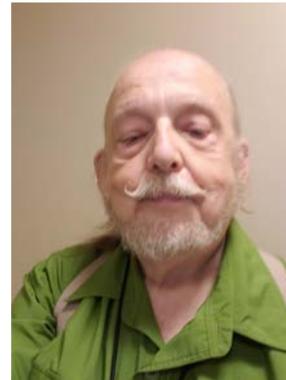
Speakers



Natalie Burke
President and CEO
CommonHealth Action



Laurie Schneider
Deputy Chief
Health Promotion and Chronic
Disease Prevention Branch
Colorado Department of Public
Health and Environment



Dr. Lawrence Barker
Senior Scientist
National Center for
Chronic Disease
Prevention and Health
Promotion
CDC



Learning, Language, and Leading: What Happens When Health Equity Gets Uncomfortable



Natalie S. Burke
President & CEO
CommonHealth ACTION



CommonHealth
ACTION



GOALS

- Establish a common language for equity-focused work.
- Develop understanding of key concepts related to health equity.
- Explore (briefly) how to apply an equity lens.
- Explore how to lead equitably.



Kalena Bovell

GET

**UN
COM
FORT
ABLE**

TM





HEALTH IS A PRODUCTION WHAT ARE WE PRODUCING?

New Jersey - 80 years
Life Expectancy (7th)

New Jersey - 69 years
Healthy Life Expectancy (10th)

11 Years
Healthy Life Lost

HEALTHIEST LIFE EXPECTANCY

50 states + Washington, DC

Top 5 States

Minnesota - 70.3 years

Hawaii - 70.1 years

California - 69.9 years

Washington - 69.1 years

Vermont - 69 years

Bottom 5 States

Mississippi - 64.9 years

Alabama - 64.6 years

Oklahoma - 64.5 years

Kentucky - 64.3 years

West Virginia - 63.8 years



Why do New Jerseyans lose 11 healthy years?

- Housing and Residential Segregation
- Education
- Transportation
- Employment
- Public Safety
- Structural Racism and Identity-based Inequity
- Healthcare
- Culture



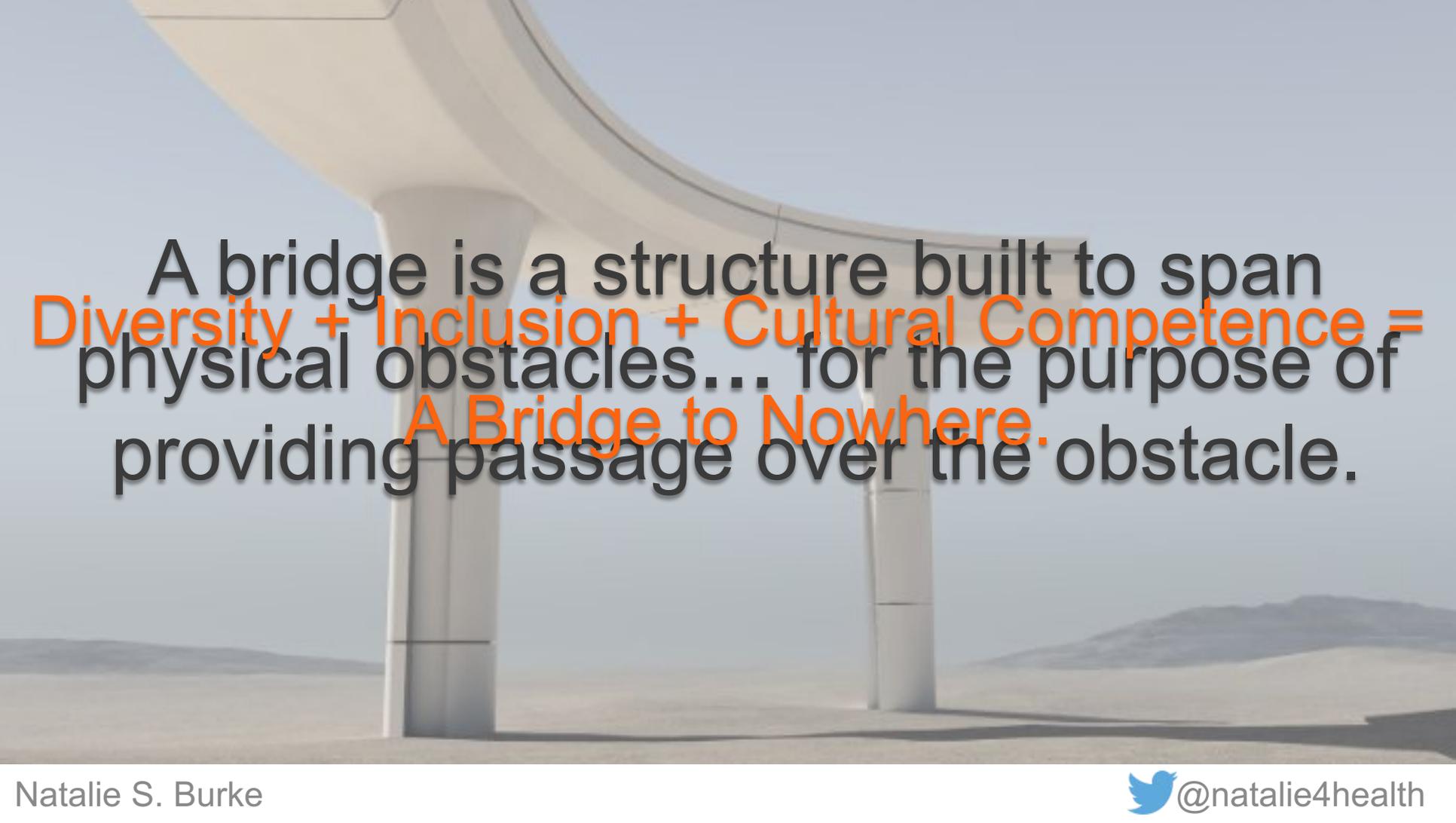
VIRGINIA



one more...
this type to force...
another employed by...
action.
... as second class matter July 28, 1908...
Va., under the Act of July 16, ...



THE BRIDGE TO EQUITY



A bridge is a structure built to span
Diversity + Inclusion + Cultural Competence =
physical obstacles... for the purpose of
A Bridge to Nowhere.
providing passage over the obstacle.

YOU CAN BE...

- ✓ Culturally Competent \neq Diverse
- ✓ Diverse \neq Culturally Competent
 - ✓ Diverse \neq Inclusive
 - ✓ Inclusive \neq Diverse
- ✓ Diverse + Inclusive \neq Equitable
- ✓ Culturally Competent + Diverse + Inclusive \neq Equitable

YOU CANNOT BE...

Equitable Without Being Diverse and Inclusive

Equity, Diversity, and Inclusion

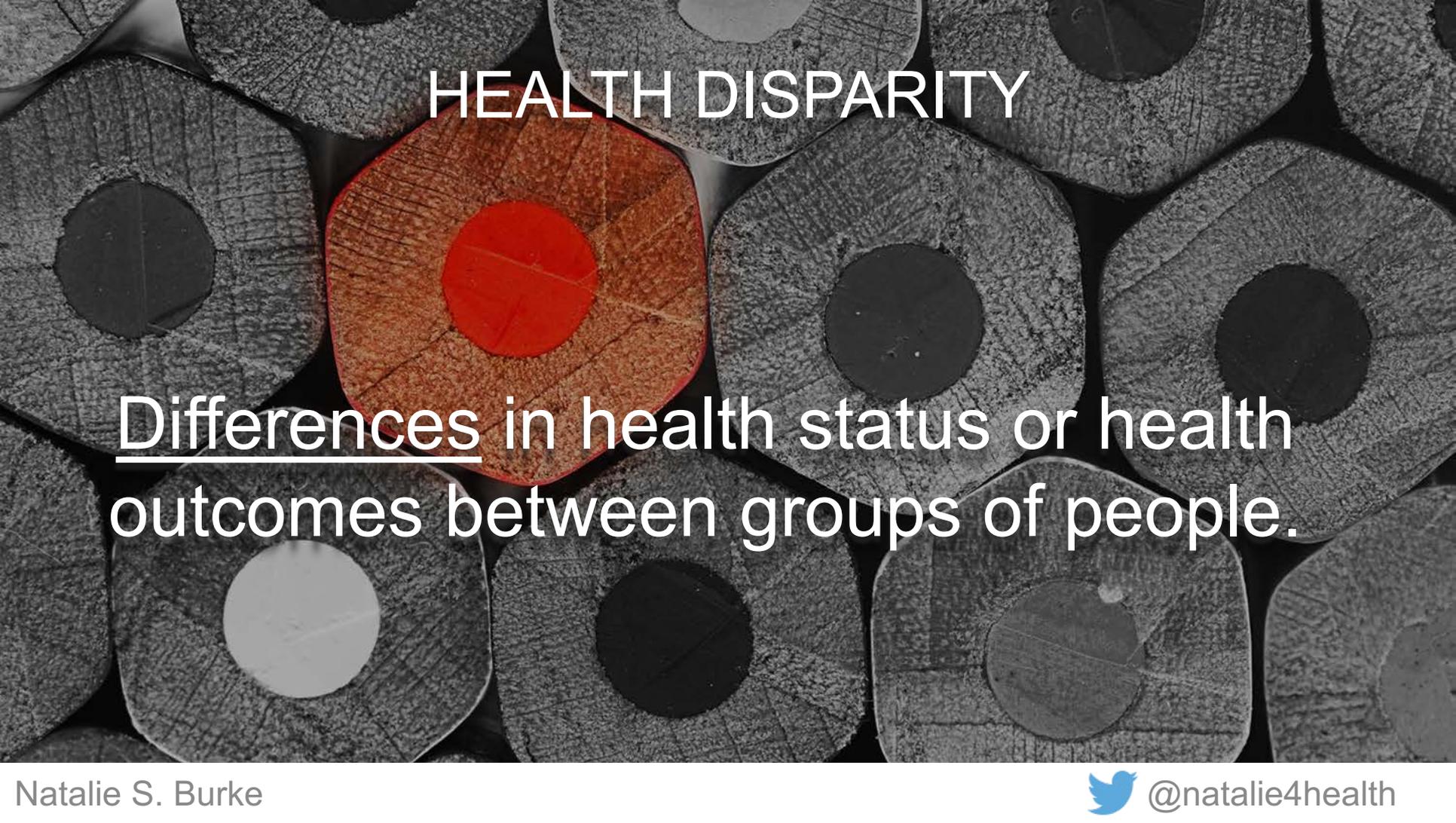
Why Not Just Health Equity?



HEALTH EQUITY

Natalie S. Burke

 @natalie4health



HEALTH DISPARITY

Differences in health status or health outcomes between groups of people.

HEALTH INEQUITY

Disparities in health that are a result of systemic, avoidable, and unjust social and economic policies and practices that create barriers to opportunity.

National Cancer Institute



HEALTH EQUITY

Attainment of the highest level of health for all people.

Healthy People 2020



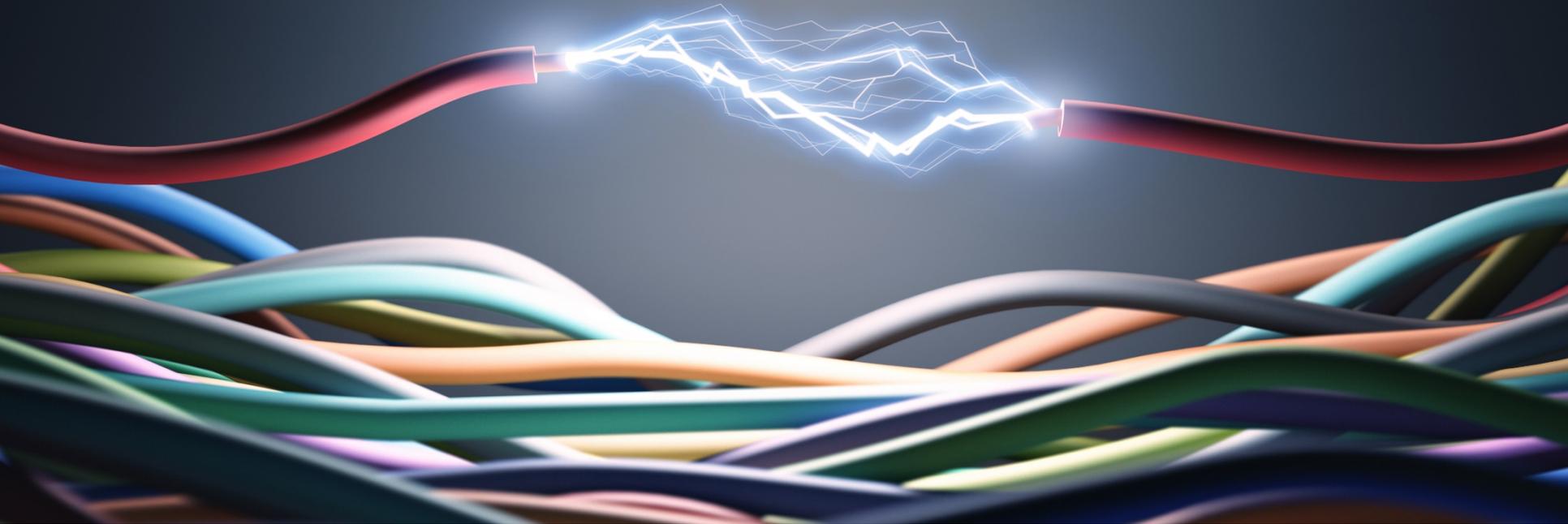


Equity requires us to provide all people with fair opportunities to achieve their full potential.



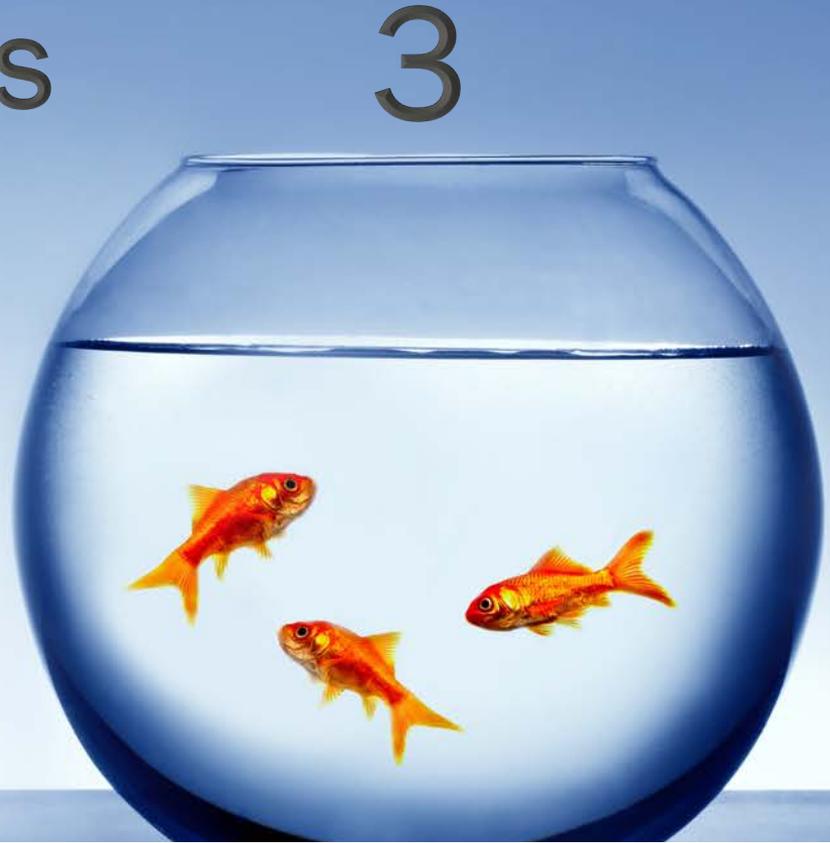
What is Fair?

Hardwired for Fairness





vs



Stereotypes about certain groups of people that exist outside of our conscious awareness.

Everyone holds unconscious beliefs about various social and identity groups.

UNCONSCIOUS BIAS



IN-GROUP BIAS



PREJUDICE

A judgment or opinion, usually but not always negative, formed without sufficient data, before facts are known and/or in disregard of facts that contradict it.

Power is the ability to define reality
for yourself and for others.



- PREJUDICE
- UNCONSCIOUS BIAS + POWER
- IN-GROUP BIAS

DECISIONS
BEHAVIORS
ACTIONS

→ -ISMS

-ISMS

- ✓ Systems of Privilege and Oppression
- ✓ Based on Social Identities

Gender, Race, Sex, Sexual Orientation, Education,
Age, Class, Language, and Country of Origin

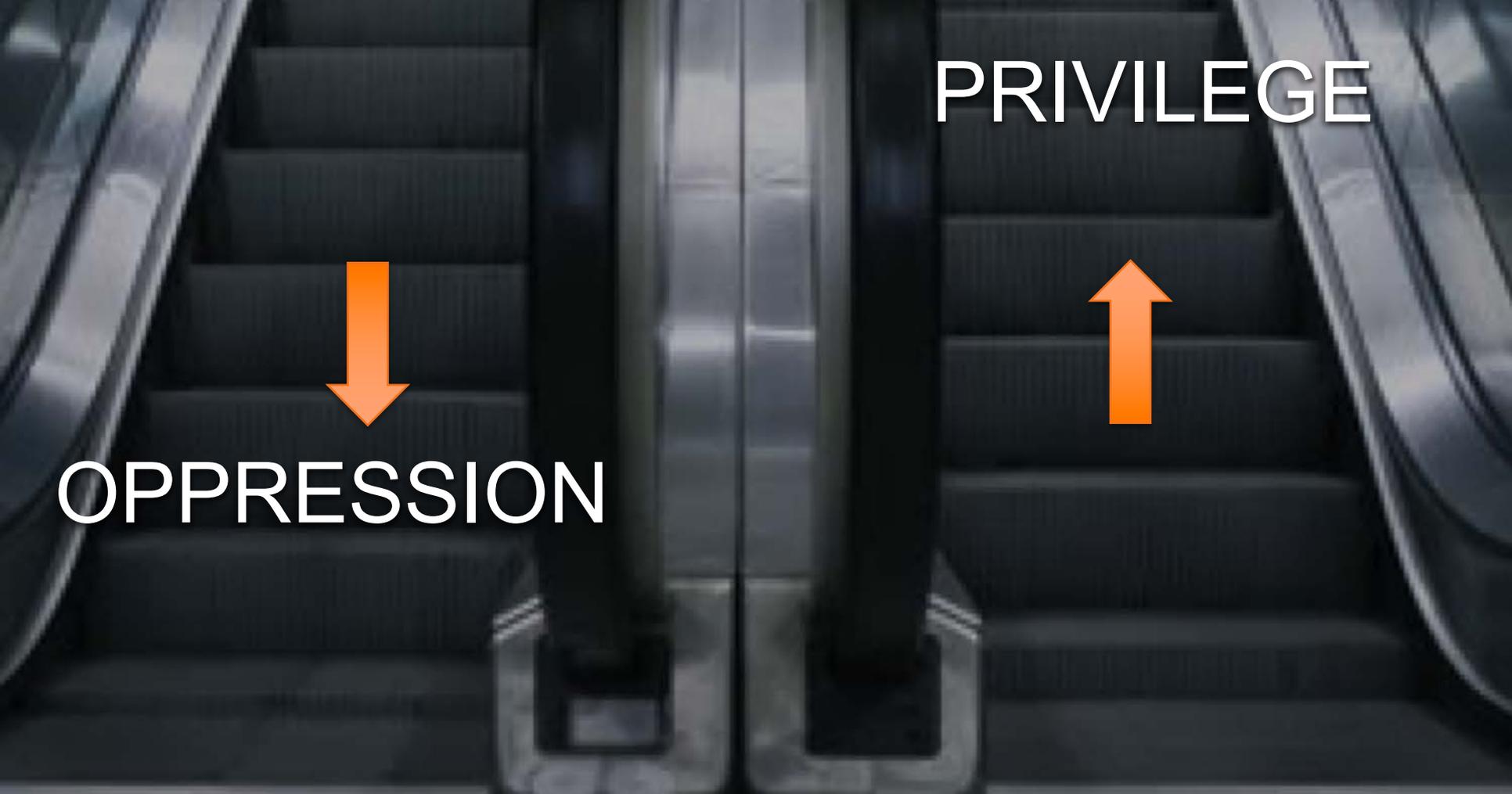
- ✓ Rooted in Beliefs of Superiority and Inferiority



PRIVILEGE AND OPPRESSION

PRIVILEGE: When one group has something of value that is denied to others simply because of the groups to which they belong rather than because of anything they have done or failed to do.

OPPRESSION: The systematic targeting or marginalization of one group by a more powerful group for the social, economic, and political benefit of the more powerful group.



PRIVILEGE

OPPRESSION

PRIVILEGE IS KILLING THE PRIVILEGED



WHITE PRIVILEGE IS KILLING WHITE PEOPLE

BROOKINGS NOW

**Working class white Americans are
now dying in middle age at faster
rates than minority groups**

Alison Burke - Thursday, March 23, 2017

White non-Hispanic midlife
of despair" in the U.S.
Ages 50-54 d



B Economic Studies
at BROOKINGS



Natalie S. Burke

 @natalie4health

OPPRESSION IS KILLING THE OPPRESSED



CHRONIC STRESS



Natalie S. Burke



@natalie4health

PERSPECTIVE TRANSFORMATION

The process of becoming critically aware of how and why our assumptions have come to constrain the way we perceive, understand, and feel about our world; changing these structures of habitual expectation to make possible a more inclusive and integrating perspective; and, finally, making choices or otherwise acting upon these new understandings.

Mesirow (1978)

PERSPECTIVE TRANSFORMATION



Head

- Logic
- Data
- Facts



- Fairness
- Justice
- Meaning

Heart



EQUITY LENS

The lens through which you view conditions, circumstances, and processes to understand who experiences the benefits and burdens of a given policy, program, or practice.

CommonHealth ACTION

LEADING WITH AN EQUITY LENS

<https://implicit.harvard.edu/implicit/>

YOU

Decisions. Behaviors. Actions.

Woke
Helping Professional
Servant Leader
Advocate
Ally

We judge ourselves by our intentions.
We judge others by their impact.

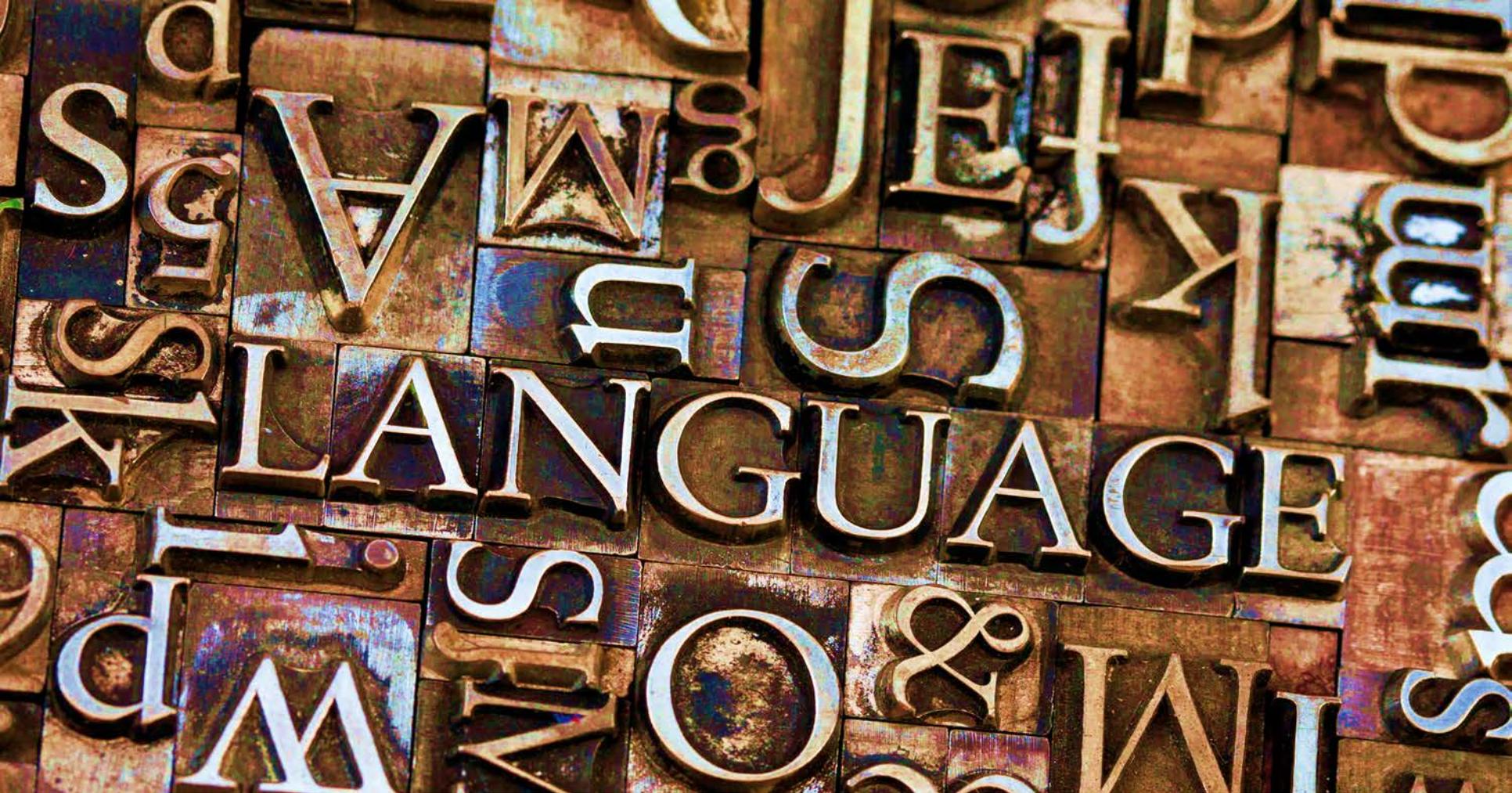




Equitable Leadership Requires:

IMPACT > INTENT

EXPERIENCE > EXPECTATION



Natalie S. Burke

 @natalie4health



“No matter what
people tell you,
words and ideas can
change the world.”

Robin Williams



Natalie S. Burke



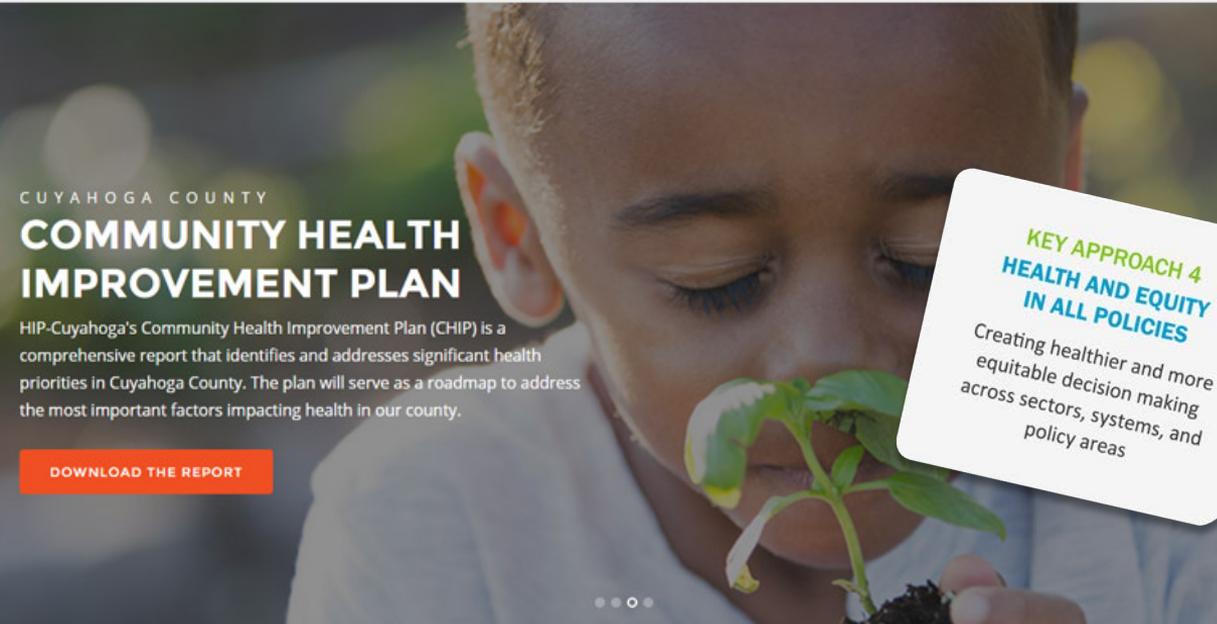
Words Have Power

Vulnerable

Empower

Under-Served

Non-White



CUYAHOGA COUNTY

COMMUNITY HEALTH IMPROVEMENT PLAN

HIP-Cuyahoga's Community Health Improvement Plan (CHIP) is a comprehensive report that identifies and addresses significant health priorities in Cuyahoga County. The plan will serve as a roadmap to address the most important factors impacting health in our county.

DOWNLOAD THE REPORT



ABOUT HIP-CUYAHOGA

Health Improvement Partnership-Cuyahoga (HIP-Cuyahoga) understands that neighborhoods and communities are not all created equal, and some people are born and live in places where it is difficult to grow up healthy. The conditions in which people live, and the opportunities they have, form the foundation for health and without them, people are more likely to live shorter, sicker lives. That's why more than 100 community partners have come together as the HIP-Cuyahoga Consortium to build opportunities for EVERYONE in Cuyahoga County to have a fair chance to be healthy. When healthy living is easier, we all live longer and healthier lives.



<https://hipcuyahoga.org>

Natalie S. Burke

@natalie4health



- In 2001, the Minnesota legislature established the Eliminating Health Disparities Initiative to address health disparities and “improve the health status of Minnesota’s populations of color and American Indians.”
- Health arguments and data used in policy change focused on SDOH
- State framework guides local health departments
- Cross-sector engagement changes outcomes
- MDH work supports creation of Foundational Practices for Health Equity
- Statewide Health Improvement Partnership incorporated health equity lens
- Health Equity Data Analysis strengthens local public health capacity to advance equity
- State Community Health Services Advisory Committee develops Advancing Health Equity Workgroup
- 2012 Minnesota Statewide Health Assessment focused explicitly on racism

www.healthequityguide.org

Center for Health Equity

who we are

Minnesota ranks, on average, among the healthiest states in the nation. But the averages alone tell an incomplete story. A closer look at the data reveals that communities of color, American Indians, lesbian, gay, bisexual, transgender and queer (LGBTQ) communities, the disability community, rural communities and low-income communities experience the highest inequities in the state.

The Center for Health Equity (CHE) was created in 2013 to advance health equity within the Minnesota Department of Health and across the state. CHE's mission, approaches and values guide how we do this work.

OUR MISSION IS TO
**CONNECT, STRENGTHEN
AND AMPLIFY HEALTH
EQUITY EFFORTS WITHIN
MDH AND ACROSS THE
STATE OF MINNESOTA**

what we do

We are a **network hub** – leading, connecting and strengthening networks of health equity leaders and partners across MDH and Minnesota communities.



I We provide **leadership in advancing health equity** and cultivate health equity leaders within MDH and across Minnesota communities.

A We **amplify the work of communities** most impacted by health inequities and support them to drive their own solutions.

our approach

RACIAL EQUITY

We recognize that health equity cannot be achieved without naming the impacts of structural racism and working toward racial equity. Leading with race allows us to more clearly see the state of the health of all communities in Minnesota.

RESILIENCE

We acknowledge that the roots of inequities are tied to a legacy of historical trauma in communities. We recognize that solutions to health inequities can often be found within the strength and resilience of communities.

INTERSECTIONALITY

We value the many identities and lived experiences of each person. Because individual, community and systems-level factors interact to create the world we live in, our approaches to equity are both intersectional and multipronged.

NETWORK LEADERSHIP

We believe that leadership comes from within and across communities and that we are stronger when we bridge differences and unite around commonalities. We believe that effective leadership is adaptive, collaborative and inclusive.

COMMUNITY-DRIVEN DATA AND DECISIONS

We believe those most impacted by health inequities should have a say in how their data are collected and interpreted, and that communities should play a leading role identifying their own health challenges and developing solutions.

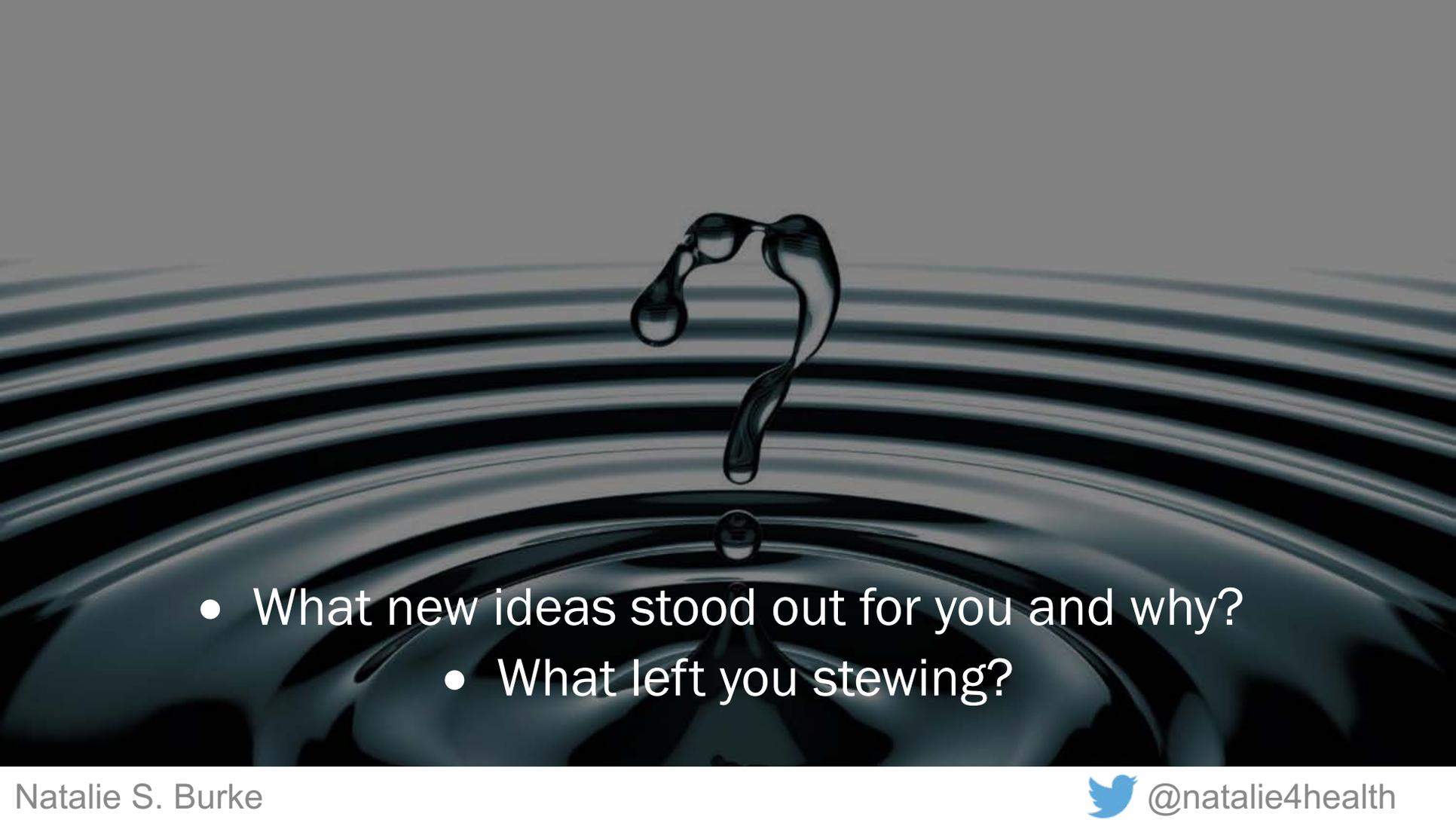
SYSTEMS THAT HEAL, NOT HARM

We strive to bring a health equity perspective to decision-making across sectors and policy areas, and to reshape our policies and systems in Minnesota so that they strengthen communities, not marginalize or divide.



Triple Aim of Health Equity

- Implement a health in all policies approach with health equity as the goal
- Expand our understanding of what creates health
- Strengthen the capacity of communities to create their own healthy future

- 
- What new ideas stood out for you and why?
 - What left you stewing?



THANK YOU!

For additional information visit:

- <https://medium.com/@natalie4health>
- nburke@commonhealthaction.org

Laurie Schneider
Deputy Chief
Health Promotion and Chronic Disease
Prevention Branch
Colorado Department of Public Health
and Environment

Q & A
+
Discussion

Data Management Plans (DMPs) for CDC-Funded Programs

Lawrence Barker, PhD

Senior Scientist

National Center for Chronic Disease Prevention and Health Promotion

August 1, 2019



Data Management and Access – 2016 CDC Policy

- ❑ CDC-funded project leads are expected to describe how they intend to manage, preserve, and make accessible to the public the “public health data” generated or collected with CDC funds in a **Data Management Plan (DMP)**.
- ❑ Applies to
 - * projects begun in fiscal year 2017 forward
 - * ongoing surveillance systems



“Public Health Data”

- ❑ “Public health data” means digitally recorded data commonly accepted in the scientific community as a basis for public health findings, conclusions, and implementation.
 - Research
 - Surveillance
 - Evaluation (sometimes)

- ❑ “Public health data” do not include grantee progress reports, administrative data, preliminary analyses, communications with colleagues, etc.
 - If a project has no public health data, no DMP needed; application must so state



What Should be Included in a DMP?

- ❑ The DMP should include:
 1. A description of the data to be collected or generated in the project;
 2. Standards to be used for the collected or generated data;
 3. Mechanisms for, or limitations to, providing access to the data, including a description of provisions for the protection of privacy, security, property rights;
 4. Description of data standards and documentation accompanying release;
 5. Plans for archiving and long-term preservation of the data, or explaining why long-term preservation and access are not justified.



What Should be Included in a DMP?, continued

- ❑ The DMP may be a checklist, paragraph or other format



The DMP Development and Assessment Process

- ❑ A DMP will be updated for accuracy as plans solidify or change during the project's period of performance.
- ❑ The submission and assessment of a DMP will usually occur:
 1. In the application submitted in response to a NOFO, and
 2. After initial decision to fund – within first 30 days (research) or 6 months (non-research), and
 3. At least annually thereafter, at the time of non-competing continuation application for NOFOs, and
 4. When final progress reports are submitted; including information regarding the deposition of the data



The DMP Review

Criterion 1: A description of the data to be collected or generated in the proposed project

- Does the DMP describe the type of study, the study design, and anticipated time frame? (data instrument, protocols, etc.)
- Does the DMP describe how often the data will be collected, where it will be maintained, and who will be responsible for the data during the project period?



The DMP Review, continued

Criterion 2: Standards to be used for the collected or generated data

- Does the DMP describe use of widely accepted methods for ensuring data quality?
- Does the DMP provide a plan to ensure data quality?



The DMP Review, continued

Criterion 3: Mechanisms for, or limitations to, providing access to the data including a description of provisions for the protection of privacy, confidentiality, security, intellectual property, or other rights

- Does the DMP describe a plan to protect the data with appropriate guidelines for data security, privacy and confidentiality (removal of PII, data base identifiers, etc.)?
- Does the DMP provide a description of the protection of other data provisions (intellectual property rights, institutional limitations, etc.)?
- Does the DMP describe what level of access (public use, restricted access, no access) of data may be provided taking into consideration protections?
- **If the data won't be made available to the public, a justification is required.**



The DMP Review, continued

Criterion 4: Statement of the use of data standards that ensure all released data have appropriate documentation that describes the method of collection, what the data represent, and potential limitations for use:

- Does the DMP describe what established standards (e.g. ICD10, FIPS) will be used for data and metadata to ensure usability and interoperability of the data?
- Does the DMP outline what documentation will be available for analysis (e.g. data dictionary, sample code)?
- Does the DMP outline documentation that will be available regarding data source (e.g. population studied, response rate, caveats)?



The DMP Review, continued

Criterion 5: Plans for archiving and long-term preservation of the data, or explaining why long-term preservation and access are not justified

- Does the DMP provide a description of the planned long term preservation? If not, does the DMP provide a justification for why the data will not be stored?
- Does the DMP describe the planned final location of the data (publically accessible repository, institutional or governmental repository, etc.)?
- Does the DMP provide a link or other contact information for the archived data with a description of when the data can be accessed, who has access, and how?



The Final DMP

The final DMP will include the location of each dataset, any restriction to access, and any changes to the plans for long term preservation of the data.

- The final version of a collected and/or generated data set intended for release or sharing should be made available **within thirty (30) months** after the end of the data collection or generation, except for surveillance data, which should be made accessible **within a year (12 months)** of the end of a collection cycle.
- The recipient will be informed if further actions are needed to meet the DMP's stated objectives.



Sample DMP Template

Description of the Data

In the following table, identify the data to be generated or collected.

Title	Study Type/Design	Frequency of Data Collection	Data Collection Timeframe	Where Data Will Be Maintained	Responsible Person
Dataset A					
Dataset B (Repeat as needed)					

Description of Standards for Collecting Data

Describe the data collection/generation methods and procedures

Describe a plan to ensure data quality

Providing Access to Data

Describe a plan to protect the data through appropriate guidelines for data security, privacy, and confidentiality (removal of PII, data base identifies, etc.)

Describe what level of access (public use, restricted access, no access) of data may be provided, including justifications if data will not be made available to the public

Description of Standards Accompanying Release of Data

Describe the established standards to be used to ensure usability and interoperability of data

Describe the documentation that will be available regarding data source (e.g., population

The DMP may be a checklist, paragraph or other format

Informed Consent and Privacy

- ❑ The DMP (3rd element) must be consistent with any informed consent language that was given to respondents.
- ❑ An informed consent is required for research with human subjects (and is recommended when information is collected in non-research).
 - For example, an appropriate informed consent can tell respondents that each individual's information will be kept private and that the aggregated dataset, without identifiers, may be used in publications and shared.
- ❑ Similarly, the DMP must be consistent with any data use agreements you have regarding access and archiving.



Data Management and Access Extramural Considerations

- ❑ Recipients will be responsible for data stewardship, data preparation and making data accessible, unless the funding program specifies that the data will be submitted to CDC for aggregation / analysis / sharing.
- ❑ Recipients should ensure the quality of the data that they make accessible, and should follow the data quality standards set by their organization prior to making data accessible.
- ❑ CDC will not take responsibility for data quality or technical assistance to potential users of awardees' data.



DMP, Access and Archiving When CDC is Compiling Awardees' Data

- ❑ CDC is the steward of the data it possesses.
- ❑ CDC expected to share/archive (unless the data reporting was done under an explicit agreement saying otherwise, or there are other reasons not to).
- ❑ With CDC taking on this responsibility, individual awardee not expected to duplicate efforts to share/archive, or develop DMP for standardized methods.



Data Management and Access Costs Associated with Data Sharing

- ❑ Costs associated with public health data collection, access, archiving, and long term preservation may be included as part of the total budget submitted with grant and cooperative agreement applications.
- ❑ Budget for such costs will be determined by each program and will be outlined in the NoA.
- ❑ No funds will be available beyond the period of performance of the award.



Journal Publications

- ❑ If the federally-funded dataset is used *in a peer-review journal publication*, the data should be released at the time of publication unless the dataset has already been released (by you or another entity) or cannot be shared for some reason.
 - The form and content of the release data can range from a machine-readable version of the tables in the paper to a full line listing of the underlying data.
- ❑ Publication does not create a post-hoc need for a DMP because the DMP is a plan for the *dataset itself*. However, if you anticipate publishing from the outset, you should create a DMP.



“Public Health Data”, Continued ...

- ❑ How do we determine if data collected through non-research, non-surveillance activities – such as assessments and evaluations – are public health data? **The purpose is the key.**
- ❑ If the purpose is to understand the impact of a program, policy, or intervention; and/or results from the data collection will be used to make policy-related decisions, then it’s public health data.
 - [examples: program outcome evaluation, observational data used for policy development, information used for CDC’s decisions on what types of programs to fund]
- ❑ If the purpose is to improve the design or operations of a program, process, system, or service delivery mechanism, then it’s not.
 - [examples: quality improvement (QI) project, organizational performance measurement and management system, formative or process evaluation, customer satisfaction survey or customer needs assessment survey]



“Public Health Data”, Continued ...

- ❑ How do we determine if secondary data – data collected or generated by another entity but re-used as public health data with federal funding – needs a DMP? **The purpose is the key.**
- ❑ Usually is not required for use of secondary data (data collected, generated, or published by other institutions or other projects).
- ❑ However, *if CDC or an awardee feels it is advisable* to clearly delineate plans for the secondary dataset, it can be included in a DMP.
 - This is particularly relevant when the secondary dataset is not available to others and its original use was not as a public health dataset – for example, if private medical records are obtained to form a research dataset, then a DMP is needed for the research dataset.



Access Options for Data

- ❑ **Freely accessible to public, e.g. can be downloaded from internet site**
- ❑ **Restricted access, e.g. can be used at Research Data Center or with data use agreement**
- ❑ **No access**

Some Reasons *Not* to Share or Archive Public Health Data

- ❑ Cost outweighs expected benefit
- ❑ Data quality inadequate
- ❑ Sharing precluded by licensing or other agreement
- ❑ Sharing would compromise proprietary rights
- ❑ Adequate data already available publicly
- ❑ Data no longer relevant
- ❑ Data too complex for most users*
- ❑ Data cannot be shared without compromising subjects' privacy*

* In these cases, consider whether restricted access is appropriate

What Does a DMP Look Like?

- **The DMP may be a checklist, paragraph, or other format**
- **There is no standard CDC form to use when creating a DMP at this time**
- **CDC can offer example templates – their use is not required**
- **These external websites have other examples:**
 - University of California: <https://dmp.cdlib.org/>
 - USGS: <https://www.usgs.gov/products/data-and-tools/data-management/data-management-plans>
 - ICPSR: <http://www.icpsr.umich.edu/icpsrweb/content/datamanagement/dmp/plan.html>



How is the DMP assessment used?

- ❑ The review of the application DMP should focus on the applicant's understanding of the DMP's required components, as details might not yet have been decided.
 - If DMP is absent or inadequate, CDC works with awardee to improve it during early months of award (first 6 months for program award; first 1 month for research)
 - Funds may be restricted until adequate DMP in place
 - DMP should be in place before data collection / generation begins

- ❑ In continuations, focus on whether plans seem feasible and aligned with the spirit of federal policy.

- ❑ Final DMP gives us information about access/storage and allows CDC to monitor awardee compliance.



NACDD Announcements

- **Chronic Disease Directors Discussion Forum on LinkedIn:** if you haven't joined already, get a join link from Abby Lowe-Wilson, alwilson@chronicdisease.org.
- **State chronic disease prevention strategic plans:** if you are willing to share yours, please send jalongi@chronicdisease.org.
- **New CDD orientation:** will run September-December 2019. Contact tengel@chronicdisease.org.



NACDD Announcements

- **Survey of States:** coming out next month – earlier than in past years.
- **STAR applications:** also happening earlier than previous years. Stay tuned for more info on that.
- **Emerging Leaders cohort courses:** schedule under development. More info to come soon.
- **Leadership mentoring pilot:** evaluation results currently under review.



Next CDD Forum Webinar

Amber Mendiola

Chronic Disease Director, CNMI

Scheduled for

6:00 pm Eastern on

Thursday, September 5th, 2019



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