

## SECTION 7: Data, Research, and Evaluation for Health Equity

As described in earlier sections of this guide, research on the relations between health inequities and indicators of socioeconomic status, including income, race, ethnicity, and living and working conditions, is unequivocal. These social conditions have been described as “fundamental causes of disease” because they determine access to resources needed to avoid risks and can be linked to multiple diseases (Link & Phelan, 1995). This is an important rationale for place-based strategies that target living and working conditions, which are likely to have a positive impact on a range of health outcomes simultaneously. However, the specific causal linkages between social conditions and health inequities are not always well understood and can vary by community. For this reason, even strong associations between social conditions and health inequities at the macro-level may not provide enough information to understand community-specific needs or to promote action at the community level. Furthermore, better data and concerted measurement strategies are needed to evaluate changes at the community level and to assess the impact of policy changes more broadly across the state of Delaware. For these reasons, the *National Stakeholder Strategy for Achieving Health Equity* (NPA, 2011), described in previous sections of this guide, identifies “improving data availability, coordination, utilization, and diffusion of research and evaluation outcomes” as one of its five over-arching goals.

Section 7 describes the kinds of data and capacity needed to understand and monitor health inequities at the community and state levels. It includes a discussion of strategies for evaluating health equity initiatives, and highlights ongoing challenges with respect to evaluation. This section concludes with a summary of research priorities to advance health equity. Overall, it provides an overview of the challenges in collecting and analyzing data regarding the social determinants of health (SDOH) and health equity, and does not describe the complexity of the analyses necessary to draw conclusions using such data.

### Data to Identify and Understand Health Inequities

It is critical to have a comprehensive understanding of population health status, including inequities in health across various characteristics, such as income level, race/ethnicity, sexual orientation, gender, gender identity, education level, and other indicators of socioeconomic status. It is important to note that health status data is not necessarily available for all population groups. For example, health status data is largely lacking for members of the Lesbian, Gay, Transgender, Bisexual, and Questioning (LGTBQ) population. A 2011 report from the Institute of Medicine (IOM), titled *The Health of Lesbian, Gay, Bisexual, and Transgender*

*People: Building a Foundation for Better Understanding*, highlights the need for targeted data collection and research regarding the health status of this population (IOM, 2011).

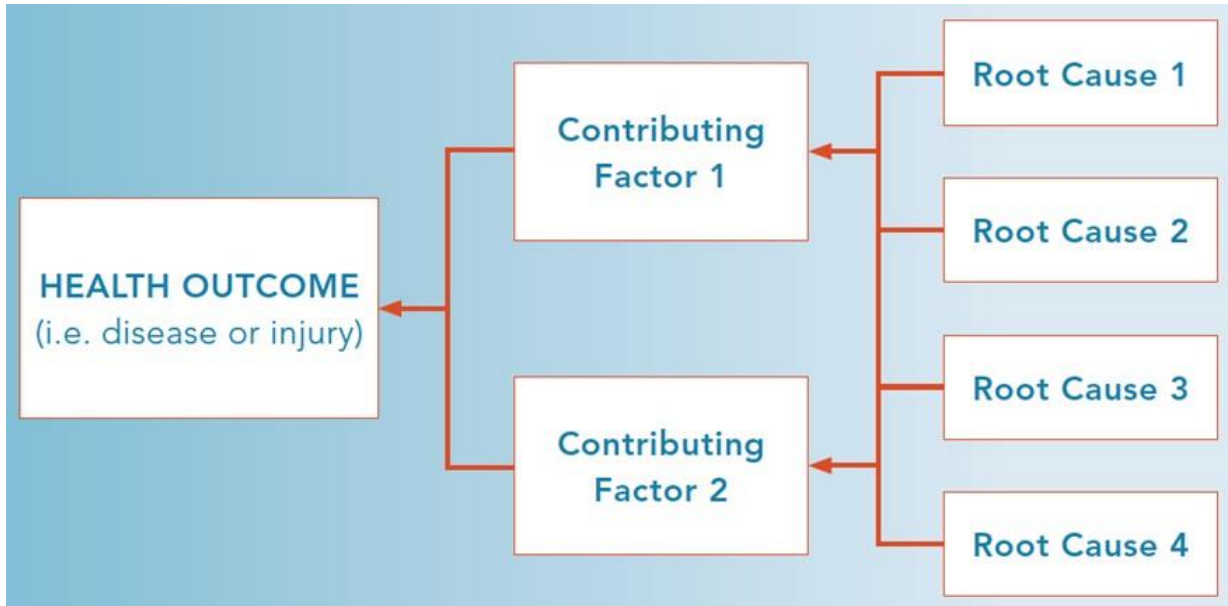
Additionally, it is important to have a clear understanding of the underlying or upstream causes for health inequities, broadly defined as social determinants of health (SDOH). Both types of data—health status and SDOH—are necessary to describe baseline status and to monitor changes over time as well as to make comparisons by place. Baseline data helps practitioners, policy makers, and community residents identify priorities and ensure that interventions reflect the community’s needs and resources. Tracking changes over time helps to ensure that interventions remain focused on those priorities and accountable to stakeholders. Importantly, neighborhood-level data are needed to facilitate the identification of priorities and other kinds of decision-making. This can be challenging because many existing data sources do not allow for neighborhood-level analysis and/or would require substantial resources to do so.

### Innovative Types of Data

Data that describes SDOH are needed to highlight the ways in which unequal power and privilege influence the distribution of resources required for health (Knight, 2014). For instance, in addition to monitoring high school graduation rates, it is valuable to collect information and monitor changes in per capita spending on public education. Similarly, the availability of affordable housing is an important SDOH, but the level of racial segregation in a defined community is necessary to paint a more complete picture.

Many models analyze the underlying causes and factors of health outcomes. One model is the root cause mapping process described in the policy section, Section 6. It is useful for identifying important indicators of community health and inequities such as per capita spending and racial segregation. The root cause diagram, reproduced in Figure 28, highlights how data collection efforts also need to shift upstream. However, it should be noted that more exhaustive models, such as causal diagrams (see Pearl, 2000), depict the relations between causes and indicators and more accurately represent how root causes interplay to influence health outcomes. In either case, looking at the upstream causes of health inequities allows stakeholders to focus on the most meaningful indicators and helps shift the focus from individual risk factors and behaviors to community health and the structures that underlie inequities. Referring back to the obesity example discussed in Section 6, two contributing factors to obesity are poor diet and lack of physical activity. However, they are not the root causes of obesity. Rather, elements or structures within the built environment underlie these individual risk factors. Using this diagram to identify root causes of obesity might lead stakeholders to collect and track data on convenience and fast food retail locations, and/or the availability and safety of parks and playgrounds.

**Figure 28. Root Cause Diagram**



Source: Reproduced from Rudolph, Caplan, Ben-Moshe, & Dillon, 2013.

Data on social and structural determinants are not readily collected or collected in systematic ways. This may require creativity and investments in novel approaches to data collection, such as community asset mapping; Photovoice, which utilizes photography as a means of communicating social issues; and walking audits. It likely involves partnering with other sectors that have existing data to support a broader understanding of SDOH and health inequities. Furthermore, community members should be engaged in identifying, collecting, and interpreting new kinds of data for health equity. As described by the Centers for Disease Control and Prevention (CDC) in their *Practitioner Guide for Advancing Health Equity*, “the perspectives of community members can bring static data to life by revealing the lived experience behind the data” (CDC, 2013, p. 19). The CDC’s guide also offers a systematic list of questions for practitioners in government and community-based organizations to reflect upon when building their capacity for identifying and understanding health inequities:

- Where are we now?
  - What are our organization’s current practices for identifying and understanding health inequities?
  - Can we clearly articulate health inequities related to the health issues we are trying to prevent and/or address? If so, list those health inequities.
- What types of information can we use to identify health inequities in our community?

- What process can we set up to get a full understanding of health inequities in our community?
- What type of information do we need to ensure we have a full understanding of health inequities in our community?
- Have we looked beyond basic health risk behaviors and standard outcome data to examine social, economic, and physical indicators that may contribute to or maintain health inequities?
- Have we examined community context and historical factors that may help our understanding of existing health inequities?
- What tools and resources can we use to identify and understand health inequities?
  - What combination of data sources do we need to better understand experiences of populations affected by health inequities?
  - What sources or partners may already have the data we need for assessing community environments or health behaviors?
  - Where can we go to understand the historical context of health inequities in the community?
- How can we engage community members in gathering and analyzing data?
  - How do we currently engage community members in our data collection and analysis process?
  - What process can we put in place to routinely engage populations affected by health inequities in collecting and analyzing data?
- What are our next steps?
  - What can we do differently to improve or enhance our ability to identify and understand health inequities?
  - What is our plan of action to implement those changes? (CDC, 2013, p. 21).

*“Without a clear understanding of existing health inequities, and the root-causes contributing to them, well-intentioned strategies may have no effect on or could even widen health inequities”  
(CDC, 2013).*

## Strengthening Existing Data Capacity

Understanding health inequities and their determinants can be improved by collaborating across sectors that may already collect the kinds of data that are needed. Similarly, it may be possible to make greater use of existing data within public health surveillance systems or within health and human service agencies. This involves linking data systems in ways that provide a more comprehensive view of community health. Adding data from one database to another can be resource intensive, and may require addressing legal barriers in addition to overcoming technical barriers. It is critical to ensure the protection of privacy when working with individual-level data, particularly as the groups most affected by inequities may already experience disadvantages related to their identity.

Fortunately, in the state of Delaware, the potential for such linkages can be facilitated by initiatives such as the Master Client Index (MCI), which tracks unique clients in each of the programs within the Department of Health and Social Services (DHSS) and the Department of Services for Children, Youth and their Families (DSCYF) (see [http://dhss.delaware.gov/dhss/dms/irm/files/mci\\_interfacing\\_requirements.pdf](http://dhss.delaware.gov/dhss/dms/irm/files/mci_interfacing_requirements.pdf)). Similarly, the Delaware Health Information Network (DHIN) is a statewide health information exchange among health care providers that facilitates an integrated data to improve patient outcomes and patient-provider relationships, while reducing service duplication and health care spending (see <http://dhin.org>). These, and other data-sharing initiatives, can provide the foundation for more concerted health equity oriented efforts.

Several national databases can be used to understand health inequities and their causes at the local level. The *Data Set Directory of Social Determinants of Health at the Local Level* contains an extensive list of existing data sources across 12 dimensions of the social environment, including: economy, employment, education, political, environmental, housing, medical, governmental, public health, psychosocial, behavioral, and transportation (Hillemeier, Lynch, Harper & Casper, 2004). Within each dimension, the directory includes several important indicators and data sources to describe those indicators. For instance, the political dimension identifies voter registration and voting rates as important indicators of civic participation and offers a specific data table within the Census Bureau dataset as a source for those indicators. The behavioral dimension includes indicators commonly used in public health surveillance, such as smoking rates and levels of physical activity. However, it also includes indicators such as the average local price of cigarettes and physical education requirements in schools. These latter indicators speak to the social and structural characteristics of the environment, which allow public health practitioners and partners to better understand upstream root causes. For the full directory, visit: [http://www.cdc.gov/dhds/dsp/docs/data\\_set\\_directory.pdf](http://www.cdc.gov/dhds/dsp/docs/data_set_directory.pdf). Appendix C from the *CDC Practitioner Guide for Advancing Health Equity* (2013) (see

<http://www.cdc.gov/nccdphp/dch/pdfs/health-equity-guide/foundationalskills.pdf>) contains additional examples of resources for identifying and understanding health inequities.

Existing data collection and surveillance activities can also be strengthened with respect to the collection of race, ethnicity, and language data. Although race, ethnicity, and language data is captured in databases such as vital statistics and health care records, it is not collected consistently through other surveys, programs, or databases. It is recommended that race, ethnicity, and language data be collected across sectors and collected by a variety of agencies including government, non-profit organizations, and academic institutions, among others. A race, ethnicity, and language workgroup of the Minnesota Department of Health and the Minnesota Department of Human Services specifically recommends the following:

- More detailed categories of race and ethnicity data should be used so that the data are more useful in understanding health issues and needs for particular groups.
- State agencies and organizations that collect and use health data should be regularly engaged with diverse communities to promote full understanding of how race, ethnicity, language, and culture affect quality, access, and cost of health services.
- Data collected by state agencies and health care organizations should be as accessible to communities, as possible. The criteria and process for obtaining access to data should be provided to and discussed with the communities, and agencies should take steps to ensure that information about relevant datasets is easily available online.
- A workgroup (such as the one that developed these recommendations) should continue on an ongoing basis so communities, health care stakeholders, and government agencies can partner to improve data collection policies and practices and, using the data, eliminate health inequities.
- A uniform data “construct” should be developed so that all health data collected use the same categories for race, ethnicity, and language. The uniform construct should be used not just by state health agencies, but also by licensing boards, other governmental agencies, health plans, hospitals, clinics, non-profit agencies, quality and performance measurement programs, and others who collect, analyze, and report health data. In this way, disease burden, risk and protective factors, access to care, and quality of care can be measured and communicated for smaller populations within an overall population. The uniform construct should build on existing frameworks for data collection, to eliminate duplication of effort. The data construct should be flexible so categories can be changed as needed. A process should be developed for assessing changes in

racial/ethnic populations in the state and determining when populations are of a sufficient size to be reported as a separate category.

- Programs that rely on survey data should consider over-sampling or mixed mode approaches to obtain larger numbers for communities of color (MDH/MDHS, 2011).

For more information about Minnesota's race, ethnicity, and language workgroup, its process for developing recommendations, and a more detailed discussion of the recommendations, visit:

<http://www.health.state.mn.us/ommh/publications/raciaethnicdata2011.pdf>.

### **Selected Data Tools for Health Equity: GIS, HIA, CHA**

Capacity to address health inequities at the community level can be strengthened by using various tools that help describe public health issues and available resources at the community level. One such tool involves the use of Geographic Information Systems (GIS) data. GIS data may be used in concert with health data to generate maps, which provide a powerful tool for visualizing health inequities at the community level. More specifically, maps can be used to analyze spatial patterns of health and illness in tandem with social inequities such as poverty and income, race/ethnicity, and environmental health hazards (MDH, 2014). For example, the maps presented in Section 3 that reflect income level, educational attainment, infant mortality, and life expectancy by ZIP code are GIS maps that were developed by Delaware's Division of Public Health (DPH) and its Office of State Planning Coordination (OSPC). Ultimately, GIS maps can distill otherwise complex information into easily understood images. Importantly, they can be used to promote policy change, particularly because they can focus attention on areas defined by political boundaries (e.g. congressional districts).

The use of Health Impact Assessments (HIAs) described in Section 6 require a different kind of analytical approach, research skills, and sources of data than traditionally used in public health. However, they also offer an important way of understanding existing health inequities and the changes (both positive and negative) that may result from proposed policy changes. The methods for conducting HIAs described earlier are consistent with the data and evaluation needs outlined in this section. Specifically, they call for community-based approaches to data collection and analysis; are grounded in the principles of equity, inclusion and democracy; often rely on mixed data collection methods (i.e. quantitative and qualitative approaches); and make connections between health and social and environmental conditions and structures. There is also a strong focus on dissemination and utilization of the results of the analysis. For these reasons, capacity for conducting HIAs should be developed and/or enhanced to advance health equity in Delaware.



Another opportunity for addressing health equity data needs at the community level exists through the use of community health assessments conducted by non-profit hospitals. The Affordable Care Act (ACA) now requires tax-exempt hospitals to regularly (at least every three years) conduct community health needs assessments and develop plans to address those needs. The law strengthens the hospitals' obligation to work with public health agencies and others in this regard. Therefore, public health practitioners can partner with hospital administrators to support their data collection efforts and encourage them to implement action plans that focus on SDOH and equity.

### Limitations of Data Collection and Analysis for Health Equity

The kinds of data needed to describe health inequities and their causes are not always available or accessible. Investments in new kinds of data collection may be needed to fill these gaps. Importantly, data collection systems need to be maintained to track changes over time and allow for the evaluation of interventions. Furthermore, investments may be needed to allow for easy access to the data once collected (e.g. interactive websites) and to effectively communicate the findings. Investments in data collection and analysis are wasted if the information is not shared in useful ways. Infographics, or images used to portray data, can be particularly effective in conveying information to the public and policymakers. Figure 30, shared courtesy of the Robert Wood Johnson Foundation to Build a Healthier America, shows how the average life expectancy for babies born to mothers in New Orleans can vary by as much as 25 years across neighborhoods just a few miles apart. Below are links to two additional examples of infographics oriented to health equity: [http://www.hpoe.org/Reports-HPOE/EoC\\_Infographic\\_FINAL.pdf](http://www.hpoe.org/Reports-HPOE/EoC_Infographic_FINAL.pdf) and [http://healthequity.sfsu.edu/sites/sites7.sfsu.edu.healthequity/files/What%20are%20Health%20Inequities\\_1.pdf](http://healthequity.sfsu.edu/sites/sites7.sfsu.edu.healthequity/files/What%20are%20Health%20Inequities_1.pdf). Each of these examples demonstrates the power of images in conveying this type of information and can be adapted to reflect the reality of health inequities in Delaware.



**Figure 30. Metro Map: New Orleans, LA**



Source: Robert Wood Johnson Foundation, 2013. Retrieved from <http://www.rwjf.org/en/about-rwjf/newsroom/infographics/new-orleans-map.html>.

Another data challenge, inherent in working at the community level, is the limitation of small sample sizes. Ideally, data are analyzed by neighborhood to provide the most comprehensive understanding of local needs, assets, and priorities. However, the more granular the level of data collection, the greater the challenge in reporting rates and other statistical measures, and interpreting changes over time. This is because small changes can appear large and be potentially misleading. For instance, if there are 10 cases of a disease one year and nine cases the following year, this could be interpreted as a 10 percent drop. A larger area might have 1,000 cases one year and 999 the following year, revealing a 0.1 percent drop. In both instances, there is one less person with the disease, but the reduction may or may not be relevant in the context of the population as a whole. When working with small numbers, it is difficult to know if a change is meaningful, or the result of random chance or other anomaly.

Statisticians often aggregate data into larger geographic regions or over multiple years to address this challenge. However, such aggregation is less helpful when developing and evaluating place-based initiatives at the local level.

Another barrier, that is somewhat easier to overcome than others, is the lack of a skilled workforce. Surely, practitioners working in epidemiology and surveillance need strong analytical capabilities, including skills in statistics and quantitative analytics. However, it is also true that health equity work requires that practitioners be skilled in qualitative research methods. Similarly, there is a need for workers to think creatively about the kinds of data necessary to understand health inequities and describe them in ways that compel action. For example, storytelling approaches, such as Photovoice and media advocacy, are likely to leave a lasting impression on audience members.

Lastly, data collection, analysis, interpretation, and dissemination for health equity require meaningful community engagement and empowerment. It is often a challenge for public health practitioners and partners to dedicate the time and resources necessary to leverage and sustain community engagement. However, for data collection and analysis to impact change, the data must be easily understood and utilized by those most responsible for making change—community members, stakeholders, and policy makers. Therefore, it is in the best interest of public health practitioners and partners to engage and empower communities. By including community members, stakeholders, and policy makers in the data collection and analysis process, it is more likely that they will use the information to develop appropriate and effective interventions.

### Principles for Successful Use of Data for Health Equity

In its report to the state legislature of Minnesota, the Minnesota Department of Health identified “four keys to the successful use of data for addressing health inequities” (MDH, 2014). These recommendations apply to the collection of new data, the improvement of existing data, and the use of tools such as GIS mapping and HIA (all described above). The four keys to success include:

1. **Make the data useful in terms of analysis, interpretation, and application.** This suggests that many different kinds of techniques may be needed for the collection, analysis, and reporting of data related to health equity. The approaches that are used will depend on the purpose or intended use of the data.
2. **Results must be disseminated effectively.** Practitioners must consider their audience when deciding how to share their findings to achieve maximum impact. For example, data meant to inform policy change will be of little use unless policy makers can

understand and appreciate the information. Different and creative channels for dissemination should be considered, such as interactive platforms and websites, newsletters, emails, and community forums. A public access web portal with interactive capabilities, such as allowing users to select indicators and geographic locations, can be particularly useful. At the same time, this approach may require substantial ongoing investment of staff to manage the portal's operation and financial support.

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### *Sample Strategy*

In Delaware, efforts to effectively disseminate data to community members have occurred through community dinners. The community dinner model seeks to engage individuals in places within their community, such as a school or recreational meeting area, to make data and information easily accessible. Resources required to successfully implement a community dinner rely on partnerships. Often organizations contribute staff members' time, funds to order food, and space to house the event. Community dinners are a favorite tool to gather stakeholders and community members together, and have been implemented across the state. Christiana Care Health System and the Sussex County Health Promotion Coalition have set the tone for hosting community dinners, having achieved success in discussing health-related topics with local residents.

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- 3. It is essential to involve the community in data collection, analysis, and dissemination.** The community should help to determine what data are needed and how the findings should be used. This may require practitioners to help build the capacity of community members so they are equipped to engage in some of the more technical aspects of data collection and analysis. "Community involvement in monitoring health inequities will increase awareness, ensure health inequity data are responsive to the needs of communities, create a sense of ownership of the data, and facilitate a collaborative, equitable partnership in creating health equity policies, programs and practices" (MDH, 2014, p. 67).

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### *Sample Strategy*

In Delaware, Christiana Care Health System employed Photovoice, which uses photography to communicate social issues, to engage Black youth in an analysis of the

issues that shape their lives. As participants in this community-based participatory research project, the youth were regarded as co-researchers and assisted in developing the research question while holding autonomy in the research process. Results indicated that the youth saw violence and substance abuse/addiction as barriers to their personal success (Christiana Care Health System, 2014, p. 13). Photos representing safety, gun violence, teen pregnancy, and risky behaviors (such as gambling, tobacco use, and addiction to prescription and illicit drugs) were evidence of concerns for these youth (Christiana Care Health System, 2014, p. 13). By coupling these data with statistical reports and peer-reviewed research, the Photovoice approach provided validation of what is known in academia and represents a unique opportunity to view the social determinants of health through the lenses of those most vulnerable to their effects. The Photovoice approach exemplifies community engagement and quality data collection and analysis.

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### *Sample Strategy*

Another innovative example that involved community members in data collection is the *CommunityRx* system in the Chicago area. With funding from the Center for Medicare and Medicaid Innovation, a group of partners began developing a system comprised of a continuously updated electronic database of community health resources that will be linked to the Electronic Health Records of local safety net providers. In real time, the system will process patient data and print out a “HealthRx” for the patient, which includes referrals to community resources relevant to the patient’s health and social needs. To identify community resources for the database, new jobs were created for individuals residing in Chicago’s low-income communities. Many high school youth were employed to collect data on community health resources as part of the Urban Health Initiative’s MAPSCorps program. The *CommunityRX* project includes the creation of a new type of health worker, called Community Health Information Experts (CHIEs), who help patients use the system and engage community-based service providers in using its generated reports. For additional information, visit <http://www.uchospitals.edu/news/2012/20120508-communityrx.html>.

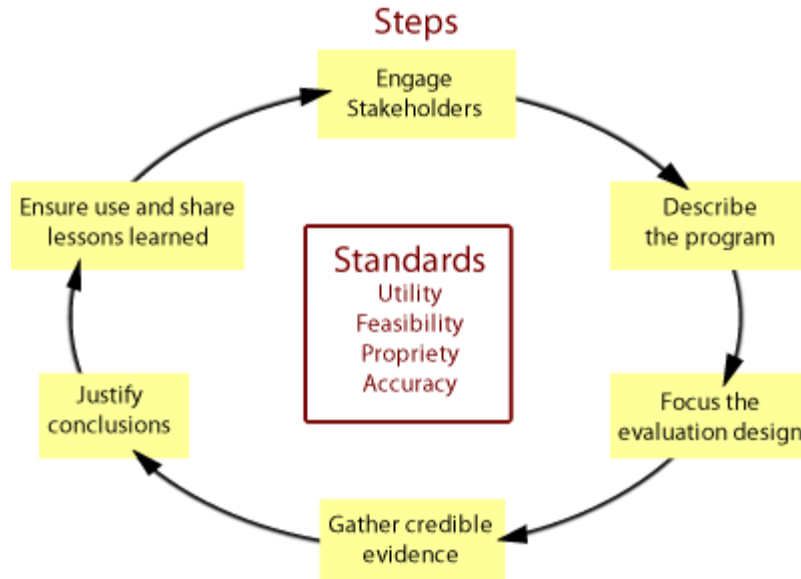
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- 4. Effective collection and use of data for health equity requires a skilled workforce.** This may involve recruiting new staff with research expertise, retraining existing staff, or simply supporting staff who possess the appropriate skills by providing the time, tools, and resources necessary to engage in surveillance, analysis, and dissemination of health equity data. Importantly, a workforce skilled in epidemiology is one that includes staff knowledgeable about health equity and SDOH, in addition to possessing analytical skills and research expertise. Mobilizing a skilled workforce toward an enhanced focus on qualitative methods and community-based participatory research is also warranted for a holistic description of the public health issue and potential interventions. Finally, a culture of continuous learning within state agencies and community-based organizations can support the successful use of health equity data (MDH, 2014, pp. 65-67).

## Evaluation for Health Equity

Evaluation is one of the Ten Essential Public Health Services outlined by the CDC. Ultimately, evaluation involves a value judgment about how well something worked and whether it should be continued. In the interim, evaluation is critical for informing the ongoing work of any initiative and helps to ensure that stakeholders are focused on activities thought to be the most effective. Effective program evaluation is a systematic method of improving and accounting for public health actions (CDC, 1999). A framework for evaluating public health efforts, developed by public health leaders at the CDC, is widely used within the field. An illustration of the key elements of the framework is presented as Figure 29, and a detailed discussion of the framework can be found at <ftp://ftp.cdc.gov/pub/Publications/mmwr/rr/rr4811.pdf>.

**Figure 29. Framework for Evaluation in Public Health**



Source: Centers for Disease Control and Prevention, 1999.

The evaluation of health equity initiatives is particularly important, considering that it can reveal the effects of initiatives on different groups, ensure that stakeholders do not lose sight of the intention to reduce gaps in health status, and ensure equity in the distribution of resources needed for optimal health. The importance of understanding what works, for whom, under what conditions, and whether health inequities have decreased, increased, or remained the same requires a deliberate focus on equity in evaluation efforts (CDC, 2013). In their *Practitioner Guide for Advancing Health Equity*, the CDC offers a number of questions for practitioners in government and community-based organizations to reflect upon when working to incorporate health equity into evaluation efforts:

- Where are we now?
  - How are we currently assessing the effect(s) of our efforts to address health equity?
- How do we start the evaluation process with health equity in mind?
  - Do we have the expertise to develop, implement, and assess an equity-oriented evaluation plan?
  - What process can we establish to routinely engage community stakeholders, including those experiencing health inequities, in all aspects of our evaluation efforts?
  - What are our current health equity strategies, activities and goals?

- How can our logic model be modified to reflect our health equity activities and goals?
- How can we consider health equity in evaluation questions and design?
  - How can we reframe or create new evaluation questions to better understand our effect on health inequities?
  - What are the key variables we should use to track the influence of our efforts on populations experiencing health inequities?
  - How can our sampling plan be designed or modified to answer our health equity-oriented evaluation question(s)?
- How can we integrate health equity principles in the data gathering process?
  - What processes do we have in place to determine when culturally appropriate tools or methodologies are needed?
  - If modifications are needed, how can we ensure our evaluation tools meet the needs of populations experiencing health inequities (e.g., language and literacy needs)?
  - Are the data we are collecting reflective of the real experience of the populations experiencing inequities? Are other approaches needed?
  - Does our performance monitoring system allow us to track and identify needs that may arise when implementing efforts in underserved communities?
  - How can we structure our evaluation processes to understand the long-term effects of our efforts on health inequities?
- How can we understand our effect on health equity through our analysis plan?
  - Does our analysis plan allow us to answer the following: What worked? For whom? Under what conditions? Is there any differential impact? Have inequities decreased, increased, or remained the same?
  - If not, how can we modify the analysis plan to answer these questions?
  - Does our outcome evaluation allow us to determine differential effects across population groups?
  - Does our process evaluation allow us to understand the key factors that influenced the outcomes of our efforts in underserved communities?
  - What actions do we need to take to improve or enhance our evaluation plan to understand our effects on health equity (e.g., have inequities decreased, increased, or remained the same)?



- How can we share our evaluation efforts with diverse stakeholders?
  - How and where do we typically disseminate our evaluation findings?
  - What commitment can we develop to ensure we share findings, even if negative?
  - How can we ensure we share our findings in plain and clear language that can be understood by stakeholders, partners, and community members?
  - How can our findings be used to support more action in communities of greatest need?
  - How can we revise the ways in which we share lessons learned to help others concerned with addressing health inequities?
  
- What are our next steps?
  - What can we do differently to improve or enhance our ability to conduct health equity-oriented evaluations?
  - What is our plan of action to implement improvements in our evaluation efforts? (CDC, 2013, p. 33).

Evaluation efforts are most useful when considered at the outset of the initiative. In fact, thinking about evaluation during the planning phase of a health equity initiative can contribute to the likelihood of its success. It encourages participants to think in depth about the goals of the initiative and what success looks like in the short-term as well as the long-term. This requires participants to clearly articulate their theory of change, or the rationale for their approach, and helps them communicate this effectively with other stakeholders. Similarly, incorporating evaluation at the outset of a program provides an opportunity to identify intermediate measures of progress towards the ultimate goal of achieving health equity, which is particularly important for place-based initiatives or community-based efforts that target upstream SDOH. In such cases, stakeholders must consider the relation between the targets of the intervention (e.g. affordable, quality housing) and longer-term outcomes related to health status and health equity (lower rates of asthma among low income children). Finally, incorporating evaluation into early planning phases encourages stakeholders to consider important questions related to needed resources and the capacity available for evaluation.

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### Sample Strategy

A good example of using evaluation during the planning stages of an intervention is provided by an organization called the Children and Families Commission of Orange County

(CFCOC). CFCOC was created as a result of Proposition 10 in California, where funding from a tax on tobacco products is used to support early childhood development for children ages 0-5. CFCOC's vision is that *all children (in the county) are healthy and ready to learn*. Through an extensive planning process, CFCOC identified the following goals to reach their vision:

1. Healthy Children – Promote the overall physical, social, emotional and intellectual health of young children.
2. Early Learning – Provide early learning opportunities for young children to maximize their potential to succeed in school.
3. Strong Families – Support and strengthen families to promote good parenting for the optimal development of young children.
4. Capacity Building – Promote an effective and quality delivery system for young children and their families.

The planning process helped to clarify for the organization and its community stakeholders the importance of individual-level parental support and systems support (or the capacity of community-based organizations) for promoting the health and education of young children. Attention to evaluation in the early stages of planning allowed CFCOC to identify indicators of success pertinent to each goal, ensuring that stakeholders considered data sources and the capacity for data collection and analysis. Finally, by incorporating evaluation into the planning phase, CFCOC connected upstream factors and its ultimate vision. For Fiscal Year 2012-2103, CFCOC reported the following indicators of success along the path to their vision:

- ❖ 142,296 shelter bed nights were provided to pregnant women, mothers, and young children.
- ❖ 40,654 children participated in a program to increase the frequency of reading at home.
- ❖ 18,728 children received dental services including restorative and emergency treatment and dental visits for children with special needs.
- ❖ 15,997 mothers received breastfeeding education, intervention, and support.
- ❖ 5,958 children were linked to a place for regular medical care (a "health home") (CFCOC, 2013).

More information about CFCOC may be found at <http://www.occhildrenandfamilies.com/>.

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## Sample Strategy

In Delaware, the Nurse-Family Partnership (NFP) provides a similar example of a coordinated strategy that incorporates evaluation from the outset for meeting multiple objectives. Implemented by Children and Families First, the NFP is an evidence-based community health program that links newly pregnant, first-time mothers with a registered nurse. The nurse provides home visits throughout the woman's pregnancy and during the first two years of the baby's life. NFP has three distinct, but complementary, goals:

1. Improve pregnancy outcomes by helping women engage in good preventive health practices, including thorough prenatal care from their health care providers, improving their diets, and reducing their use of cigarettes, alcohol, and illegal substances.
2. Improve child health and development by helping parents provide responsible and competent care.
3. Improve the economic self-sufficiency of the family by helping parents develop a vision for their own future, plan future pregnancies, continue their education, and find work (Nurse-Family Partnership, 2011).

The program was launched in Delaware in 2010. Evaluation data revealed early success in terms of positive health outcomes for babies. As of 2014, 90 percent of babies served by the program were born full-term; and 88 percent were born at a healthy weight. Furthermore, 82 percent of mothers in the program initiated breastfeeding, and 21 percent were still breastfeeding at their six month follow-up (Wallace, 2014). These evaluation data contributed to a recent increase of \$1.3 million in state appropriations, which doubles the number of women and babies served.

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## Evaluating Complex Community Initiatives

The evaluation of comprehensive place-based initiatives, "described in Section 4, is particularly challenging due to the complexity of this type of initiative as well as the uniqueness of communities. Thomas Kelly from the Annie E. Casey Foundation describes the essence of this challenge:

"Most comprehensive place-based initiatives consist of multiple interventions over a number of years at individual, group, institutional, social and political levels. Any one of

these interventions could be an evaluation in and of itself, but with [this approach] you want to capture what matters” (Kelly, 2010, p. 19).

Based on his experience working with the evaluation of the Casey Foundation’s *Making Connections* initiative, Kelly developed *Five Simple Rules for Evaluating Complex Community Initiatives*. These include the following:

1. Evaluations of complex, major initiatives are not experiments but part of the community change process.
2. Evaluations need a strong focus on the processes of community change.
3. Evaluations need to measure ongoing progress toward achieving outcomes and results to help a community guide its change process and hold itself accountable.
4. Evaluations need to understand, document, and explain the multiple theories of change at work over time.
5. Evaluations need to prioritize real-time learning and the community’s capacity to understand and use data from evaluations (Kelly, 2010).

A more detailed description of each of these rules, and strategies for accommodating them, can be found at [http://www.frbsf.org/community-development/files/T\\_Kelly.pdf](http://www.frbsf.org/community-development/files/T_Kelly.pdf). Additional tools and resources to support evaluation of community-based health equity initiatives can also be found in the Community Toolbox referenced in previous sections of this guide (<http://ctb.ku.edu/en/table-of-contents/evaluate/evaluate-community-initiatives/measure-success/main>). Finally, the CDC provides links to a number of valuable resources for evaluation at <http://www.cdc.gov/eval/resources/index.htm>.

## Evaluation Challenges

The process of evaluation can be tedious and confusing and is not free of barriers. Because a successful evaluation relies on the use of data collection and analysis, the barriers inherent in those processes are also applicable to evaluation (see *Limitations of Data Collection and Analysis for Health Equity* on page 149 of this guide). In addition, the evaluation process is subject to other barriers, which are more likely due to the substantial partnering that is necessary during the evaluation process. Regarding health equity efforts, this process is also subject to barriers that arise due to the complexities involved in assessing long-term outcomes related to SDOH.

Ideally, the evaluation process begins during the planning phase of developing an intervention. Because this phase is often highly collaborative and involves input from numerous

stakeholders and community members, the evaluation process is often subject to much debate. Therefore, public health practitioners and partners will benefit from clearly defining their desired outcomes and deciding on the appropriate measures for assessing these outcomes early in the planning phase. Similarly, by garnering buy-in for the evaluation process early on, stakeholders will be more likely understand the importance of the evaluation, and then later make changes (such as resource allocation and alterations in program design) when the evaluation results indicate room for improvement.

Specifically in regard to the evaluation of health equity-focused interventions, it is important to understand the limitations of assessing interventions that target SDOH. Typically, grants are awarded for short-term interventions (i.e. three to five years), which stunts the ability to assess impacts on the SDOH, such as income level and educational attainment. Therefore, the evaluation process for such interventions should include measures that can be used to indirectly assess the likely impact on SDOH.

*“We must learn not only whether an intervention can work, but how, why and for whom, and how we can do better” (Schorr & Bryk, 2015).*

To overcome the challenges described in this section, practitioners may need to build upon traditional evaluation methods and consider alternate approaches. For instance, when logic models are used to guide program implementation and evaluation, they must incorporate equity-related activities and outcomes. Because changes in living conditions (such as an increase in the number of affordable housing units or an increase in average wages) may be the target of the intervention, they should also be the focus of the evaluation. Evaluators must recognize that changes in health outcomes related to changes in the physical and social environment may take several years, if not generations, to manifest. Although tools like logic models can be useful in articulating the expected long-term changes, evaluators may need to consider intermediate outcomes and unique measures as indicators of impact. Case studies and other qualitative evaluation methods, for instance, can be used to help demonstrate impact. Finally, since health equity-focused interventions typically target culturally diverse groups, culturally appropriate tools and methodologies are essential to effective evaluation of health equity interventions. Information regarding culturally appropriate measures that can be incorporated into evaluation can be found at the San Diego Prevention Research Center’s website: <http://sdprc.net/lhn-cam.php>.

In summary, evaluation is a critical component to achieving health equity and should be as multi-faceted, responsive, and flexible as the initiatives themselves (Preskill, Parkhurst, & Splansky-Juster, 2014). Practitioners and other community stakeholders should explore resources available to support evaluation, such as partnerships with universities and other

research organizations. Additionally, because of the growing attention to health equity nationally, and the limited availability of evidence-based strategies for achieving health equity, federal agencies and national funders may be a resource for financial support and/or technical assistance. The U.S. Department of Health and Human Services' Office of Minority Health offers support for identifying funding sources in response to specific organizational needs (visit <http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=43>). Similarly, other organizations maintain lists of available funding opportunities that are regularly updated. For instance, the Association of American Medical Colleges posts weekly updates of funding opportunities to support research on health disparities and health equity (visit <https://www.aamc.org/initiatives/research/healthequity/350530/fundingandtrainingopportunities.html>). Readers are encouraged to subscribe to electronic mailing lists that provide this information and conduct regular scans.

## Research Priorities to Advance Health Equity

Experts and community leaders have identified a number of research priorities to support efforts to advance health equity. Among the most important is that researchers need to shift from a disparities model to an equity model (Srinivasan & Williams, 2014). This means greater attention should be paid to social and structural determinants of health, rather than individual risk factors. Similarly, more attention should be placed on evaluating solutions to health inequities that are driven by social, economic, and environmental factors. Given some of the challenges highlighted above, research must be multi-disciplinary. Additionally, it is important to improve our research capacity for multi-factorial and multi-level analyses, as well as to address challenges related to statistical power and small sample sizes (Srinivasan & Williams, 2014). These methods require highly skilled statisticians and epidemiologists and often take more time and effort than traditional research, so building such a capacity requires targeted investments.

Improved research for health equity also requires meaningful community engagement and participation. Research is needed that reflects community priorities, is meaningful to the community, and is better connected to the lived experiences of the people most affected by health inequities (Knight, 2014). To this end, the *National Stakeholder Strategy for Achieving Health Equity* calls for investments in community-based participatory research and the evaluation of community originated intervention strategies (NPA, 2011). The report identified several specific objectives in this area, including the following:

- Identify and work with community-based organizations and programs to determine and disseminate replicable best and evidence-based practices for ending health disparities;

- Work with researchers and evaluators to develop useful and practical models for evaluating community-originated intervention strategies, including new metrics from interventions that reflect communities' immediate needs;
- Engage community members and enhance their capacity to be equal partners in the conceptualization, planning, design, implementation, interpretation, evaluation, and dissemination of public health interventions, programs, and initiatives; and
- Strengthen community ownership of data and research and evaluation products by promoting the principles of community-based participatory research (NPA, 2011, p. 135.)

Similar to the need for collaboration to develop health equity strategies, research for health equity must also be better coordinated. This includes working across sectors and building partnerships between academic or research institutions, state agencies, and community-based organizations. Finally, research must be translated and applied to advance health equity. As explained by the NPA (2011):

“Knowledge transfer is challenging but obligatory. Often, findings that may be valuable to communities are published in journals, reports, and other formats that are not widely distributed to them or easily accessible to non-research audiences. Nontraditional media should be used to disseminate data and information to improve accessibility. Improving the health outcomes of minority and underserved communities will take the combined efforts of medical scientists, statisticians, anthropologists, economists, sociologists, epidemiologists, policy analysts, psychologists, social workers, community developers, and others working in collaboration with community organizations” (NPA, 2011, p. 133).

Delaware is making strides to conduct and translate community-based research. As mentioned in Section 5, Delaware was recently awarded a multi-year grant from the National Institutes of Health to enhance the state’s capacity for clinical and translational research. Specifically, the Delaware Clinical and Translational Research Program (DE-CTR ACCEL) is a partnership between the University of Delaware, Christiana Care Health System, Nemours Health and Prevention Services/Alfred I. duPont Hospital for Children, and the Medical University of South Carolina. Its goal is to improve the state’s infrastructure and capacity for conducting research that leads to better clinical outcomes and applying knowledge about effective interventions in the clinical setting. The DE-CTR is part of the ACCEL program, which represents a long-term research partnership that can be leveraged to enhance the research and evaluation capacity needed for health equity. More specifically, community engagement and outreach is a priority for the ACCEL program, and can be an important avenue for health equity-



oriented research. For more information about the DE-CTR ACCEL program and related funding and research opportunities, visit: <https://de-ctr.org/>.

Finally, from a translation and application perspective, research is needed that makes clearer linkages for the public and policymakers about the connection between policy decisions and health. Powerful ideologies and preexisting assumptions about the role of behavior, health care, and individual responsibility must be overcome to promote the changes needed to advance health equity. Health impact assessments are one tool for addressing this challenge. Other approaches include providing training and technical assistance to professional associations, foundations, advocacy groups, and community organizations on how to interpret and use research and evaluation findings to inform their decisions and program designs (NPA, 2011, p. 137). As a standard of practice among researchers and evaluators and their sponsors, the NPA (2011) recommends promoting strategies to make findings accessible, easily understood, and used by policymakers and the public to inform programming and services (NPA, 2011, p. 137).

## Glossary – Section 7

**Community-Based Participatory Research (CBPR):** An approach to research that involves an equitable partnership between and among community members and researchers in all aspects of the research process and in which all partners contribute expertise and share decision-making and ownership. The aim of CBPR is to increase knowledge and understanding of a given phenomenon and integrate the knowledge gained with interventions, policy, and social change to improve the health and quality of life of community members.

**Evaluation:** A systematic way to improve and account for public health actions. It can be used to judge the impact of a particular intervention as well as describe and improve the process of implementation.

**Geographic Information Systems (GIS):** A computer system designed to capture, store, manipulate, analyze, manage, and present all types of spatial or geographical data. GIS may be used to develop maps that present health data according to place.

**Health Impact Assessment (HIA):** A systematic process that uses a variety of data sources and research methods, and considers input from a range of stakeholders to determine the potential effects of a proposed policy, plan, or action on the health of a population and the distribution of those effects within the population.

**Place-based initiative (PBI):** A social change effort that is concentrated in a specific geographic area. Health equity strategies focused on living conditions in a specific geographic community are often referred to as PBIs because the target of the interventions is the place itself (or characteristics of the place), rather than the people living there.

**Surveillance:** The continuous, systematic collection, analysis, and interpretation of health-related data needed for the planning, implementation, and evaluation of public health efforts.

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