



Using Data to Promote Health Equity



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Maine Health Equity Surveillance Plan 2016: Recommendations for Using Data to Promote Health Equity

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Table of Contents

Acknowledgements	2
List of Tables and Figures	5
Introduction: Using Data to Promote Health Equity	7
Healthy Equity Surveillance Framework	9
Chapter 1: Using Public Health Surveillance Systems to Advance Health Equity	10
Health Equity Data System Summaries	16
Chapter 2: Presenting Data on Health Disparities	25
Chapter 3: Measuring Social Determinants of Health	36
Social Determinants of Health Report Outline	38
Social Determinants of Health Indicators with Definitions	41
Chapter 4: Populations Experiencing Health Disparities	61
Native American Tribal Populations	62
People of Color	68
Refugees and Immigrants	72
Hispanic/Latino Population	77
Migrant and Seasonal Farmworkers	81
Gay, Lesbian, Bisexual and Transgender Mainers	85
Persons with Disabilities	91
Children and Youth with Special Health Needs	96
Women	104
Older Adults Living in Rural Areas	108
Key Findings and Recommendations	113

List of Tables and Figures

Chapter 1	
Table 1. Health Equity Data Set Overview	13
Table 2. Missing data analyses of selected indicators within major public health surveillance systems	13
Figure 1. Maine’s hospital discharge data by race and year, 2008-2012	14
Chapter 2	
Sample Table Shell: Indicators of health and social determinants of health by education level, Maine, 2015	26
Sample Table Shell: Indicators of health and social determinants of health by income level, Maine, 2015	27
Sample Table Shell: Indicators of health and social determinants of health by ethnicity, Maine, 2015	28
Sample Table Shell: Indicators of health and social determinants of health by racial group, Maine, 2015	29
Sample Table Shell: Indicators of health and social determinants of health by rurality, Maine, 2015	30
Sample Table Shell: Indicators of health and social determinants of health by sexual orientation, Maine, 2015	31
Sample Table Shell: Indicators of health and social determinants of health by sex, Maine, 2015	32
Sample Maps: Indicators of health and social determinants of health by county, Maine, 2015	33
Chapter 3	
Figure 1. Determinants of population health	35
Table 1. Examples of social determinants of health	36
Chapter 4	
Table 1. Selected data elements related to immigration	72
Table 2. BRFSS Questions related to health problems or impairments	92

Table 3. American Community Survey disability concepts	96
Table 4. Maine Integrated Youth Health Survey questions on special health needs by module	97
Table 5. Summary of available data sources with information on children with special health care needs	99
Table 6. Selected data sources for women	104

Using Data to Promote Health Equity: Introduction

What is Health Equity?

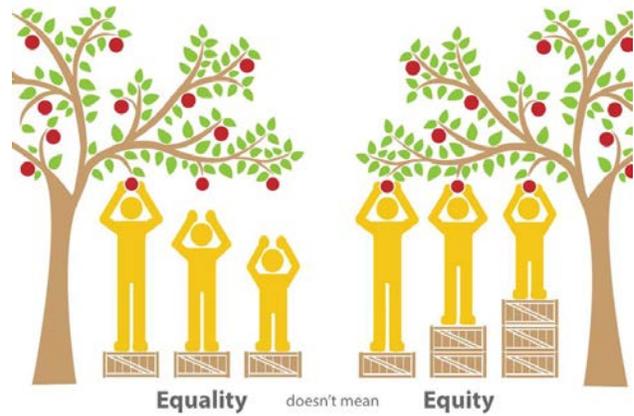
Health Equity is the “attainment of the highest level of health for all people.”¹

Health Inequities are differences in health that are avoidable, unfair, and unjust.²

Health Disparities are differences in health outcomes among groups of people linked with social, economic and/or environmental disadvantage.¹ Health disparities are avoidable and inequitable.³

Healthy inequities can be caused by:

- **Social conditions:** When a person or group is treated differently because of their race, sex, class, sexual orientation, or immigration status.
- **Economic conditions:** Unequal opportunities can lead to less access to educational and employment opportunities.
- **Environmental conditions:** Where you live can affect your health due to neighborhood conditions, economic opportunities, school quality, access to healthy food, opportunities for physical activity, exposure to violence, cleanliness of the environment, and social support.



Why Measure Health Inequity?

In order to apply evidence-based practices and policies to health inequity, valid and informative data are needed to understand the scope of the problem and the factors contributing to health disparities. It is also critical to continue to monitor inequities to ensure progress towards comprehensive, long-term reductions.

To increase health equity, it is critical to:

1. Identify inequalities in health.
2. Identify the inequalities that can be reduced through changes in social and health policy and practices.⁴

Traditionally public health surveillance is conducted to assess the health of a population. It generally includes identifying population health status and trends. **From a health equity perspective, it is important to identify differences in health that are associated with the historical and current socio-economic advantages or disadvantages of a particular group.**

An Overview of This Report

This report is based on a framework designed to summarize the current status of data analyses, data systems, and data availability on health equity. The three lenses of this framework include:

A. Public health data: systems, analysis, and presentation

Chapters 1 and 2 include a discussion of:

- Public health surveillance systems typically used to assess the health of the population in Maine.
- How to effectively use surveillance data from a health equity perspective.
- Indicators in public health surveillance systems used to identify disparities by population groups, as well as social and economic indicators (i.e., “equity stratifiers”).
- Quality and availability of equity stratifier indicators.
- A proposed reframing of how health status data can be presented to highlight health inequities.

B. Intersection between health and social determinants

Identification of health status most often focuses on comparing difference in health status between population groups (e.g., race and ethnicity, age groups), but there are many factors related to where we live, work and play that impact health.

Chapter 3 includes:

- A discussion of social determinants of health.
- A proposed health equity report outline focused on social determinants of health.
- A list of measurable social determinants of health indicators with definitions.

C. Populations with disparities

One of the challenges of using traditional public health data systems to address health equity is the lack of data on populations at risk for health disparities, such as refugees, migrants, LGBTQ and tribal members. Data on these groups in many data systems are simply not collected. When data are collected, the data collection methods are often not adequate to reliably capture their experiences.

Chapter 4 includes:

- A review of data available on ten populations in Maine with health disparities.
- Recommendations to improve data collection, analysis, and availability for each population.

Key findings and recommendations

Chapter 5 includes:

- Key findings based on stakeholder interviews, literature reviews, and data analyses, along with recommendations for improvement. This section also includes all of the recommendations from Chapter 4.

¹ U.S. Department of Health and Human Services. The Secretary’s Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020. Phase I report: Recommendations for the framework and format of Healthy People 2020 [Internet]. Section IV: Advisory Committee findings and recommendations [cited 2010 January 6]. Available from: http://www.healthypeople.gov/sites/default/files/PhaseI_0.pdf

² Health Equity Institute, San Francisco University. <http://healthequity.sfsu.edu/content/defining-health-equity>

³ Braveman P. What is health equity: And how does a life course approach take us further toward it? *Maternal and Child Health Journal* 2014. 18:366-372.

⁴ Nolen LB, Braveman P, Dachs NW, Delgado I, Gakidou E, Moser K, Rolfe L, Vega J, Zarowsky C. Strengthening health information systems to address health equity challenges. *Bulletin of the World Health Organization*. 2005. 83(8): 597-603.



USING DATA TO PROMOTE HEALTH EQUITY IN MAINE



HEALTH EQUITY SURVEILLANCE FRAMEWORK

DISPARATE POPULATIONS

Studying groups of individuals whose health is disproportionately worse than what would be acceptable.

- **Persons with Disabilities**
- **Tribal Members**
- **Refugees/Immigrants**
- **Racial and ethnic minorities**
- **Lesbian, gay, bisexual, transgender individuals**
- **Women**

SOCIAL DETERMINANTS OF HEALTH

Looking beyond demographic characteristics to determine the factors that influence health in our lives, homes and communities.

- **Poverty**
- **Unemployment**
- **Neighborhood Safety**
- **Availability of Services**
- **Violence**

IDENTIFYING HEALTH DISPARITIES

Analysis of health indicators by demographic and geographic characteristics to identify population groups at greater risk for poor health outcomes.

- **Age**
- **Income**
- **Education**
- **Race and ethnicity**
- **Geography**
- **Disability status**
- **Sexual orientation**
- **Sex/Gender Identity**

Chapter 1: Using Public Health Surveillance Systems to Advance Health Equity

In This Chapter

Traditionally in public health, health disparities are identified by analyzing data by demographic characteristics, such as age, sex, race, ethnicity, education and income. These analyses allow us to examine how health outcomes and behaviors vary across populations. This methodology has helped highlight racial and ethnic disparities in several health outcomes such as infant mortality, heart disease and diabetes.¹ **A key to this method of analyzing health disparities is to have multiple socio-demographic variables available for analysis and to have high quality data on these characteristics to ensure accurate measurement and reporting.**

Having data that are reliable and accurate is critical for policy and programming decisions. Compared to the U.S. and many other states, Maine's population is relatively small at 1.3 million people. The population of racial and ethnic minorities in Maine is less than five percent. Small population size can create challenges when trying to learn about racial and ethnic disparities. Incorrect or incomplete data can lead to incorrect assumptions and/or lack of information about health disparities. It is essential that measurements be correct and representative of the population to inform policy decisions. **The purpose of this chapter is to review the current data landscape and provide a roadmap for future improvements.**

"CDC and its partners can use data on health disparities to help direct actions to address the many health disparities that exist in the United States. The future health of the nation will be determined, to a large extent, by how effectively federal, state, and local agencies and private organizations work with communities to eliminate health disparities among those populations experiencing a disproportionate burden of disease, disability, and death."

*-Centers for Disease and Prevention
www.cdc.gov/disparitiesanalytics*

In this chapter, we review:

- Data systems traditionally used in public health to examine prevalence, trends, and health disparities.
- Key demographic indicators available in each data system.
- Gaps and limitations in these systems.
- Recommendations for improving systems.

Public Health Surveillance Data

Public health surveillance is defined as the "continuous, systematic collection, analysis and interpretation of health-related data." This review only includes systems that:

- 1) collect data on an ongoing basis;
- 2) are available to Maine's health department staff.

The discussion is also restricted to data systems that the State of Maine can adapt and improve. For this reason, we are not discussing national surveys, such as the National Survey of Children's Health and the American Community Survey.

There are two types of data generally used for public health surveillance in Maine.

- **Ongoing, Population-level Surveys:** This includes surveys that are conducted on an ongoing basis to provide population health data at the state and sometimes county or sub-county level. These surveys include: Maine's Behavioral Risk Factor Surveillance System (BRFSS), the Maine Integrated Youth Health Survey (MIYHS), and Maine's Pregnancy Risk Assessment Monitoring System (PRAMS).
- **Administrative Data:** These data systems are designed to collect information for administration, not research. These systems generally collect data for the purposes of registration, record keeping and/or billing. These systems include hospital discharge data, birth and death certificate data, medical claims data and electronic disease registries.

This chapter contains a summary of each dataset that includes: years available, indicators to identify health disparities, limitations and recommendations for use and improvement. Table 1 (on next page) summarizes selected variables that can be used to identify health disparities in Maine's public health surveillance systems. Additional analyses focused on the accuracy and completeness of race and ethnicity were also conducted.

Table 1. HEALTH EQUITY DATA SET OVERVIEW*

Data set	Years of availability	Income	Education	Health Insurance	Age	Sex	Sexual orientation	Race	Ethnicity	County/Public Health District	Zipcode	Town	Geocode (Maine County/Town Code)	Census Tract	Rural/Urban (RUCA codes from SHNAPP)	Military	Disability	Mental Illness	CHSN (Children with Special Health Needs)	Migrant	Immigrant /Refugee	Language
Death Certificate Data	1999-2013	-	Y	-	C	Y	-	Y	Y	C	-	Y	Y	-	C	L	-	Cl-suicide	-	-	-	-
Birth Certificate Data	1999-2013	-	Y	-	C	Y	-	Y	Y	Y	-	Y	Y	-	Y	L	-	L	-	-	L	-
Hospital discharge data	1993-2012	-	-	L	Y	Y	-	L	L	Y	L	Y	Y	-	L	-	-	C	-	-	-	-
Emergency Department Data	2000-2011	-	-	L	Y	Y	-	L	L	Y	L	L-city	Y	-	L	-	-	C	-	-	-	-
MIYHS (Maine Integrated Youth Health Survey)	2009-2015	-	Y	-	Y	Y	Y	Y	Y	Y	-	-	-	-	-	-	Y	-	-	-	-	Y
BRFSS (Behavioral Risk Factor Surveillance System)	2004-2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	L	Y	Y	-	-	-	Y
PRAMS (Pregnancy Risk Assessment Monitoring System)	1998-2013	Y	Y	Y	Y	Y	-	Y	Y	Y	-	-	-	-	L	-	-	-	-	-	-	-
Maine CDC Environmental Health Tracking Network	2000-2011	-	-	-	Y	Y	-	-	-	Y	-	L	-	-	-	-	-	-	-	-	-	-

Y=Yes, available in the dataset
 C=can be calculated with existing data
 L=limited data (data not available for all years)
 - =data not available

Race and Ethnicity Surveillance Data

Health disparities between racial and ethnic groups have been identified in the U.S and in Maine.^{1,2}

Accurate data are critical to assessing and monitoring these disparities, and informing community level prevention and intervention efforts.

Until this report, the quality of race and ethnicity data in Maine’s administrative datasets had not been systematically analyzed and documented. **The following sections will review the completeness and validity of the race and ethnicity variables in Maine’s hospital inpatient, hospital outpatient, and death certificate data.**

The manner in which race and ethnicity has been collected in administrative data systems has evolved over time. These changes represent movement towards standardized definitions, but make it difficult to assess change over time. For example, the death files prior to 2003 had one field for race and one field for ethnicity, making it impossible to document those with more than one race. In 2010 it became possible to track those with more than one race because data collection on race and ethnicity switched to a series of checkboxes for

self-identification of race and ancestry. The 2010 death certificate also included two “write-in” fields for additional information such as tribal affiliation and details on other race. This additional information will alleviate some of the misidentification issues on the death files, particularly among the Native American population in Maine. The Maine birth certificate was similarly revised in 2013 to include checkboxes and write-in fields for race/ethnic self-identification.

Completeness

Completeness was determined by evaluating the percent of missing data in the race and ethnicity fields each year. Overall, in statewide surveys and administrative datasets, race and ethnicity are consistently recorded (only one to two percent is missing; Table 2). However, in several of these datasets not every year of data is complete. For some datasets only the most recent years of race and ethnicity data should be used. For example, hospitals began submitting race and ethnicity data as part of the hospital discharge dataset in 2007, but there were problems with incomplete data and incorrect coding in 2007 and 2008. For the hospital discharge data set, only race and ethnicity data from 2009 or later are recommended for analyses.

Table 2. Missing data analyses of selected indicators within major public health surveillance systems.

Dataset	Most recent year available	Percent with non-missing values					
		Race	Ethnicity	Sex	Income	Education	Age
Death certificate file	2013	99% ¹	90% ¹	100%	NA	98%	100%
Birth Certificate file	2014	NYA	NYA	NApp	NA	99%	99%
Maine Hospital Discharge data ²	2012*	99%	96%	100%	NA	NA	96%
Maine Outpatient Emergency Department extract ²	2012*	79%	77%	100%	NA	NA	99%
Pregnancy Risk Assessment Monitoring System	2013	99% ³	99% ³	NA ⁴	96%	86%	100% ⁴
Behavioral Risk Factor Surveillance System	2014	99%	99%	100%	89%	99%	99%
Maine Integrated Youth Health Survey	2015	99%	97%	99%	NA	NA	99%

* 2011 missing data percentages are reported here. Per new policy, race and ethnicity are available through special request only. Data request is in process.

NA=Not available; NApp=Not applicable; NYA=Not yet available, but anticipated.

1. There are a small percent of records that have write in values only and no race; these are disproportionately Asian/Pacific Islanders.
2. Completeness of race and ethnicity for hospitalization and ED datafiles is based on the number of records that have a value of unknown.
3. Data are from the birth certificate, which is linked with PRAMS.
4. The PRAMS survey is only completed by women.

Accuracy

Accuracy was determined by comparing the distribution of race in each dataset to statewide census distributions by hospital. Similar statewide comparisons were made for the death and Emergency Department (ED) data. Birth data were analyzed through 2012.

Inconsistencies in race reporting were found in some datasets. For example, in the 2008 inpatient data, the number of hospitalizations for Native Americans exceeded what would have been expected. Investigation revealed that the coding of race at one of the largest hospitals was not correct. This error invalidates any analyses of race using the 2008 hospital discharge data (Figure 1).

In the 2012 death certificate dataset, there were some records that had values in the field for tribal affiliation but no data entered in the corresponding race checkbox. Therefore, if deaths are counted

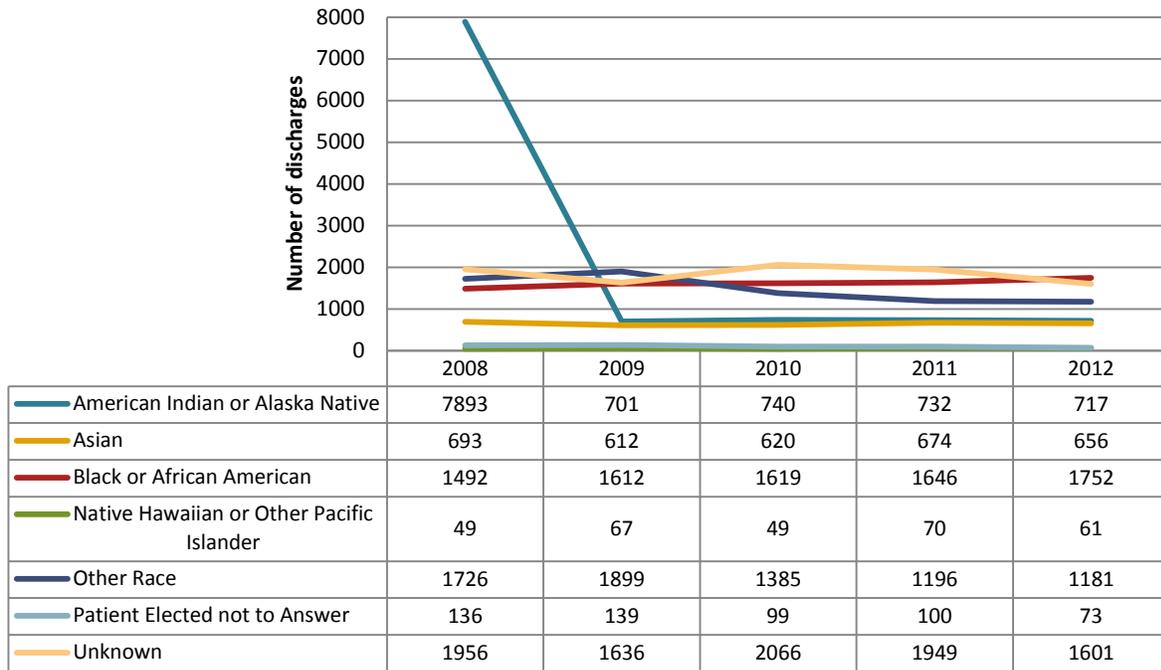
using only the race field, the number of Native Americans who died in 2012 will be underestimated. Any analysis of deaths by race in 2012 should include both tribal affiliation and race. This data quality problem illustrates the necessity of having data checks to ensure the quality of the primary data.

As a result of the analysis of race and ethnicity data in all administrative databases in Maine, the following data are recommended for analyses that include race and/or ethnicity:

- Hospital inpatient files from 2009 forward
- Outpatient files from 2010 forward
- Birth certificate files as of 2012
- All death data (with the 2012 fix for Native Americans)

Birth data files for 2013-2015 with updated race and ethnicity data are still in the review process.

Figure 1. Maine hospital discharges by race and year, 2008-2012*



*Source: Maine Hospital Data Organization (MHDO)

HEALTH EQUITY DATA SYSTEM SUMMARIES

VITAL STATISTICS DEATH CERTIFICATE DATA

Description

Maine's vital statistics death certificate file contains cause of death, residence and demographic data for deaths that occur in Maine, as well as deaths for Maine residents that occur out of state.

Years Available

Data are available from 1999-2013. Death certificates are available for pre-1999 but because of changes in cause of death coding from ICD9 to ICD10 systems, values for indicators pre- and post-1999 are not equivalent.

Timeline

This dataset is updated yearly as the data become available. As of 2016, 2014 death data are available.

Subgroups

- Year
- County/public health district
- Ethnicity*
- Education*
- Age
- Rural/urban
- Veteran status (beginning 2012)
- Sex
- Race*
- Tobacco related (beginning 2012)

*Coding for these groups has changed over time. See *Data Use Notes* below.

Data Use Notes:

1. Education variable changed over time. Pre-2012 data have numeric value for single grade levels. Post-2012 grades are grouped according to U.S. standard groupings. There are notes on coding equivalents in the [Instruction manual, part 4: CLASSIFICATION AND CODING INSTRUCTIONS FOR DEATH RECORDS, 1999-2001](#)
2. Race data format was changed starting in 2003. Prior to 2003 race data was a single variable with values for race (1 = white, 2 = black, etc.). In 2003 the format was changed to checkboxes for ancestry and race which allowed multiple race and ethnicity to be filled in. There is no way to identify bi- or multi-racial individuals prior to 2003. According to the classification document above, multi-racial is coded as "other" prior to 2004.
3. In the 2012 death certificate dataset, there were some records that had values in the field for tribal affiliation but no data entered in the corresponding race checkbox. Any analysis of deaths by race in 2012 should include both tribal affiliation and race.

HOSPITAL DISCHARGE DATA

Description

Hospital discharge data for Maine hospitals contain diagnosis, age, payer, residence and some demographic data. All hospitals submit data to the Maine Health Data Organization, except for TOGUS Veterans' Hospital.

Years Available

Data are available from 1999-2012.

Timeline

Data are updated annually as they become available. As of 2016, 2012 hospital discharge data are available.

Subgroups

- Year
- County/public health district
- Ethnicity (beginning 2009)*
- Payer*
- Age
- Rural/urban
- Zip code
- Sex
- Race*
- Hospital service area

* Coding for these groups has changed over time. See *Data Use Notes* below.

Data Use Notes:

1. Payer group data may be unreliable going forward; there were some discrepancies between payer name and type. Going forward, the hospitals may be using different coding. Use with caution.
2. Hospitals began reporting race and ethnicity data in Q3 2007, however there were some coding issues through 2008. Data are reliable from 2009 to 2012.

EMERGENCY DEPARTMENT DATA

Description

Emergency department discharge data are extracted from the hospital outpatient data files. The file contains ED records from outpatient data files that are, in some instances, combined with hospital discharge data to identify patients who have been admitted through the emergency room. This file does not include records from TOGUS Veteran's Hospital.

Years Available

Data are available from 2000-2012.

Timeline

Data are updated annually as they become available. As of 2016, 2012 outpatient ED data are available.

Subgroups

- Year
- County/public health district
- Ethnicity (beginning 2009)*
- Payer*
- Age
- Rural/urban
- Zip code
- City (beginning 2012)
- Sex
- Race (beginning 2009)*
- Hospital service area

* Coding for these groups has changed over time. See *Data Use Notes* below.

Data Use Notes:

1. Hospitals began reporting race and ethnicity data from emergency department visits starting 2009. The recommendation is to use data from 2010 or later.
2. In the future, the hospitals may be using different coding for the payer groups. Use with caution.

VITAL STATISTICS BIRTH CERTIFICATE DATA

Description

The file contains birth certificate data for all births in Maine as well as out-of-state births to Maine residents.

Years Available

Data are available from 1999-2014. In 2013, Maine switched to the revised U.S. standard birth certificate. There are several fields that are not comparable between the old and revised birth certificates. See below for more information.

Timeline

Data are available on an annual basis. Provisional quarterly files can also be obtained. As of 2016, provisional 2014 birth data are available.

Subgroups

- Year
- County/public health district
- Parental Ethnicity*
- Insurance
- Prenatal care
- Age (mother)
- Rural/urban
- Zip code
- Town
- Risk factors (including smoking)
- Infant Sex
- Parental Race*
- Hospital service area
- Parental Education*

* Coding for these groups has changed over time. See *Data Use Notes* below.

Data Use Notes:

1. The birth certificate underwent a revision in 2013, moving to the U.S. revised standard. Evaluation of the fields on the new birth certificate is still in process. However, based on data collection methods, it is not possible to compare education, race or ethnicity on the revised and old birth certificates.
2. Ethnicity and race for the updated 2013 version of the birth certificate is not yet available. The recommendation is to wait for the next release of the birth certificate data to evaluate the race and ethnicity data.

MAINE INTEGRATED YOUTH HEALTH SURVEY

Description

Health risk behavior data on students in Maine from four surveys:

- Parents of kindergarteners and 3rd graders
- 5th and 6th graders
- 7th and 8th graders
- 9th to 12th graders

Topics include: safety, chronic disease/oral health, sexual health, substance use, physical activity/nutrition, protective factors, and other health risk behaviors. Topics vary by age group and survey version. Measured height and weight are available for kindergarten, 3rd and 5th grade. A dental screen is part of the K/3 survey.

Years Available

2009-2015 (biennially)

Timeline

The survey is conducted in the odd number years. Data are released six to nine months after survey is administered.

Subgroups

- Age
- County/public health district
- Ethnicity
- Primary home language
- Sex
- Race
- Sexual orientation
- Disability (limited)
- Grade level
- Free/reduced lunch (K/3 only)

Data Use Notes:

1. Middle and high school modules have four versions (i.e., not all questions are asked of all middle/high school students.) Versions C of the middle and high school modules fulfill the CDC Youth Risk Behavior Survey requirements.
2. The survey is modified prior to each administration; not every question can be trended.
3. Missing data analysis of 2009-2015 data revealed that race/ethnicity data may not be reliable for younger students (primarily 5/6, but also 7/8 to a lesser degree).
4. Schools with less than 10 students in the participating grade are not surveyed, which may exclude some very rural communities. Survey is administered in public and quasi-private schools. Private schools, alternative schools, and juvenile detention centers are not included.
5. Over 60,000 students take the MIYHS; it is has one of the largest surveys of its kind in the U.S..
6. Questions on the 5/6 module have not been cognitively tested, meaning it is not known if question wording is age-appropriate, which could impact the quality of the data.
7. Surveys are only available in English and students must be able to respond to the survey independently. This excludes some children with disabilities and those with limited English proficiency.

BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

Description

A representative health risk/behavior survey of Maine's adult population (landline phone survey 2010 and prior; cell phones added in 2011).

Years Available

1994-2014

Timeline

Data are collected continuously (questionnaire changes at the beginning of the calendar year); multi-year data set; data are released from the Maine CDC around December of the following year.

Subgroups

- County/public health district
- Ethnicity*
- Education
- Employment status
- Health insurance
- Age
- Income groups (1995-present)
- Marital status
- Sex
- Race[†]
- Zip code (2000, 2005-present)
- Disability[‡]
- Veteran status (2000-present)[§]
- Blind status (2013-present)
- Sexual orientation

* Question changed in 2013.

† Question changed in 2001.

‡ Four questions asked starting in 2013.

§ Responses changed in 2007; Question changed in 2011.

Data Use Notes:

- Before 2011, the survey was only administered in households with landlines, which may have excluded some of Maine's more vulnerable populations (e.g. low income, rural, homeless). In 2011 cell phones were added and weighting methodology changed; data collected before 2011 cannot be compared to data from 2011 and beyond.
- The phone interview style leaves room for social desirability bias, especially for more sensitive topics.
- BRFSS has a core set of questions, optional modules and state-added questions that may change each year depending on funding and state priorities.
- The survey is available in English and Spanish; states have the option to translate it into other languages if they need to. Maine has only surveyed in English. Maine does not oversample minorities, which is a technique some states use to make sure there are adequate data to report on minority populations.

PREGNANCY RISK ASSESSMENT MONITORING SYSTEM

Description

PRAMS is an ongoing, population-based surveillance system designed to identify and monitor selected maternal behaviors and experiences before, during and after pregnancy among women who have recently given birth to a live infant. Data are collected monthly from women using a mail/telephone survey. Data from the survey are linked to birth certificates.

Years Available

1994-2013

Timeline

Data are collected continuously throughout the year. Data are released on an annual basis.

Subgroups

- County/public health district
- Parental Ethnicity*
- Parental Education
- Maternal Employment status
- Health insurance
- Maternal Age
- Household Income
- Marital status
- Infant Sex
- Parental Race

Data Use Notes:

- The survey instrument is changed every four years. Changes to the survey questions can impact trends over time.
- Data are linked to the Maine birth certificate. The birth certificate is used to collect some of the demographic information (e.g., race, ethnicity, age). Maine's birth certificate changed in August 2013 and this will impact PRAMS starting in 2013.
- Low birth-weight infants are oversampled.

Strengths and Challenges Using Surveillance Data for Health Equity

Strengths

- Public health surveillance data are collected on an ongoing basis; it is possible to have up-to-date information on populations of interest.
- Data are collected from almost everyone in the population (e.g., death and birth data), allowing for a complete picture of factors related to births, deaths, and hospitalizations.
- Large numbers allow for in-depth analysis of health issues.
- Diverse types of data are collected from multiple sources.

Challenges

- **Definitions and data collection methods can change over time.** Changes in data collection make analysis of trends challenging. For example, updates to the vital statistics files have provided more detailed race and ethnicity data, but it is now necessary to develop additional code to create equivalents across the years. Similarly, changes in the weighting methodology for the BRFSS have restricted analyses to 2011 and later, or 2010 and earlier, but the data are not comparable across those time frames.
- **Definitions vary across datasets.** Standard definitions and/or data collection strategies are not consistent across datasets making it difficult to compare health outcomes and risks.
- **Lack of timely data.** For some datasets, it can take two to three years before the data are released for use. For example, as of June 2016, the latest hospital discharge data

available were 2012. The demographics of Maine are changing quickly; timely, accurate data are essential for a true picture of health disparities to emerge.

- **Accurate and consistent evaluation of race and ethnicity data is needed.** Research conducted in Maine in 2002 identified problems with classification of Native American race on death certificates. Race and ethnicity data only started being collected in hospital discharge data in 2007. Across datasets, collection of certain demographics is not consistent, making it difficult to compare. OMB³ guidelines are not always followed for the collection of race and ethnicity. Ongoing evaluation is needed to ensure accurate reporting.
- **Lack of data collected on populations of interest.** There are gaps in the types of data available in administrative and population survey datasets. For example, no public health surveillance data system collects data on Maine's transgender population and many do not have information on Maine's LGBTQ population. Similarly, it is difficult to identify tribal members, refugees, migrants, and persons with disabilities in most surveillance systems.
- **Small numbers make it difficult to conduct analyses on disparate populations.** Due to the small sizes of minority populations in Maine, it is difficult to conduct meaningful and reliable analyses in some surveillance systems, especially surveys. Small numbers often necessitate either combining racial and ethnic groups, or pooling a large number of years; both methods have the potential to mask disparities.
- **Surveys may lack cultural relevance.** Not all groups have the same definitions for what is

being asked (e.g., physical activity). In addition, issues specific to certain populations are not captured in most surveys (e.g., historical trauma, experiences with racism).

- **Need for local-level data.** Communities need data relevant to their population for planning activities and interventions that will address community priorities and needs. Small numbers limit the level of geographic specificity allowable.

Recommendations

1. Examine collection of race and ethnicity data across public health and health care data systems and work to improve accuracy and consistency.

- Provide education on Office of Management and Budget guidelines to those collecting data on race and ethnicity.
- Train intake personnel to be comfortable with asking race and ethnicity questions.

2. Make existing data systems more inclusive of diverse populations.

- Add transgender items to survey questions.
- Include items assessing foreign-born status on surveys and in death certificate, birth certificate, and hospital data.
- Revise sampling techniques of surveys (e.g., BRFSS and PRAMS) to get better estimates of small populations. This may involve working with specific counties where oversampling could better reflect the population.

3. Use innovative analytic methods to provide data at a more local level.

- Methods could include small area estimation and spatial smoothing techniques.⁴

4. Work with local partners to ensure that survey content reflects community concerns.

- Community members and local stakeholders should be included on survey steering committees to ensure that data collected represent their concerns and the topics they need to learn about.

¹ Centers for Disease Control and Prevention. CDC Health Disparities and Inequalities Report: United States, 2013. MMWR 2013;62(Suppl 3). <http://www.cdc.gov/mmwr/pdf/other/su6203.pdf>

² Maine Shared Community Needs Assessment, 2015. <http://www.maine.gov/dhhs/mecdc/phdata/SHNAPP/documents/2016-State-Report.pdf>

³ Office of Management and Budget, Executive Office of the President. This office issues government-wide guidelines for "Ensuring and Maximizing the Quality, Objectivity, Utility, and Integrity of Information Disseminated by Federal Agencies."

⁴ Anderson EM, Diehr PH, Luke DA. Public health surveillance of low frequency populations. *Annual Review of Public Health*. 2004. 25:25-52.

Chapter 2: Presenting Data on Health Disparities

Re-framing Data Presentation to Improve Health Equity

In order to document the existence of health inequities, data are needed on health status and health care measures. **Health measures** should include a broad range of health status and health care indicators. These can include: mortality, morbidity, risk behaviors, and quality of life indicators. **Health care measures** should include access and utilization of health care, preventive health care, quality of care, and health insurance. **These need to be combined with indicators that reveal inequalities between groups.**¹ These indicators are often referred to as stratifiers; they divide populations into subgroups. From a health equity perspective, we will refer to these stratifiers as **equity stratifiers.**¹ They include socioeconomic status, sex, race, ethnicity, geographic region and other social determinants of health.¹

Health researchers and epidemiologists often present data in tables to describe a population, select behaviors, or health outcomes. Often the tables highlight one type of health behavior such as a mammography screening for breast cancer, stratified by age, sex, race, etc. This type of data presentation documents health disparities for a specific condition or risk and highlights opportunities for public health intervention. However, the focus on one condition or risk factor at a time ignores how systematic disadvantage affects health across a range of health outcomes. **To document the consistent relationship between health status and equity stratifiers, we propose making this relationship more explicit by documenting patterns and trends between different populations for many indicators.**



We recommend three methods for improving data presentation to promote health equity:

1. Create health equity data tables organized by equity stratifiers, rather than health status.
2. Use maps to illustrate geographic disparities in health and social determinants of health.
3. Develop and use innovative methods for data visualization that highlight health inequities.

Health Equity Data Tables

Organizing tables by equity stratifiers reveals how inequities disproportionately affect health. These stratifiers include where people live, what people are exposed to, or how individuals self-identify. This type of table can tell a story of how social determinants of health, such as income and education, contribute to poor health outcomes. This information provides insight into why a population might experience disparate outcomes and how public health practitioners and services can help serve the community, reduce health disparities, and promote health equity.

Table shells (see the next six pages) were created for each of the following equity stratifiers:

- Educational attainment
- Income
- Ethnicity
- Race
- Rurality
- Sexual Orientation
- Sex

These stratifiers were selected because they are available in commonly used public health surveillance systems. Future efforts should involve linking data systems that include other social determinants of health. This would better make the connection between health outcomes and factors at the community level that impact health. (e.g., employment opportunities, poverty level, violence).

Each one-page table shell is designed to facilitate comparisons across many indicators. For some groups, there are many categories, so not as many indicators can fit per page. Where possible, visual aids will be used such as Sparklines (line graphs) or maps to quickly show areas disproportionately affected by particular health outcomes. The indicators that will be presented in the tables will be based on data availability, as well as existence of health inequities. The tables will be used to highlight inequitable outcomes and risk factors. Being able to describe how particular populations are affected by these health status and outcome measures can influence how resources (policy, advocacy, funding) are allocated.

Mapping

Maps can help illustrate and understand the relationships between health outcomes, risk factors and social determinants of health.² They allow for increased interpretation of data at a sub-state and sub-county level and can inform local intervention and prevention efforts. For an example of how

maps can be used to show health disparities, see page 32.

Data Visualization

With new software it is becoming easier to produce easy to read data-related products, such as infographics and interactive websites. These types of products can be invaluable to educate policy-makers, stakeholders and the public about the importance of health inequities and highlight areas of need to drive people to act.

Indicators of Health and Social Determinants of Health by Education Level, Maine, 2015

Education Level	Less than high school diploma	High school diploma or GED	Some college	Bachelor's degree or higher	Sparkline
Indicator	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	2011-2015
	XX.X [95.0 - 95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	
	XXX.X [XXX.X - XXX.X]	XXX.X [XXX.X - XXX.X]	XXX.X [XXX.X - XXX.X]	XXX.X [XXX.X - XXX.X]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	

Indicators of Health and Social Determinants of Health by Income Level, 2015

Income Level	Less than \$15,000	\$15,000-24,999	\$25,000-34,999	\$35,000-49,999	\$50,000 or more	Sparkline
Indicator	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	2011-2015
	XX.X [95.0 - 95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	
	XXX.X [XXX.X – XXX.X]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					
	XX.X [95.0 - 95.0]					

Indicators of Health and Social Determinants of Health by Racial Group, Maine

	N	Estimate	95% CI
Indicator, Year			
American Indian or Alaska Native			
Asian			
Black or African American			
Other Race			
Native Hawaiian or Pacific Islander			
Two or more races			
White			
Indicator, Year			
American Indian or Alaska Native			
Asian			
Black or African American			
Other Race			
Native Hawaiian or Pacific Islander			
Two or more races			
White			
Indicator, Year			
American Indian or Alaska Native			
Asian			
Black or African American			
Other Race			
Native Hawaiian or Pacific Islander			
Two or more races			
White			
Indicator, Year			
American Indian or Alaska Native			
Asian			
Black or African American			
Other Race			
Native Hawaiian or Pacific Islander			
Two or more races			
White			
Indicator, Year			
American Indian or Alaska Native			
Asian			
Black or African American			
Other Race			
Native Hawaiian or Pacific Islander			
Two or more races			
White			

Indicators of Health and Social Determinants of Health by Rurality, Maine, 2015

Rurality	Metro	Large Rural	Small Rural	Isolated Rural	State Total
Indicator	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]
	XX.X [95.0 - 95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]
	XXX.X [XXX.X – XXX.X]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				
	XX.X [95.0 - 95.0]				

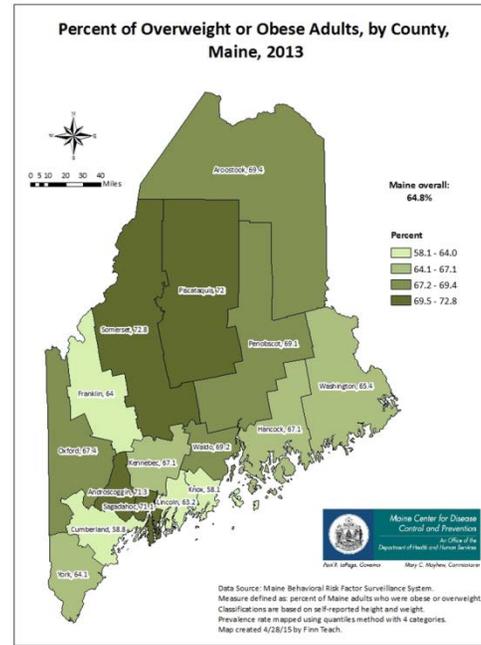
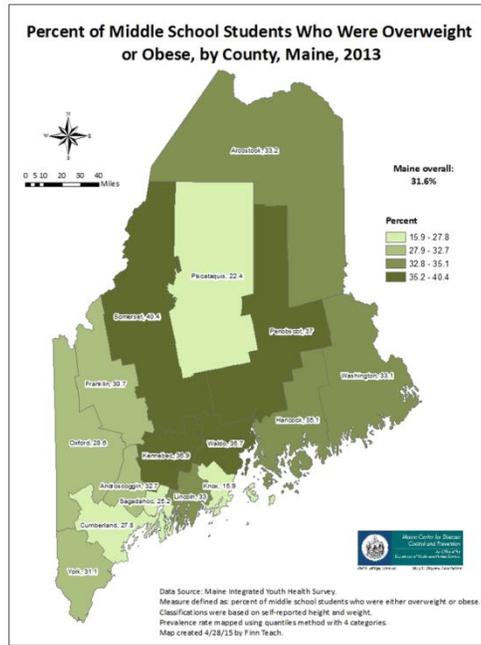
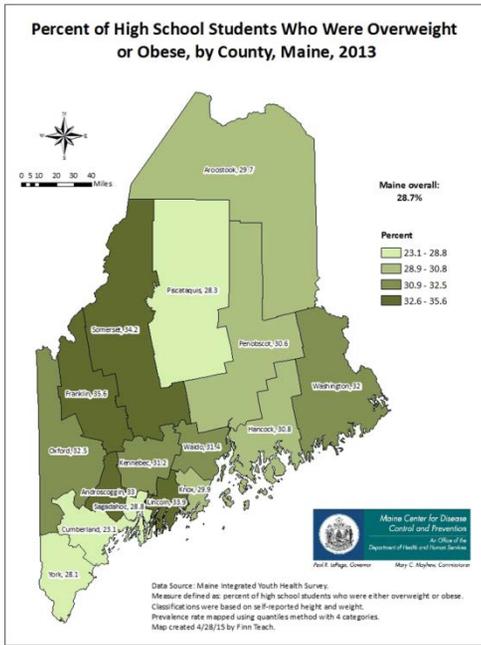
Indicators of Health and Social Determinants of Health by Sexual Orientation, Maine, 2015

Sexual Orientation	Bisexual	Heterosexual or straight	Homosexual (gay or lesbian)	Other	State Total
Indicator	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]	Estimate [95%CI]
	XX.X [95.0 - 95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]	XX.X [95.0-95.0]
	XXX.X [XXX.X – XXX.X]	XXX.X [XXX.X – XXX.X]	XXX.X [XXX.X – XXX.X]	XXX.X [XXX.X – XXX.X]	XXX.X [XXX.X – XXX.X]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]
	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]	XX.X [95.0 - 95.0]

Indicators of Health and Social Determinants of Health by Sex, Maine

	Year	Female		Male	
		Estimate	95% CI	Estimate	95% CI
Demographics					
General Health Status					
Access					
Cardiovascular Health					
Diabetes					
Physical Activity, Nutrition, and Weight					
Tobacco Use					
Substance Abuse					
Oral Health					
Maternal and Child Health					

Indicators of Health and Social Determinants of Health by County, Maine, 2015



These are sample maps for another program and are not necessarily the indicators that will be shown. This text box will be used to emphasize counties afflicted with health inequity by indicator.

¹ Nolan LB, Braveman P, Dachs NW, Delgado I, Gakidou E, Moser K, Rolfe L, Vega J, Zarowsky C. Strengthening health information systems to address health equity challenges. *Bulletin of the World Health Organization* 2005; 83(8):597-603.

² Minnesota Department of Health. *Advancing Health Equity in Minnesota, Chapter Four: Data: The Foundation for Advancing Health Equity*. 2014.

Chapter 3: Measuring Social Determinants of Health

What are social determinants of health?

Health starts in our homes, neighborhoods, schools, workplaces and communities.

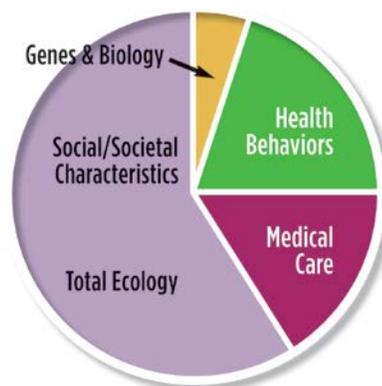
Measures of health often include indicators that reflect health status and health care, such as causes of deaths, hospitalization rates for injury, and health care visits. However, population health is influenced by many other factors including where we live, work and play. Research has confirmed that these broader living conditions, known as the social determinants of health, may have the greatest impact on health and life-expectancy (Figure 1).

The World Health Organization (WHO) defines social determinants of health as the “conditions in which people are born, grow up, live, work and age.”¹ They include such factors as:

- Socioeconomic status
- Education
- Physical environment
- Social support networks
- Access to health care

Figure 1.

Determinants of Population Health



Tarlov, A.R., Public Policy Frameworks for Improving Population Health. Annals of the New York Academy of Sciences, 1999. 896(SOCIOECONOMIC STATUS AND HEALTH IN INDUSTRIAL NATIONS: SOCIAL, PSYCHOLOGICAL, AND BIOLOGICAL PATHWAYS); p. 281-293.

These factors impact every aspect of life, shaping our social, emotional, and physical health throughout the lifespan. Examples of each type of factor are described in Table 1.

The relationship between social determinants and health outcomes suggests that the underlying causes of individual and community health outcomes are not solely the result of genes, individual behavior, or access to health care.

Table 1. Examples of Social Determinants of Health

Socioeconomic Status	Education	Physical Environment	Social Support Network	Access to Health Care
<ul style="list-style-type: none"> • Employment • Income • Expenses 	<ul style="list-style-type: none"> • Literacy • Language • Early childhood education • Vocational training • Higher education 	<ul style="list-style-type: none"> • Housing • Transportation • Safety • Parks • Playgrounds • Walkability 	<ul style="list-style-type: none"> • Social integration • Support systems • Community engagement 	<ul style="list-style-type: none"> • Health coverage • Provider availability • Provider linguistic and cultural competency • Quality of Care
Health Outcomes Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations				

Measuring and reporting on social determinants of health

A health equity perspective enhances our understanding of health measures and the social and economic factors that can lead to differences in health outcomes. But in order to develop an understanding of the social determinants of health, public health professionals and policymakers need good data highlighting the conditions perpetuating health inequities.

In 2016, a literature search was conducted to identify social determinants indicators that could be reported on for Maine. The resulting list of indicators, their definitions, and their availability at the state-level are described in the following pages.

As part of this surveillance plan, we propose to develop a report focused on these social determinants of health.

- ✓ These determinants will be analyzed in relation to health outcomes and health status indicators to illustrate the relationship between social determinants and health.
- ✓ This report will provide a baseline for understanding the relationship between social determinants and health.
- ✓ The report will help public health professionals look beyond individual behavior or access to treatment when planning population health prevention and intervention efforts.
- ✓ The data in the proposed health equity report will be focused on social determinants of health. The proposed indicators are defined in detail below.



Maine Health Equity Report

Outline



Health starts where we live, learn, work and play



- Healthy and Supportive Relationships



- Access to a Healthy and Safe Place to Live



- Safe, Supportive Schools that Promote Achievement



Every Mainer should have the chance to live a healthy life



- Access to health care



- Access to Services
- Access to Education and Employment

Too many Mainers don't have the same opportunities to be healthy as others



- Racial and Ethnic Minorities
- Women
- Lesbian, Gay, Bisexual, Transgender
- Rural/Isolated
- Individuals with Disabilities
- Individuals Living in Poverty
- Individuals with Mental Illness
- Immigrants and Migrant workers



Recommendations to Reduce Health Disparities in Maine



Health and Health Equity in Maine: Proposed Outline with Social Determinant Indicators

Health starts where we live, learn, work and play.

Chapter	Indicator*	Data Source*
Healthy and Supportive Relationships	Percent of parents who read to their children at least 3x per week	National Survey of Children's Health
	Percent of adolescents who report eating at least 7 meals per week as a family	MIYHS
	Percent of adolescents who report that their parents support them and want them to succeed	MIYHS
	Percent of children aged 0-17 living with at least one parent employed year round, full time	Current Population Survey
	Percent of children living in a supportive neighborhood	National Survey of Children's Health
	Percent of children that meet age-specific criteria for a positive home environment summary measure	National Survey of Children's Health
	Percent of children and adults who experienced adverse childhood experiences	National Survey of Children's Health/BRFSS
	Child maltreatment rate per 1,000	Child Maltreatment Data Book
	Percent of adolescents who have ever been sexually assaulted	MIYHS
	Percent of women who experienced intimate partner violence during pregnancy, and adulthood, and percent of teens who experienced dating violence	PRAMS BRFSS MIYHS
	Percent of adolescents who have been bullied and/or harassed	MIYHS
Access to a Healthy and Safe Place to Live	Percent of adolescents who report they feel like they belong in their community	MIYHS
	Percent of children who meet safety index for safe neighborhood and school	National Survey of Children's Health
	Number of farmer's markets per county per population	USDA
	Crime rate per 100,000	Maine Department of Public Safety
	Percent of renters and mortgage holders that pay more than 30 percent of income for housing	ACS
	Percent of households with poor housing conditions (cost >30 percent of income, more than one person per room; no working kitchen; no working bathroom)	ACS
	Percent of adults who are homeless	Maine Housing Authority, Shelter Reports, HUD

	Percent of children with elevated blood lead level	Maine EPHT
	Average air pollution days by county	Maine EPHT
	Percent of occupied housing units with no vehicle available	ACS
	Low food access areas	USDA
Safe, supportive schools that promote achievement	Percent of children eligible for free and reduced lunch	DOE
	Percent of adolescents who have a teacher who cares about him/her	MIYHS
	Fourth grade math and reading proficiency	DOE
	High school graduation and dropout rates	DOE
Every Mainer should have the chance to live a healthy life.		
Chapter	Indicator*	Data Source*
Access to health care	Health insurance coverage type (including uninsured)	ACS
	Health insurance eligibility guidelines	Kaiser State Health Facts
	Percent of adults who visited a dentist in the past year	BRFSS
	Percent of high school students who visited a dentist in the past year	MIYHS
	Percent of adults with a usual source of health care	National Health Interview Survey
	Percent of children with a medical home	NSCH
	Percent of adults who were screened for cervical, breast and colon cancer based on recommended screening frequency	BRFSS
	Rate of full-time physicians per 100,000 people	America's Health Rankings
	Rate of practicing dentists per 100,000 people	America's Health Rankings
	Percent of primary care offices accepting new patients	National Electronic Health Records Survey
	Federally designated physician and dental area map	Maine Office of Rural Health and Primary Care
	Annual Flu shot	BRFSS
	Up to date immunizations for children up to age 2	National Immunization Survey
	Percent of adults who needed to see a doctor in the past year, but were unable to due to cost	BRFSS
Access to services	Percent of households with access to the internet	ACS
	Percent of eligible population enrolled in SNAP, TANF, WIC	Office of Child and Family Services & Food Research and Action Center
	Eligibility guidelines for SNAP, TANF, WIC	USDA, Maine DHHS

Access to education and employment	Direct enrollment in two or four-year college after high school	DOE
	Public preschool	DOE
	Employment rates	ACS
Too many Mainers don't have the same opportunities to be healthy as others		
Chapter	Indicator*	Data Source*
Racial and ethnic minorities	Race/ethnic breakdown	ACS
	Refugees in Maine	Catholic Charities
	Percent of those over age 5 who speak a language other than English at home	ACS
Women	Percent of female single-head of households	ACS
	Percent of women in the workforce	ACS
Persons with disabilities	Percent of adults and children with disabilities	ACS/MIYHS
Income and Education	Median household income	ACS
	Living wage	MIT Livable Wage Calculator
	Poverty of individuals	ACS
	Poverty of families	ACS
	Children living in poverty	ACS
	Median child care cost as percent of annual income	Maine Office of Family and Child Health
Sexual Orientation	Prevalence of GLBT population	BRFSS/MIYHS
Mental health and stress	Mean number of stressors experienced by women prior to and during their pregnancy	PRAMS
	Percent of adults with activity limitations due to mental/emotional problems	BRFSS
	Percent of adults with depression diagnosis	BRFSS
	Percent of adults with anxiety diagnosis	BRFSS
	Percent of adults with current depressive symptoms	BRFSS
Rural/isolated	65+ year olds living alone	ACS

*For more information see detailed definitions

Social Determinants of Health – Indicator Definitions

Healthy and Supportive Relationships

Percent of parents who read to their children at least 3x per week

Description: Parents who read to children aged 0-5 multiple times per week

Data Source: National Survey of Children's Health

Numerator: During the past week, how many days did you or other family members read to [CHILD'S NAME] ? = ">=3"(K6Q60)

Denominator: All who answered question except those who didn't know or refused

Unit of Analysis: Individual

Data Availability: Quadrennially (May be available annually starting in 2017)

Notes: Parents or other family members

Percent of adolescents who report eating at least 7 meals per week as a family

Description: Eating with family in past week

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: During the past 7 days, how many meals did you eat with your family? = at least 7 meals (hn161, mn120)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: Indicator 6.8 in NSCH K8Q11 is similar

Percent of adolescents who report that their parents support them and want them to succeed

Description: This is a composite measure including adolescents with parents who are supportive and want them to succeed.

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: I have parent(s) who try to help me succeed = "Very or often" or "Extremely or almost always" (hn197)

I have a family that gives me love and support = "Very or often" or "Extremely or almost always" (hn200)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: Composite measure requiring additional non-routine analysis.

Percent of children aged 0-17 living with at least one parent employed year round, full time

Description: Children living with at least one employed parent

Data Source: Current Population Survey

Numerator: Number of children aged 17 years and under living with at least one parent who is employed 35 or more hours per week for 50 to 52 weeks per year

Denominator: Number of children aged 17 years and under living with at least one parent

Unit of Analysis: Individual

Data Availability: Annual

Notes: Year-round, full time employment is defined as usually working full time (35 hours or more per week) for 50 to 52 weeks. Children living with parent excludes children living with relatives other than parents.

Percent of children living in a supportive neighborhood**Description:** Children (Aged 0-17) Live in Supportive Neighborhoods**Data Source:** National Survey of Children's Health (NSCH)**Numerator:** Those who agreed with 2 or more of the following 4 statements about neighborhood or community:

- People in my neighborhood help each other out = "Agree" (K10Q30)
- We watch out for each other's children in this neighborhood = "Agree" (K10Q31)
- There are people I can count on in this neighborhood = "Agree" (K10Q32)
- If my child were outside playing and got hurt or scared, there are adults nearby who I trust to help my child = "Agree" (K10Q34)

Denominator: All who answered question except those who refused or didn't know**Unit of Analysis:** Individual**Data Availability:** Quadrennially (May be available annually starting in 2017)**Notes:** N/APercent of children that meet age-specific criteria for a positive home environment summary measure**Description:** Postive Home Environment

Children who met 0 age-appropriate criteria; children who met 1-2 age-appropriate criteria; children who met 3-4 age-appropriate criteria; children who met all age-appropriate criteria.

Data Source: National Survey of Children's Health (NSCH)**Numerator:** In order to successfully meet the home environment summary measure, the following age-specific criteria must be met: 1) No exposure to household smoking (all children ages 0-17); 2) Family shares meals on 4 or more days per week (all children ages 0-17); 3) Children watch less than 2 hours of television per day (children ages 1-17); 4a) Young children are read/sung to everyday (children ages 0-5); 5a) Young children were breastfed Ever (children ages 0-5); 4b) Older children have no TV in bedroom (children ages 6-17); 5b) School age children usually/always do required homework (children ages 6-17); 6b) Parents of school age children have met most/all child's friends (children ages 6-17).**Denominator:** All who answered question except those who didn't know or refused**Unit of Analysis:** Individual**Data Availability:** Quadrennially (May be available annually starting 2017)**Notes:** N/APercent of children and adults who experienced adverse childhood experiences**Description:** Children with adverse childhood experiences**Data Source:** National Survey of Children's Health**Numerator:** Composite measure measured by the following 9 items broken down into 'Children with no adverse family experiences', 'Children with 1 adverse family experience', 'Children with 2 or more adverse family experiences':

- How often it has been very hard to get by on income
- Child lived with a parent who got divorced or separated
- Child lived with a parent who died
- Child lived with parent who served time in jail or prison
- Child witnessed domestic violence
- Child ever a victim/witness of neighborhood violence
- Child ever lived with anyone who was mentally ill or suicidal
- Child lived with anyone who had problems with alcohol or drugs
- Child treated or judged unfairly because of his/her race or ethnic group

Denominator: All who answered all 9 questions except those who didn't know or refused

Unit of Analysis: Individual

Data Availability: Quadrennially (May be available annually starting in 2017)

Notes: N/A

(Alternate ACES) Description: Adults with adverse childhood experiences

Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)

Numerator: Composite measure would need to be created based on the following and categorical values determined: ACEDEPRS, ACEDIVRC, ACEDRINK, ACEDRUGS, ACEHURT, ACEHVSEX, ACEPRISN, ACEPUNCH, ACESWEAR, ACETOUCH, ACETHEM

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: One-time (2011 Part A)

Notes: N/A

Child maltreatment rate per 1,000

Description: Any maltreatment* of a child

*Maltreatment is defined as "a recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation; or an act or failure to act, which presents an imminent risk of serious harm"

Data Source: Child Maltreatment Data Book

Numerator: Children who received an investigation or alternative response to reports of child maltreatment; a child for whom the state determined at least one maltreatment was substantiated or indicated, or the child received a disposition of alternative response victim.

Denominator: Population of U.S. children (U.S. Census)

Unit of Analysis: Individual

Data Availability: Annually

Notes: Child Maltreatment/ ACF HHS Report (Table 3):

<https://www.acf.hhs.gov/sites/default/files/cb/cm2013.pdf>

Percent of adolescents who have ever been sexually assaulted

Description: Forced to have sexual intercourse; Forced sexual contact

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: Have you ever been physically forced to have sexual intercourse when you did not want to?="Yes" (hn28)

Have you ever been forced (physically or otherwise) to have sexual contact? = "Yes" (hn29a, mn17a)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: These will be presented as two individual measures

Percent of women who experienced intimate partner violence during pregnancy, and adulthood, and percent of teens who experienced dating violence

(Women) Description: Intimate partner violence during pregnancy

Data Source: Pregnancy Risk Assessment Monitoring System (PRAMS)

Numerator: During your most recent pregnancy, did your husband or partner push, hit, slap, kick, choke, or physically hurt you in any other way? (Survey Question 43)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Most recent data from 2010

Notes: Detailed tables: <http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/prams/tables2010/index.shtml>

(Adult) Description: Intimate partner violence in the last year

Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)

Numerator: Have you ever been frightened for your safety or the safety of your family or friends because of anger or threats by a current or former intimate partner? ="Yes" (NFRG_SFTY, 2014A)

During the last 12 months, have you experienced physical violence or had unwanted sex with a current or former partner? = "Yes" (SEX_VLNC, 2014A, asked if SVSAFE =1)

Denominator: All who answered question and were in a safe place to do so. Response to questions is contingent on variable SVSAFE

Unit of Analysis: Individual

Data Availability: Annually (see note)

Notes: May not be asked annually. SEX_VLNC was asked in 2007A, 2008B, 2010A, 2011A, 2012A LL, 2014A. NFRG_SFTY was asked in 2011A, 2012A LL 2014A

(Teen) Description: Dating violence in past year

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: During the past 12 months, how many times did someone you were dating or going out with physically hurt you on purpose? (Count such things as being hit, slammed into something, or injured with an object or weapon.) = least 1 time (hn216)

Denominator: All who answered question except those who said they did not date within the last year (Answer option A)

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: N/A

Percent of adolescents who have been bullied and/or harassed

Description:

- Bullied on school property in last year
- Bullied away from school property in last year
- Cyber bullied in last year

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: During the past 12 months, have you ever been bullied on school property?="Yes" (hn34, mn22)

During the past 12 months, have you ever been bullied away from school property?="Yes" (hn35)

During the past 12 months, have you ever been electronically bullied? (Count being bullied through e-mail, chat rooms, instant messaging, websites, or texting.)="Yes" (hn36b, mn152a)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: Additional non-routine analysis required. These will be presented as three individual measures.

Access to a Healthy and Safe Place to Live

Percent of adolescents who report they feel like they belong in their community

Description: Feeling like you matter in your community

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: Do you agree or disagree that in your community you feel like you matter to people?="Strongly agree" or "Agree" (hn191a, mn148)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: N/A

Percent of children who meet safety index for safe neighborhood and school

Description: Safety Index for safe neighborhood and school

Data Source: National Survey of Children's Health (NSCH)

Numerator: Child met criteria for the neighborhood and school summary measure

Denominator: All who answered question except those who refused or didn't know for any of the questions

Unit of Analysis: Individual

Data Availability: Quadrennially (May be available annually starting in 2017)

Notes: Composite of these questions: K10Q11, K10Q12, K10Q13, K10Q14, K10Q30, K10Q31, K10Q32, K10Q34, K10Q40, and K10Q41

Number of farmers' markets per county per population

Description: Ratio of Farmers' markets to population by county. A farmers' market is a retail outlet in which two or more vendors sell agricultural products directly to customers through a common marketing channel. At least 51 percent of retail sales are direct to consumers.

Numerator: Number of Markets in County

Source: County-level data for farmer's markets were compiled by USDA Agricultural Marketing Service, Marketing Services Division.

Source: USDA Food atlas: <http://www.ers.usda.gov/data-products/food-environment-atlas/go-to-the-atlas.aspx>

Denominator: Population of County

Unit of Analysis: Markets by County Population

Data Availability: 2009, 2013

Notes: Longitude and latitude, state, address, name and zip code of farmer's market in US is available by same Farmers Markets Directory and Geographic Data for 2015. This data can be downloaded in an Excel file here: [Farmers Markets Directory and Geographic Data - Data.gov](http://FarmersMarketsDirectoryandGeographicData-Data.gov)

Crime rate per 100,000

Description: State crime rate

Data Source: Maine Department of Public Safety, Maine State Police Uniform Crime Reporting Unit

Numerator/ Denominator: Population estimates received from the Uniform Crime Reporting Division of the FBI, using provisional estimates of the Bureau of the Census

Unit of Analysis: Statewide and countywide

Data Availability: Annually

Notes: Last available state rates from 2014 can be found here:

http://www.maine.gov/dps/cim/crime_in_maine/2014pdf/019%20Rates.pdf

Percent of renters and mortgage holders that pay more than 30 percent of income for housing

Description: Percent of renter-occupied units spending 30 percent or more of household income on rent and utilities

Data Source: American Community Survey is the original source of data (Table GCT2515).

Numerator: Renter-occupied units spending 30 percent or more of household income on rent and utilities

Denominator: All renter occupied units

Unit of Analysis: Rental Unit

Data Availability: 2009-2014

Notes: Community Commons has produced a set of figures on these measures. They can be viewed here: <http://www.communitycommons.org/> along with the cost burdened households for Maine.

Description: Percent of mortgaged owners spending 30 percent or more of household income on selected monthly owner costs

Data Source: American Community Survey (Table GCT2513)

Numerator: Mortgaged owners spending 30 percent or more of household income on selected monthly owner costs

Denominator: All mortgaged owners

Unit of Analysis: Individual mortgaged owners

Data Availability: 2009-2014

Notes: The HP2020 measure also looks at those earning less than 200 percent of the poverty level who spend more than 30 percent of income on housing. Include as an additional column if possible.

Percent of households with poor housing conditions (cost >30 percent of income, more than one person per room; no working kitchen; no working bathroom)

Description: This measure is a composite of three indicators:

- Cost of housing >30 percent of income
- More than one person per room
- No working kitchen, no working bathroom

Data Source: American Community Survey (Table DP04)

Numerator: Households who meet three criteria: 1) Lacking complete plumbing and kitchen facilities, 2) the cost of housing is >30 percent of household income, 3) More than one person occupies each room.

Denominator: All Households

Unit of Analysis: Household

Data Availability: Annually

Notes: Additional non-routine analysis required

Percent of adults who are homeless

Description: Homelessness (3 different individual definitions are available)

Data Sources:

- Point in Time Survey, conducted by Maine Housing Authority
- Yearly Maine Housing Emergency Shelter Counts
- HUD 2010 Homeless Assessment Report

Numerator:

Source: Point in Time Survey, conducted by Maine Housing Authority

Overview: Count of those who were in homeless shelter or unsheltered. The survey was conducted on a single night in January. There is some demographic information, however because the sample is not representative of all homeless people (and arguably even those who stay in emergency shelters) it is not clear how useful this is. Trend data are available.

Source: Maine Housing Emergency Shelter Counts

Overview: This figure represents a count of all persons utilizing emergency shelters and domestic violence shelters over the entire year. There is no demographic information available. Trend data are available.

Source: HUD Homeless Assessment Report

Overview: A compilation of the Maine Point in Time Survey data (described above), as well as other data from various Homeless Management Information Systems. The HMIS-based data in the sample includes information on all persons who used an emergency shelter, transitional housing, or permanent supportive housing at any time during a one-year period, from October 1 through September 30. There is some demographic information available, but it does not appear to be publicly available. Trend data are available.

Denominator: Total adult population

Unit of Analysis: Individual

Data Availability: Annually

Notes: These three sources were used in SHA tables

Percent of children with elevated blood lead level

Description: Children with elevated blood lead level

Data Source: Maine Environmental Public Health Tracking System

Numerator: Number of children with elevated blood lead level ≥ 10 micrograms/dL

Denominator: Number screened for blood lead level (excluded if prior history of elevated blood level)

Unit of Analysis: Individual

Data Availability: Annually or Combined Years. Most recent combined is 2009-2013.

Notes: Available statewide, by county, and by public health district

Average air pollution days by county

Description: Air Pollution by County

Data Source: Maine Environmental Public Health Tracking System

Numerator: Number of days with maximum 8-hour average ozone concentration over National Ambient Air Quality Standards

Denominator: County

Unit of Analysis: County

Data Availability: Annually, 2001-2008

Notes: N/A

Percent of occupied housing units with no vehicle available

Description: Tenure by vehicles available

Data Source: American Community Survey (Table B25044)

Numerator: Number of owner occupied and tenant occupied units with 0 cars available

Denominator: All occupied units

Unit of Analysis: Housing units

Data Availability: 2009-2014

Notes: N/A

Low food access areas

Description: Low-access census tract at least 10 miles

Definition: A rural tract with at least 500 people or 33 percent of the population living at least 10 miles from the nearest supermarket, supercenter, or large grocery store.

Low-access tract at least 1 mile

Definition: An urban tract with at least 500 people or 33 percent of the population living at least 1 mile from the nearest supermarket, supercenter, or large grocery store.

Data Source: USDA Food atlas: <http://www.ers.usda.gov/data-products/food-environment-atlas/go-to-the-atlas.aspx>

Unit of Analysis: Census tract

Data Availability: Annually

Notes: Available by seniors, low-income, and children, and population

Safe, Supportive Schools that Promote Achievement

Percent of children eligible for free and reduced lunch

Description: Children eligible for free and reduced lunch

Data Source: Maine Department of Education

Numerator: Number of children eligible for free and reduced meal program (as reported to each school district within a state county).

Denominator: Total enrolled students in school district and county

Unit of Analysis: Individual

Data Availability: Annually

Notes: Data available as split between free and reduced lunch or combined:

https://portal.maine.gov/sfsr/sfsrdev.ED534.ED534_report

Percent of adolescents who have a teacher who cares about him/her

Description: Adolescents who have a teacher who cares and gives support

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: Do you agree or disagree that at least one of your teachers really cares and gives you help and support when you need it?="Strongly agree" or "Agree" (hn186, mn143)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: N/A

Fourth grade math and reading proficiency

Description: Fourth grade math and reading proficiency

Data Source: Maine Department of Education

Numerator: State [test] average of fourth grade math and reading proficiency (separate measures)

Denominator: N/A

Unit of Analysis: Individual

Data Availability: Biennially (2013)

Notes: Data available for U.S. comparison and trend-over-time (1992-current):

<http://nces.ed.gov/nationsreportcard/states/>

High School Graduation and Dropout Rate

Description: Percent of students who graduated and dropped out of high school

Data Source: Maine Department of Education

Numerator: Graduation count/dropout count

Denominator: (first time 9th graders in year - 4) + (Transfers-In) - (Transfers-Out)

Unit of Analysis: Individual

Data Availability: Annually

Notes: ACGR rate. Excel spreadsheet available for download:

<http://www.maine.gov/education/gradrates/gradrates.html>

Additional non-routine analysis involving assignment of schools to county and public health district would be required for geographic-level analysis.

Access to Health Care

Health insurance coverage type (including uninsured)

Description: Health Insurance Coverage
Data Source: American Community Survey (Table DP03)
Numerator: Public, Private, No Insurance
Denominator: Civilian Noninstitutionalized Population
Unit of Analysis: Individual
Data Availability: Annually
Notes: N/A

Health insurance eligibility guidelines

Description: Medicaid/CHIP income eligibility limits as a percent of the federal poverty level (Adults, Children, Pregnant Women)
Data Source: Kaiser State Health Facts
Definition: The percent of the MAGI-converted income standards (+/- 5 percent of federal poverty level for:
 -Adults (Parents and Childless Adults)
 -Children (0-19)
 -Pregnant Women
 -Lawfully residing immigrant children and pregnant women
Unit of Analysis: N/A
Data Availability: Annually
Notes: Lawfully residing immigrant children and pregnant women is measured as yes/no whether they can be eligible for Medicaid without 5-year wait (ICHIA option) under the same guidance as a full citizen.

Percent of adults who visited a dentist in the past year

Description: Dental visit within the past year
Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)
Numerator: How long has it been since you last visited the dentist or a dental clinic for any reason?="1, within the past year (anytime less than 12 months ago" (LASTDENT, 2014)
Denominator: All who answered question except those who refused or didn't know
Unit of Analysis: Individual
Data Availability: Biennially (even years)
Notes: N/A

Percent of high school students who visited a dentist in the past year

Description: Dental visit within the past year
Data Source: Maine Integrated Youth Health Survey (MIYHS)
Numerator: When was the last time you saw a dentist or dental hygienist for a check-up, exam, teeth cleaning, or other dental work?="During the past 12 months" (hn182)
Denominator: All who answered question except those who refused or didn't know
Unit of Analysis: Individual
Data Availability: Biennially (odd years)
Notes: N/A

Percent of adults with a usual source of health care

Description: Have a usual source of health care

Data Source: National Health Interview Survey

Numerator: Those who specified a usual source of care (AHCPLKND)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Annually

Notes: This question could be analyzed as a yes/no or by source of care

Percent of children with a medical home

Description: Children with a medical home

Data Source: National Survey of Children's Health (NSCH, Indicator 4.8)

Numerator: Children whose health care meets the medical home criteria

[AAP seven qualities - accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective]

Denominator: All who answered question

Unit of Analysis: Individual

Data Availability: Quadrennially (2011/2012)

Notes: Criteria changed significantly between 2003 and 2007 survey, slight change for 2011 survey

Percent of adults who were screened for cervical, breast and colon cancer based on recommended screening frequency

Description: Cancer Screening (Cervical, Breast, Colon)

Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)

Numerator: Individuals who meet these criteria:

Cervical - Women aged 21-65 who have had a pap test within the last three years

Breast- Women over 40 who have had a mammogram in the past two years

Colon - Adults 50 or older who are up-to-date with colorectal cancer screening past 3 years

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Annually

Notes: These are individual measures

Rate of full-time physicians per 100,000

Description: Physicians per 100,000

Data Source: America's Health Rankings

Numerator: Number of primary care physicians (including general practice, family practice, OB-GYN, pediatrics, and internal medicine)

Denominator: 100,000 (U.S. Census)

Unit of Analysis: Individual

Data Availability: 2013

Notes: Original data source from the AMA is unavailable: Physician Characteristics and Distribution in the United States, 2014 edition. Relevant reference information is on page 95 of 152.

Rate of practicing dentists per 100,000**Description:** Dentists per 100,000**Data Source:** America's Health Rankings (see notes)**Numerator:** Number of dentists identifying themselves as a private practitioner, dental school faculty or staff, armed forces dentist, government-employed dentist, hospital staff dentist, graduate student intern or resident, or other health and dental organization staff members**Denominator:** 100,000 (U.S. Census)**Unit of Analysis:** Individual**Data Availability:** Annually**Notes:** America's health rankings notation specifically asks to reference original source. Original source is found here: <http://www.ada.org/en/science-research/health-policy-institute/data-center/supply-of-dentists>Percent of primary care offices accepting new patients**Description:** Primary care offices accept new patients**Data Source:** National Electronic Health Records Survey**Numerator:** Number of office-based physicians accepting new patients by private insurance, Medicare, and Medicaid**Denominator:** Number of office-based physicians**Unit of Analysis:** N/A**Data Availability:** 2013**Notes:** NCHS Data Brief: <http://www.cdc.gov/nchs/data/databriefs/db195.pdf>Federally designated physician and dental area map**Description:** Federally Designated Shortage Areas, Physician and Dentists**Data Source:** Maine Office of Rural Health and Primary Care**Numerator:** Number of federally designated physicians meets the threshold for a shortage set by HRSA**Denominator:** Geographic area of interest**Unit of Analysis:** N/A**Data Availability:** 2016**Notes:** <http://www.maine.gov/dhhs/dlrs/rhpc/documents/hpsa-pcaa-a.pdf>Annual Flu shot**Description:** Annual Flu Shot or Spray**Data Source:** Maine Behavioral Risk Factor Surveillance System (BRFSS)**Numerator:** During the past 12 months, have you had either a seasonal flu shot or a seasonal flu vaccine that was sprayed in your nose?="Yes" (FLUSHOT5, 2014)**Denominator:** All who answered question except those who refused or didn't know**Unit of Analysis:** Individual**Data Availability:** Annually**Notes:** U.S. comparison may only be available in those 65 years or olderUp to date immunizations children age 19-35 months**Description:** Estimated vaccination coverage among children aged 19–35 months. The combined (4:3:1:3*:3:1:4) vaccine series includes ≥4 doses of DTaP, ≥3 doses of poliovirus vaccine, ≥1 dose of measles-containing vaccine, full series of Hib vaccine (≥3 or ≥4 doses, depending on product type), ≥3 doses of HepB, ≥1 dose of varicella vaccine, and ≥4 doses of PCV.**Data Source:** National Immunization Survey (for description not title)**Numerator:** Calculated by MMR**Denominator:**

Unit of Analysis: Individual

Data Availability: Annual

Notes: Additional analyses are available for medically underserved and mental health professional shortage areas: <http://www.maine.gov/dhhs/dlrs/rhpc/data.shtml>

Percent of adults who needed to see a doctor in the past year, but were unable due to cost

Description: Unable to see a doctor when needed due to cost

Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)

Numerator: Was there a time during the last 12 months when you needed to see a doctor, but could not because of the cost?="Yes" (MEDCOST, 2014)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Annually

Notes: N/A

Access to Services

Percent of households with access to the internet

Description: Household presence of a computer and access to internet

Data Source: American Community Survey (Table B28003)

Numerator: Presence and types of a computer and internet subscriptions in Household="YES" to has a computer & "YES" to "with a dial-up Internet subscription alone and "YES" to with a broadband internet subscription

Denominator: All who answered question

Unit of Analysis: Household

Data Availability: Annually

Notes: Data available for 6 counties in Maine and by racial group and ethnicity, educational attainment and labor force status, age, household income

Percent of eligible population enrolled in SNAP, TANF, WIC

Description: Eligible population enrolled in government-assistance programs: SNAP, TANF, WIC

Data Source: Various Sources (Office of Child and Family Services & Food Research and Action Center)

Numerator/Denominator:

- Percent of eligible population enrolled in TANF (OCFS)
- Percent of eligible population enrolled in SNAP (FRAC)
- Percent of eligible population enrolled in WIC (FRAC)

Unit of Analysis: Household

Data Availability: Annually

Notes: Food Research and Action Center data can be found here: <http://frac.org/reports-2/>
USDA Food Environment Atlas provides information on SNAP redemptions/SNAP-authorized stores and WIC redemptions per capita

Eligibility guidelines for SNAP, TANF, WIC

Description: Eligibility Guidelines for SNAP, TANF, WIC

Data Source: Various Sources

Numerator/Denominator: N/A

Unit of Analysis: N/A

Data Availability: Annually

Notes:

Eligibility guidelines SNAP: <http://www.fns.usda.gov/snap/eligibility>

Eligibility guidelines WIC: <http://www.fns.usda.gov/wic/wic-eligibility-requirements>

TANF application: <http://www.maine.gov/dhhs/ofi/public-assistance/APP-01-07.pdf>

Access to Education and Employment

Direct enrollment in two or four-year college after high school

Description: College Enrollment Rate

Data Source: Maine Department of Education

Numerator: Number of students enrolling in two or four year college within 1 year of graduation

Denominator: Total number of students graduated that year

Unit of Analysis: Individual

Data Availability: Annually

Notes: DOE Data Warehouse. This measure is found under 'Research and Reports':

http://dw.education.maine.gov/DirectoryManager/Web/maine_report/MaineLanding.aspx

Public preschool

Description: Certified Public Preschools

Data Source: Maine Department of Education (upon request)

Numerator: Primary schools with pre-school

Denominator: All primary schools

Unit of Analysis: School

Data Availability: Must request the data from DOE

Notes: A map is available here: <http://www.maine.gov/doe/publicpreschool/resources/map.html>

Employment and unemployment rates

Description: Employment and unemployment rates

Data Source: American Community Survey (Table DP03)

Numerator: Employment status population 16 and over that is employed/unemployed

Denominator: Population 16 and over

Unit of Analysis: Individual

Data Availability: Annually

Notes: N/A

Racial and Ethnic Minorities

Race/ethnicity breakdown

Description: Race and ethnicity

Data Source: American Community Survey (Table DP05)

Numerator: Number of individuals in each race and ethnicity category

- One race, two or more races
- One race (White, Black or African American, American Indian and Alaska Native [Cherokee tribal grouping, Chippewa tribal grouping, Navajo tribal grouping, Sioux tribal grouping], Asian [Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian], Native Hawaiian and Other Pacific Islander [Native Hawaiian, Guamanian or Chamorro, Samoan, Other Pacific Islander])

- Two or more races (White and Black or African American; White and American Indian and Alaska Native; White and Asian; Black or African American and American Indian and Alaska Native)
- Hispanic or Latino
 - o Hispanic (Mexican, Puerto Rican, Cuban, Other Hispanic or Latino)
 - o Not Hispanic or Latino (White alone, Black or African American alone, American Indian and Alaska Native alone, Asian alone, Native Hawaiian and Other Pacific Islander alone, Some other race alone, Two or more races)

Denominator: Total Population

Unit of Analysis: Individual

Data Availability: Annually

Notes: These are available as individual or combined measures.

Refugees in Maine

Description: Refugees in Maine

Data Source: Catholic Charities

Count: Number of intakes served by RISS/CCM per fiscal year by location

Unit of Analysis: Individual

Data Availability: Annually

Notes: <http://www.ccmaine.org/refugee-immigration-services/faqs>

Percent of those over age 5 who speak a language other than English at home

Description: Speak Language other than English at home

Data Source: American Community Survey (Table DPO2)

Numerator: Individuals who spoke a language other than English at home

Denominator: Individuals over 5 years old

Unit of Analysis: Individual

Data Availability: Annually

Notes: N/A

Women

Percent of female single head of households

Description: Single female head of households

Data Source: American Community Survey (Table DPO2)

Numerator: Female householder, no husband present, with children present

Denominator: Total households

Unit of Analysis: Household

Data Availability: Annually

Notes: N/A

Percent of women in the workforce

Description: Employment status

Data Source: American Community Survey (Table S2301)

Numerator: Number of employed women ages 20-64 years

Denominator: Number of women ages 20-64 years

Unit of Analysis: Individual

Data Availability: Annually

Notes: N/A

Persons with Disabilities

Percent of adults and children with disabilities

Description: Adults and children with disability

Data Source: American Community Survey (Tables S1810 and C18131)

Description: The survey includes questions about six types of difficulty: hearing, vision, cognitive, ambulatory, self-care, and independent living. Disability status is determined from the answers from these six types of difficulty.

For children under 5 years old, hearing and vision difficulty are used to determine disability status. For children between the ages of 5 and 14, disability status is determined from hearing, vision, cognitive, ambulatory, and self-care difficulties. For people aged 15 years and older, they are considered to have a disability if they have difficulty with any one of the six difficulty types.

Unit of Analysis: Individual

Data Availability: Annually

Notes: This may need to be separated by age group and a footnote should be added that this is among the non-institutionalized civilian population. American Community Survey and Puerto Rico Community Survey 2010 Subject Definitions:

http://www.census.gov/acs/www/Downloads/data_documentation/SubjectDefinitions/2010_ACSSubjectDefinitions.pdf, accessed 3/29/12

Description: High school and middle schoolers with disability

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: Would other people consider you to have a disability or long-term health problem, including physical health, emotional, or learning problems? = "Yes" (hn179a, mn138a)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: N/A

Income and Education

Median household income

Description: Median household income

Data Source: American Community Survey (Table S1903)

Numerator/Denominator: Median household income in past 12 months in 2014 inflation-adjusted dollars

Unit of Analysis: Household

Data Availability: Annually

Notes: N/A

Livable wage in Maine

Description: Living Wage

Data Source: MIT Livable Wage Calculator

Numerator/Denominator: The living wage shown is the hourly rate that an individual must earn to support their family, if they are the sole provider and are working full-time (2080 hours per year)

Definition description can be found here: <http://livingwage.mit.edu/pages/about>

Unit of Analysis: Individual

Data Availability: The last available update was 2014

Notes: The calculator is available here: <http://livingwage.mit.edu/states/23>

Poverty of individuals**Description:** Individuals living below the poverty level within the past year**Data Source:** American Community Survey (Table B1701)**Numerator:** Number of people below the poverty level within the past year**Denominator:** Number of people**Unit of Analysis:** Individual**Data Availability:** Annually**Notes:** Available by 125 percent, 150 percent, 185 percent, and 200 percent of the poverty level if willing to look at 5 year combined data (Table S1701).Poverty of families**Description:** Families living below the poverty level within the past year**Data Source:** American Community Survey (Table B17012)**Numerator:** Number of families below the poverty level**Denominator:** Number of families**Unit of Analysis:** Family**Data Availability:** Annually**Notes:** N/AChildren living in poverty**Description:** Children living below the poverty level within the last year**Data Source:** American Community Survey (Table B17001)**Numerator:** Number of children (age <18) below the poverty level**Denominator:** Number of children**Unit of Analysis:** Individual (child)**Data Availability:** Annually**Notes:** N/AMedian child care cost as percent of annual income**Description:** Annual childcare cost (Percent of median income)**Data Source:** Maine Office of Child and Family Services (calculated measure)**Definition:** Median annual childcare rates by age group (Child Care Aware® of America and Maine DHHS data)**Unit of Analysis:** Married couple household or by single female headed household**Data Availability:** Unknown**Notes:** <http://www.maine.gov/dhhs/ocfs/ec/occhs/2013-state-of-maine-market-rate-report.pdf>

Sexual Orientation

Prevalence of GLBT population**Description:** Sexual orientation**Data Source:** Maine Behavioral Risk Factor Surveillance System (BRFSS)**Numerator:** Term that best describes sexual orientation = Homosexual (gay or lesbian), or Bisexual (SXL_ORNT)**Denominator:** All who answered question except those who refused or didn't know**Unit of Analysis:** Individual**Data Availability:** Annually**Notes:** N/A

Description: Sexual orientation

Data Source: Maine Integrated Youth Health Survey (MIYHS)

Numerator: Which of the following best describes you? = Percentage of students who answered "Gay or lesbian" or "Bisexual" (hn9)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Biennially (odd years)

Notes: N/A

Mental Health and Stress

Mean number of stressors experienced by women prior to and during their pregnancy

Description: Stressors before and after pregnancy

Data Source: Pregnancy Risk Assessment Monitoring System (PRAMS)

Numerator: Total number of stressors reported. Grouped as none, 1-2, 3-5, and 6-13

Denominator: All who answered question

Unit of Analysis: Individual

Data Availability: Annually

Notes: PRAMStat:

http://nccd.cdc.gov/PRAMStat/rdPage.aspx?rdReport=DRH_PRAMS.ExploreByTopic&isClassId=CLA12&isTopicId=TOP48&go=GO

Percent of adults with activity limitations due to mental/emotional problems

Description: Activity limitations

Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)

Numerator: Are you limited in any way in any activities because of physical, mental, or emotional problems?="Yes" (QLACTLM2, 2014)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Annually

Notes: N/A

Percent of adults with depression diagnosis

Description: Depression diagnosis

Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)

Numerator: Ever told you had a depressive disorder = "Yes" (Addepev2, 2014)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Annually

Notes: N/A

Percent of adults with anxiety diagnosis

Description: Anxiety diagnosis

Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)

Numerator: Has a doctor or other healthcare provider ever told you that you had an anxiety disorder?="Yes" (ADANXEV, 2014)

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Annually

Notes: N/A

Percent of adults with current depressive symptoms

Description: Current depression

Data Source: Maine Behavioral Risk Factor Surveillance System (BRFSS)

Numerator: phqtwo="YES"

Denominator: All who answered question except those who refused or didn't know

Unit of Analysis: Individual

Data Availability: Annually

Notes: Phqtwo is a calculated variable

Rural and Isolated

65+ year olds living alone

Description: Seniors living alone

Data Source: American Community Survey (Table B09020)

Numerator: Males living alone; females living alone

Denominator: Males living in family and non-family households; females living in family and non-family households

Unit of Analysis: Individual

Data Availability: Annually

Notes: N/A

¹ World Health Organization. Social Determinants of Health. http://www.who.int/social_determinants/en/

Chapter 4: Populations Experiencing Health Inequities

In This Chapter

There are many populations in Maine whose experiences with inequities in social and economic opportunities have resulted in health disparities. Many of these populations are not well represented in traditional public health surveillance systems, making it challenging to identify and address these disparities.

In this section, the following population groups are discussed:

- **Native American Tribal population**
- **People of color**
- **Refugees and immigrants**
- **Hispanic/Latinos**
- **Migrant and seasonal workers**
- **Lesbian, Gay, Bisexual, Transgender**
- **Individuals with disabilities**
- **Children with special health care needs**
- **Women**
- **Elder adults (special focus on rurality)**

These groups were selected because either traditional public health data systems do not adequately capture their strengths and needs, or additional analyses are needed to learn more about their disparities.

To gain a better understanding of these populations, we examined existing datasets, conducted literature searches for reports on these populations, and interviewed stakeholders.

In each section we review:

- Available data on these populations
- Specific assessments and reports focused on the population



- Alternative methods of data collection
- Recommendations to improve public health surveillance on each population group.

It is important to note that the populations we investigated do not represent the diversity of the people of Maine. They are a subset of those who face inequities in health and opportunities. Furthermore, although we are describing population groups, we recognize that there is diversity within these groups; individuals have their own unique needs, strengths and challenges.

There are other populations who experience health disparities including those with mental illness, adolescents, those living in poverty, persons who are homeless, and those with limited education, among others. As Maine CDC moves towards improving data and reporting on diverse populations, it will be important to include these groups in our data collection systems and report on the challenges facing them.

The purpose of this section is to highlight where we can improve our understanding of the diverse populations in our state by improving existing data systems, using innovative methods of data collection and analysis, and increasing engagement with community partners around data.

Native American Tribal Populations in Maine

Background

About Native Americans in Maine

- Historical estimates of the pre-European native population vary from fewer than two million to more than 18 million indigenous people in what is now the U.S. and Canada.^{1,2,3,4} In the years following colonization this population decreased dramatically, largely due to disease and intentional killings by European settlers.^{3,4}
- Today, there are 566 federally recognized tribes in the United States, and many more state recognized and unofficial tribes.⁵
- There are four federally-recognized tribes in Maine (Penobscot Nation, Maliseet, Mi'kmaq, and Passamaquoddy), collectively called “Wabanaki,” which means “people of the dawn.” These four tribes are spread out along the coast into the northern portion of the state.
- According to the U.S. Census, 19,660 Mainers identified as American Indian/Alaska Native (including those who also identified as White or Black or African American) in 2015.⁶
- Those who identify as American Indian/Alaska Native alone (not in combination with another race) make up 0.6% of Maine’s population.⁶

The 2010 Wabanaki health needs assessment found that, compared to the general Maine population, tribal members have higher rates of diabetes, high blood pressure, heart attacks, depression, anxiety, obesity, and smoking, contributing to a shorter life expectancy and worse overall health.⁷ This population also had lower rates of cancer screening, with the exception of Pap smears.⁹

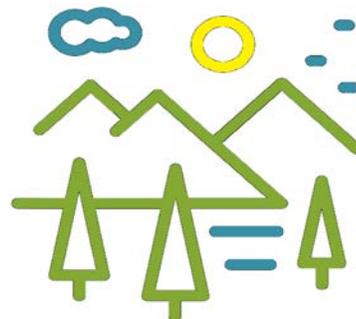
Definitions

Native American/American Indian: a member of any of the indigenous peoples of North, Central, and South America.

Alaska Native: indigenous peoples of Alaska.

Indigenous: originating in a particular place; native.

There is some debate about which term is most appropriate (Native American or American Indian). Opinions vary by geographic region, tribe, and personal preference. It is always important to accurately reflect the terms used by the data collection instrument. For example, the Behavioral Risk Factor Surveillance System (BRFSS) uses the term “American Indian or Alaska Native,” so when presenting this data it would be appropriate to use that same terminology. *If it is unclear which term to use, ask key health representatives of the tribal community.*



Nationally, mortality rates related to alcohol, tuberculosis, injury, diabetes, pneumonia, and chronic liver disease/cirrhosis are all higher for American Indian/Alaska Native people than the U.S. population.⁸ Obesity rates are also higher for this population compared to the U.S. as a whole. Many researchers and people working with tribal populations attribute weight disparities to the federal government's food distribution program, which provides primarily high-calorie processed foods on tribal reservations.¹⁰

Today, the indigenous population is more likely to live in poverty, with less education, and higher unemployment, all of which can contribute to persistent health disparities.¹⁰ Historical trauma and loss is another underlying factor that still plays a role in the health and wellbeing of many tribal people.⁹ Although the Indian Health Service provides health care to registered members of federally-recognized tribes, it does not serve those who are members of a non-recognized tribe, or who are not registered members.

Surveillance Challenges

This population can be especially difficult to reach for health data collection due to the historically strained relationship between the state and federal governments and the tribes. It is crucial to consider cultural differences when attempting to create any new programming or surveillance tools, and to consult local tribal leaders as well as tribal health liaisons.

Even when data are collected on the tribal population in Maine, there is often skepticism about the accuracy of these data, due to past experiences. In 2000, the Maine Center for Disease Control and Prevention (formerly the Maine Bureau of Health) released the "Health Status and Needs Assessment of Native Americans in Maine," which used vital statistics and BRFSS data to analyze the health of the native population in Maine.¹⁰ This

report found that the native population's health had greatly improved over the previous two decades and that their rate of cardiovascular disease mortality was lower than the rest of the state.¹³ The tribal community responded to this report by walking researchers through graveyards, showing them the many native people who had died at an early age, contrary to the report's conclusions.

This apparent misalignment indicated the need for a follow-up study, which began shortly after the publication of the first report. The follow-up study looked at potential race misclassification in the death certificate data, focusing on the native population.¹¹ This study found that race had been miscoded in 28 percent of Maine death certificates. This error may have had a significant impact on accuracy of the mortality rates reported in the 2000 report.¹⁴ This serious error demonstrates the importance of understanding data sources, and examining problematic methodology. Although the death certificate data included race data during that time, it was not reliable for this particular population. Provider and coroner education was implemented across the state following the release of these reports, but there has not been any further evaluation to test the impact of that training on racial misclassification in death certificates.

Assessing Native American/Tribal Health in Maine

State-level Population Data

The following is a summary of available data on the Native American population in Maine. Race data are included in most data sets, although the validity of these data depends on whether race is self-reported or recorded by someone else based on a visual assessment. Data on those affiliated with a

tribe and/or living on tribal land are not available in most data systems.

Federal data systems

American Community Survey (ACS)

The American Community Survey is a rich data source with information on population characteristics such as age, sex, educational attainment, employment, and poverty. Data by race are available for most indicators since the ACS produces estimates using three and five years of data for indicators with small numbers. It is also possible to get data from the ACS by tribe for: Aroostook Band of Micmac Trust Land, Houlton Band of Maliseets, Passamaquoddy, Penobscot, and Pleasant Point. Collaboration with Tribal Leaders would be needed to determine whether the ACS data accurately reflects tribal members.

CDC Wide-ranging Online Data for Epidemiologic Research (WONDER)

CDC WONDER is an online data source that provides a large variety of health data for public health research and practice. Topics include, but are not limited to, AIDS, births, cancer, injury, mortality, and vaccines. Many datasets are available by race, although individual topics may vary. Data by tribal affiliation are not available.

CDC Web-based Injury Statistics Query and Reporting System (WISQARS)

CDC WISQARS is an online database providing information on injury, violent death, and cost of injury. Some data are available by race, although individual topics vary. Data by tribal affiliation are not available.

State Data Systems

Birth and Death Certificates

Maine birth and death certificates collect data on race. However, the 2003 follow-up study to the Health Status and Needs Assessment of Native Americans in Maine revealed that 28 percent of death certificates were racially miscoded for Native Americans during the years studied in the first assessment.¹⁴ For a more complete discussion what is collected and available, please see Chapter 1. Starting in August 2013, the birth certificate includes a write-in field on the birth certificate where tribal affiliation can be entered. To determine its accuracy, additional analyses of this data are needed.

Maine Hospital Discharge and Emergency Department Data

These data are available by race, although the validity of these data depend on the practices of the hospital (whether ethnicity is self-identified or not). Tribal membership is not specified.

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) Survey includes a core demographic question on race. This means that all respondents are asked this question. As a result, it can be used to examine health disparities by race for anything on the BRFSS survey. However, these data are not considered reliable by the tribal community and it is not possible to identify tribal affiliation on the survey. The 2010 Wabanaki Health Assessment, which was modeled after the BRFSS, was conducted by the tribes in order to collect more accurate data. State-level BRFSS data are available at: http://www.cdc.gov/brfss/data_tools.htm

Pregnancy Risk Assessment Monitoring System (PRAMS)

PRAMS is a survey of new mothers in Maine conducted on an annual basis. The PRAMS survey is linked to the birth certificate file. Data on race for PRAMS come from the birth certificate. About 2,000 PRAMS surveys are completed each year. Since Native Americans represent about 0.6 percent of Maine's population, less than 30 Native American new mothers complete the survey each year. This makes analyses by race challenging. Generally ten years of PRAMS data need to be combined to get reliable estimates by Native American race. Tribal affiliation is not collected.

Maine Integrated Youth Health Survey (MIYHS)

A question on race is included in the MIYHS and the large sample size of the MIYHS allows for more reliable estimates of risk and protective factors among Native American youth compared to other data systems. However, there is still some distrust of state-collected data by the Native American population in Maine, and tribal affiliation is not collected. As a result, the tribes are planning to conduct a survey for Native American youth in Maine, modeled after the MIYHS and the 2010 Wabanaki Health Assessment. MIYHS reports can be found here:

<https://data.mainepublichealth.gov/miyhs/>

Native American Health Assessments

Wabanaki Health Assessment

In 2010, the Maine Tribal Health Directors worked with the University of Nebraska School of Public Health to create and administer a health survey modeled after the BRFSS. This survey consisted of in-person interviews, providing valuable data on many of the same topics that are included in the BRFSS (chronic disease, health risk behaviors, demographic information, etc.) with the addition of questions about historical loss and trauma caused

by centuries of loss of culture, language, land, and much more. The survey was well-received, with a response rate of over 75 percent. These data are owned by the tribes and anyone who wishes to access them must first obtain permission from the tribes. The tribes plan to conduct this survey every ten years.

Four reports from this health needs assessment (one for each of the participating tribes) were produced. Each report summarizes the results of the survey for members of that tribe, including data on chronic disease, demographics, behavioral health, and health risk behaviors. Reports can be found here:

- Penobscot Nation:
<http://www.maine.gov/dhhs/mecdc/health-equity/documents/Final%20Penobscot%20Community%20Profile2.pdf>
- Houlton Band of Maliseets:
<http://www.maine.gov/dhhs/mecdc/health-equity/documents/Final%20copy%20Maliseet%20Profile2.pdf>
- Passamaquoddy:
<http://www.maine.gov/dhhs/mecdc/health-equity/documents/Passamaquoddy%20Profile2.pdf>
- Aroostook Band of Micmacs:
<http://www.maine.gov/dhhs/mecdc/health-equity/documents/Final%20Micmac%20community%20profile2.pdf>

Hypertension Prevalence among Penobscot Indians of Indian Island, Maine

This 1985 study interviewed a random sample of people living on the reservation at Indian Island, Maine in 1981. Blood pressure readings were also taken from respondents. Researchers found this tribal population had higher rates of hypertension than the rest of the state or country. This study can be found here:

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1646205/pdf/amjph00282-0079.pdf>

Health Status and Needs Assessment of Native Americans in Maine: Final Report

In 2000, the Maine Bureau of Health (now the Maine CDC) produced a report on the health status and needs assessment of Native Americans in Maine using BRFSS data. This report spurred a strong reaction from the tribal community, who believed the data misrepresented their health status, detailed in Surveillance Challenges. The report can be found here:

<https://www1.maine.gov/dhhs/mecdc/files/nar/nar.htm>

Health Status and Needs Assessment of Native Americans in Maine: A Follow-Up Report

This 2003 follow-up report explored potential racial misclassification in death certificates in Maine, and found a 28 percent rate of racial miscoding during the years originally studied. This racial miscoding had a particularly large effect on the rate of cardiovascular-related mortality. The report can be found here:

<https://www.maine.gov/dhhs/mecdc/files/nar/narfouprep2.doc>

Underestimation of cardiovascular disease mortality among Maine American Indians: The role of procedural and data errors.

This journal article was published in the American Journal of Public Health in 2005, documenting the racial misclassification that resulted in the underestimation of cardiovascular-related mortality among Maine Native Americans in the 2000 report. The article can be found here:

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1449262/>

Native Americans, American Indians, Alaskan Natives and Tobacco Fact Sheet

This fact sheet was created by the Maine CDC in 2008, and provides data on tobacco use among the indigenous population, including current use, trends over time, and historical context. The fact sheet can be found here:

http://www.tobaccofreemaine.org/explore_facts/documents/25-809%20NativeAmerFacts.pdf

Strengths and Limitations of Existing Data

Strengths

- Most public health data sources in Maine include data on race, including Native American/American Indian.
- The Wabanaki Health Assessment is a rich data source that provides not only more data on Native Americans in Maine, but more accurate data, as the survey was designed and conducted by the tribes.
- The upcoming youth health assessment will be another rich data source that could provide vital information on the Native American youth in Maine.

Limitations/Challenges

- The most reliable data sources (2010 Wabanaki health assessment and upcoming youth health assessment) are not available to outside organizations without permission from the tribes.
- The 2003 study that found racial misclassification in the death certificate data has never been replicated, so there is no way of knowing if racial misclassification has improved since then.

- The tribes do not generally have positive relationships with state or federal government; there is a lot of mistrust.
- Many people who identify as Native American are multiracial, and even when someone identifies only as Native American it is not always possible to visually identify someone's race. The validity of data depends on whether race was self-reported or the result of a visual assessment.

Recommendations

1. Update the 2003 race misclassification study.

Although trainings were implemented following the 2003 study with the intent of improving race classification practices in the medical field, there has not been a follow-up study to determine whether or not the situation has improved. Updating this study would provide valuable information about the current state of death certificate data, and could help improve tribal perceptions of state-based data. This would be a positive step toward the State working collaboratively around data with the tribes.

2. Offer support to the tribes with any upcoming surveys (e.g. upcoming youth survey, next administration of the Wabanaki health assessment).

Offering analytic support to the tribes would be another opportunity to build relationships. It would be beneficial to open lines of communication and let the tribes know that the state has the capacity to support analytic projects if needed.

3. Add tribal affiliation field to existing public health surveillance datasets (e.g. death certificates, hospital discharge, etc.).

Death certificates have a write-in field, but it would be useful to have this as an option in other data systems and/or a separate question on statewide surveys.

¹ A Taylor. *American Colonies*. Penguin Random House: 2002.

² D Ubelaker. Prehistoric New World Population Size: Historical review and current appraisal of North American estimates. *American Journal of Physical Anthropology*. 45(3): 661-665.

<http://onlinelibrary.wiley.com/doi/10.1002/ajpa.1330450332/abstract>

³ R Thornton. Native American Demographic and Tribal Survival into the Twenty-first Century. *American Studies*. 46(3): 23-28.

<https://journals.ku.edu/index.php/amerstud/article/viewFile/2951/2910>

⁴ H Dobyns. Their Number Become Thinned: Native American Population Dynamics in Eastern North America. *The William and Mary Quarterly*. 41(4): 649-653.

http://www.jstor.org/stable/1919159?seq=1#page_scan_tab_contents

⁵ US Department of the Interior: Indian Affairs. Who We Are.

<http://www.bia.gov/WhoWeAre/index.htm>

⁶ U.S. Census Bureau: American FactFinder. Detailed Race. Universe: Total population 2010-2014 American Community Survey 5-Year Estimates.

⁷ University of Nebraska Medical Center. The Penobscot Nation Health Needs Assessment Summary Report. 2012.

<http://www.maine.gov/dhhs/mecdc/health-equity/documents/Final%20Penobscot%20Community%20Profile2.pdf>

⁸ U.S. Department of Health and Human Services. Indian Health Service. *Trends in Indian Health 2014 Edition*. Office of Public Health Support. Division of Program Statistics.

https://www.ihs.gov/dps/includes/themes/newihstheme/display_objects/documents/Trends2014Book508.pdf

⁹ T Evans-Campbell. Historical Trauma in American Indian/Native Alaska Communities: A Multilevel Framework for Exploring Impacts on individuals, Families, and Communities. *Journal of Interpersonal Violence*. 2008. 23(3): 316-338. doi: 10.1177/0886260507312290

¹⁰ P Kuehnert. Health Status and Needs Assessment of Native Americans in Maine: Final Report. Division of Disease Control. Maine Bureau of Health. January 15, 2000.

<https://www1.maine.gov/dhhs/mecdc/files/nar/nar.htm>

¹¹ P Kuehnert, J Graber, B Corkum. Health Status and Needs Assessment of Native Americans in Maine: A Follow-Up Report. Bureau of Health, Maine Department of Human Services. 2003.

<http://www.maine.gov/dhhs/mecdc/health-equity/data.shtml>

People of Color in Maine

Background

About Persons of Color in Maine

- In Maine, about five percent of the population identifies as a race other than White.¹
 - 1.1 percent identify as African American
 - 0.6 percent identify as Native American
 - 1.1 percent identify as Asian
 - 0.2 percent are some other race
 - 1.9 percent are two or more races.
- The African American population of Maine increased 120 percent between 2000 and 2015 (0.5 percent to 1.1 percent) and the Asian population increased 57 percent (0.7 percent to 1.1 percent).^{1,2}
- The counties with the largest numbers of persons of color are Cumberland, York, Androscoggin, and Penobscot.¹

In Maine, African-Americans include those whose families have lived in the U.S. for hundreds of years, as well as those who have recently arrived as immigrants and refugees. It is well documented that persons of color, especially African-Americans are at greater risk for poor health outcomes.³ Much of their health disparities are rooted in historical abuses including slavery and segregation, as well as experiences with discrimination, lack of access to quality health care, lower educational and employment opportunities, and poor housing and work conditions that date back generations and continue today. Other groups of color also have fewer educational, employment and housing options and also experience discrimination. These

Definitions

OMB Standards on Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity

In 1997, the U.S. Office of Management and Budget established standards for collecting and reporting race and ethnicity data. The standards have five categories for data on race:

1. American Indian or Alaska Native
2. Asian
3. Black or African American
4. Native Hawaiian or Other Pacific Islander
5. White

There are two categories for data on ethnicity:

6. Hispanic or Latino
7. Not Hispanic or Latino

It is recommended that race and ethnicity are collected separately and that respondents are able to select more than one racial category.³

factors make it critical to monitor health disparities among individuals of color, but also identify the social determinants of health that are reproducing health inequities.

Surveillance Challenges

Race data are collected in all of Maine's major public health data systems, including death and birth certificates, hospitalization data, and surveys like the MIYHS and BRFSS. However, collection and reporting of race are not consistent across these data sources making comparisons challenging. In addition, people of color are a relatively small population in Maine and their geographic spread

can make it difficult to examine health needs and strengths using traditional data sources. It is also difficult to determine whether health challenges for those who have lived in the U.S. for several years are the same as those who recently immigrated.

National data suggests that health disparities by race exist in every state including Maine, but producing Maine data that documents these disparities could help public health professionals make the case to address some of the underlying inequities that result in these disparities.

Assessing the Health of Persons of Color in Maine

State-level Population Data

Following is a summary of available data on the minority race population in Maine. Race data are included in most data sets.

Federal data systems

American Community Survey (ACS)

The American Community Survey is a national population survey that includes information on characteristics such as age, sex, educational attainment, employment, and poverty. Data by race are available for most indicators, but sometimes multi-year estimates must be used. The ACS produces estimates using three and five years of data for indicators with small numbers.

State Data Systems

Birth and Death Certificates

Maine birth and death certificates collect data on race. For more discussion of what is collected and available, please see Chapter 1.

Maine Hospital Discharge and Emergency Department Data

Data are available by race, although the validity of the data depend on the practices of the hospital (whether ethnicity is self-identified or not).

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) Survey includes one core question on race. This means that all respondents are asked this question. As a result, it can be used to examine health disparities by race for anything on the BRFSS survey. However, due to the small number of individuals of color that take the survey in a given year, several years of data must be combined to get valid estimates, and sometimes different races need to be combined into a “Non-White” category, as opposed to being analyzed as a separate subgroup. In 2011, the BRFSS survey methodology changed significantly, and it is no longer valid to combine current years of data with data prior to 2011. As a result of those changes and the BRFSS suppression rules, it has been difficult to get large enough samples to report on results by race. As of 2016, BRFSS will have collected five years of race data using the new methodology. This may allow for more analyses by race for some health outcomes and behaviors. State-level data are available at: http://www.cdc.gov/brfss/data_tools.htm

Pregnancy Risk Assessment Monitoring System (PRAMS)

PRAMS is a survey of new mothers in Maine conducted on an annual basis. The PRAMS survey is linked to the birth certificate file. Data on race and ethnicity for PRAMS come from the birth certificate. About 2,000 PRAMS surveys are completed each year. Generally ten years of PRAMS data need to be combined to get reliable estimates by race.

Maine Integrated Youth Health Survey (MIYHS)

A question on race is included in the MIYHS and the large sample size of the MIYHS allows for more reliable estimates of risk and protective factors among youth of color compared to other data systems. However, in MIYHS reports, race and ethnicity are not reported separately. This is not consistent with OMB standards. <https://data.mainepublichealth.gov/miyhs/>

Minority Health Assessments

Minority Health Assessment Report

The Public Health Division of the City of Portland's Department of Health and Human Services conducts a minority health assessment approximately every three to four years. The most recent report was conducted in 2014 and the previous report was released in 2011. The 2014 report was based on interviews with over 1,200 members of 18 different racial, ethnic, and language communities in Cumberland County.

The interview questions were developed in collaboration with local stakeholders and community members. The interviews were conducted by Community Health Outreach Workers and held in person, either individually or in groups. They took place at local community sites including non-profits, faith settings, schools, community centers and parks. The sample was a convenience sample. Participants were asked about health insurance and health concerns and important risk behaviors in their community. The project was funded by the Maine Health Access Foundation and the full report can be found here:

<http://portlandmaine.gov/353/County-Health-Assessments>.

There have been no other reports focused solely on minority health, but the Maine Center for Economic Policy produced, "**Asians in the Maine Economy: Opportunities for Growth.**" This report relies on data from interviews. It summarizes some social

determinants of health, such as educational attainment, geography and business ownership among Maine's Asian population.

http://www.mecep.org/wp-content/uploads/2014/09/MECEP_Asians-in-Maine_Report-4-20-2011.pdf

For more specific information about Native American and Hispanic/Latina populations in Maine, please see those sections in this chapter.

Strengths and Limitations of Existing Data

Strengths

- Most public health data sources in Maine include data on race. In some instances there are adequate sample sizes to be able to examine basic health disparities between white and non-white groups.

Limitations/Challenges

- While data are collected on this population through typical means (phone surveys, hospital data, etc.), certain minority population groups can be difficult to reach due to issues like language barriers.
- With small populations it is challenging to get a survey sample large enough to be representative. Without representative data, it is very difficult to conduct in-depth analyses and to learn about disparities within and across racial subpopulations.
- More data on social determinants of health need to be collected to demonstrate the link between these factors and health (rather than just focusing on race).

- Data collection tools are not generally in languages other than English in order to be able to capture all minority populations in the state.

Recommendations

1. Encourage standardization of data collection of race in public health and health care data systems to comply with OMB standards.

Maine's Office of Multicultural Affairs has been working with health care systems to standardize data collection of race and ethnicity.

2. Produce data briefs on populations of color in Maine to highlight health disparities and social determinants of health.
3. Work with nonprofits and local health organizations that may collect data on minority populations to see if an assessment is already being done that can be amended to collect more health data rather than starting from scratch.
4. Support the work of Portland Public Health as they conduct their Minority Health Assessment.
5. Collect qualitative data on different population groups to learn about health needs and concerns.
6. Conduct more analyses on social determinants of health at a local level to demonstrate the relationship between unequal access and opportunity and health.
7. Continue to produce tables that include race to highlight disparities in health.

¹ U.S. Census Bureau, Population Estimates, 2014.

² U.S. Census Bureau, 2000 Census Estimates.

³ Centers for Disease Control and Prevention. *CDC Health Disparities & Inequalities Report – United States, 2013*, Morbidity & Mortality Weekly Report (MMWR) Supplement, November 22, 2013, Vol.62, Supplement No. 3, pg.1-187. <http://www.cdc.gov/minorityhealth/chdireport.html>

Refugees and Immigrants in Maine

Background

About Refugees and Immigrants in Maine

- According to the U.S. Office of Refugee Resettlement, 425 refugees resettled in Maine in 2015. Of those, 44.5 percent came from Somalia, 48.2 percent from Iraq, and 4.7 percent from the Democratic Republic of Congo.¹
- According to the 2010-2014 American Community Survey, about 3.7 percent of Maine's population was born outside of the U.S., compared to 3.0 percent in 1990.²
- The foreign-born population in Maine increased by 35 percent between 2000 and 2014 compared to a 1.1 percent change in the U.S. born Maine population.²
- Catholic Charities Refugee and Immigrant Services estimates that over the past 40 years, their resettlement program has assisted over 9,000 people.³

Several studies have found that refugees and immigrants may be at risk for poor health outcomes. Exposure to trauma prior to immigration puts them at greater risk for mental health disorders. Lack of health insurance and language barriers limits their access to and use of preventive health care.⁴ Immigration itself is often the result of social determinants of health such as poverty, lack of educational opportunity, persecution, and interpersonal violence. When an immigrant arrives in the U.S. they often face barriers to accessing economic and social opportunities (such as

Definitions

Refugee: An individual who has been forced to leave their country due to persecution or fear of persecution based on race, religion, nationality, political opinion, or membership in a particular social group.

Asylee: Asylees are similar to refugees because they also fear persecution in their country of origin. The main different between a refugee and asylee is that an asylee applies for protection in the U.S. when they are already in the country or at a port of entry.

Immigrant: A person who comes to another country to take up permanent residence. A refugee is an immigrant, but not all immigrants are refugees.

Primary Refugee: An individual who arrives directly from their country of origin or refugee camp to Maine.

Secondary Migrant: An individual who came to the U.S. as a refugee and was resettled in one state, but then chose to move to Maine.

Foreign-born: Term used by the U.S. Census Bureau. It refers to people living in the U.S. at the time a survey is administered who were not U.S. citizens at birth. It includes naturalized citizens, green-card holders, refugees, asylees, those on temporary visa, and those living in the U.S. without authorization.

adequate housing, food security, and employment) which can affect health.⁵

Surveillance Challenges

One of the challenges for those who work with immigrants and refugees is the lack of data on their needs, strengths, and health concerns. Traditional public health data sources such as death and birth certificates and health surveys do not adequately document country of origin or immigrant status. Even if assessed, there is a great deal of diversity within the “new Mainer” population and the sample size of subgroups may not be adequate to gain an understanding of their health needs.

Assessing the Health of Refugees in Maine

State-level Population Data

Reports on refugees and immigrants have not yet been developed using population-based data in Maine, but some demographic and population data are available from national surveys and tracking systems. Health-related data are limited.

Federal data systems

Data on selected indicators related to immigration (e.g., country of origin, resettlement location) are available from federal data systems, such as the American Community Survey (Table 1).

State Data Systems

Maine’s death certificate has a “place of birth” field, but it is only coded for North American Territories. All other countries coded as unknown.

Maine’s Public Health Nursing program currently conducts some basic screenings with refugees entering Maine who are part of the refugee resettlement program. There are ongoing efforts to increase screenings and data collection by Maine’s Public Health Nursing Program.

Table 1. Selected Data Elements Related to Immigration

Topic	Available data	Source
Annual arrival numbers	Country of birth; age; sex; marital status; refugees admitted	Department of Homeland Security, <i>Yearbook of Immigration Statistics</i>
Foreign-born population estimates	Foreign born by state and demographics (education, income, poverty)	American Community Survey (ACS)
Immigrant Children	Number of children of immigrant families; selected characteristics (poverty, income, linguistic isolation)	Kids Count, http://kidscount.org/datacenter/compare/jsp
Language proficiency and Education	Language spoken at home by age and citizen status; educational attainment	American Community Survey (ACS)
Health Insurance	Access to health insurance by state	Current Population Survey (CPS)

Source: Migration Policy Institute, *Immigration: Data Matters*

Maine’s infectious disease surveillance system, NEDSS (National Electronic Disease Surveillance System) includes foreign-born status for select conditions (e.g., giardia), but this information is not available for all reportable infectious diseases.

The Maine Integrated Youth Health Survey (MIYHS) includes a question on primary language spoken in the home. This question is asked of students in high school, middle school, 5th and 6th grade, as well as parents of kindergarten and third graders.

- No other public health data systems currently collect state-level information on foreign-born

status or refugee status. This includes birth certificate, hospital discharge and emergency department data, as well as surveys such as BRFS, MIYHS and PRAMS.

Maine Refugee and Immigrant Needs Assessments

Refugee/immigrant needs assessments have been conducted in Portland and Lewiston/Auburn, the major metropolitan areas where most of Maine's immigrants and refugees live.

Minority Health Assessment Report

The Public Health Division of the City of Portland's Department of Health and Human Services conducts a minority health assessment approximately every three to four years. The most recent report was conducted in 2014 and the previous report was released in 2011. The 2014 report was based on interviews with over 1,200 members of 18 different racial, ethnic, and language communities in Cumberland County.

The interview questions were developed in collaboration with local stakeholders and community members. The interviews were conducted by Community Health Outreach Workers and held in person, either individually or in groups. They took place at local community sites including non-profits, faith settings, schools, community centers and parks. The sample was a convenience sample. Participants were asked about health insurance and health concerns and important risk behaviors in their community. The project was funded by the Maine Health Access Foundation and the full report can be found here:

<http://portlandmaine.gov/353/County-Health-Assessments>.

A Portrait of Health Needs: Self-reported Health Needs Among New Americans in Lewiston-Auburn

In 2013, 232 in-person interviews were conducted with New Mainers residing in Lewiston and Auburn. The interview questions covered demographics,

healthcare services and access, health concerns of the household, and preferred strategies to receive communications and programs. The questions were developed using input from focus groups of 40 New American community members. The full report can be found here:

http://www.healthyardscoggin.org/wp-content/uploads/2012/04/Healthy-Androscoggin-New-American-Report_web.pdf

Strengths and Limitations of Existing Data

Strengths

- Census Bureau data allow for ongoing tracking of numbers of foreign-born residents by key demographics over time.
- Existing assessments of Maine's refugee and immigrant populations are community-driven. Interview questions were developed with input from community members to ensure that the results were relevant to them and could be used to drive programming.
- Interviews were conducted by community members to ensure they were conducted in a culturally competent manner and to optimize the likelihood that community members would respond honestly.
- Reports of these assessments are publicly available.

Limitations/Challenges

- Population-based data on Maine's refugee and immigrant populations are not available from public health surveillance sources.
- Sampling for existing community needs assessments was not random and therefore the results of the assessments may not be representative of the population. However, the

cost of conducting a random sample survey is likely prohibitive.

- Assessments are time-consuming and can be costly; limited resources determine how frequently they can be conducted.
- Assessments have been limited to two metropolitan areas and do not include immigrants living outside of these areas. There is no information on the needs of immigrants living in rural areas.
- There is limited data analytic capacity at the local level for in-depth analyses of findings.
- Current assessments do not allow for direct comparisons to the general population. This limits our ability to identify health issues that disproportionately impact Maine's refugee and immigrant population.

Other Methods of Data Collection on Refugee Health

A literature search on refugee health revealed other potential methods to assess the health status of refugee and immigrant population. These methods and examples are summarized below.

Retrospective chart review: Reviewing medical charts of refugees can help identify health needs and health care utilization. For example, a retrospective chart review of all newly resettled refugee children at a medical center in Pennsylvania. Analysts collected data regarding physical examination findings and results of selected screening tests for TB, stool parasites, vitamin D, and vaccine-preventable diseases performed as part of the health screening.

Face-to-Face interviews: Convenience and snowball sampling methods have been used to learn more about the health needs of specific refugee groups. This methodology was used by Portland's Public

Health Division, Healthy Androscoggin, as well as others.^{6,7}

Telephone Surveys: In some states, the BRFSS has been modified to oversample specific immigrant or racial and ethnic groups. For example, Michigan conducted a BRFSS survey with their Arab population.⁸

Data Linkages: Florida linked their refugee and immigrant data to their Medicaid data to determine the percent of refugees who enroll in Medicaid and use Medicaid services.⁹

Recommendations:

1. **Support the work of Portland's Public Health Division and Healthy Androscoggin** in their continued efforts to collect data on the refugee and immigrant populations in their areas. This support could include any of the following:
 - a. Fund epidemiologists and/or statisticians to assist with sampling methodology and/or conduct analyses of assessment and produce reports in collaboration with partners.
 - b. Convene a working group of key stakeholders interested in collecting data on minority populations to collaborate on data collection methodology, survey development, and analysis. This could help combine resources and bring synergy to the assessment process.
 - c. Provide funding to assist in these efforts.
 - d. Conduct supplemental focus groups to provide additional information to assessments.
2. **Develop report on refugees and immigrants in Maine using data from American Community**

Survey, Current Population Survey, and U.S. Census.

This report would highlight what we know about Maine's refugee and immigrant population using existing national data systems.

3. Explore the possibility of linking refugee data with MaineCare data to assess immigrant refugee health needs and health care utilization.
4. Include immigrant status questions on existing surveys and public health surveillance systems.
 - a. Add questions on immigration status to:
 - Behavioral Risk Factor Surveillance System (BRFSS)
 - Pregnancy Risk Assessment Monitoring System (PRAMS)
 - Maine Integrated Youth Health Survey (MIYHS)

Language barriers may pose a challenge to refugee and immigrant participation in these surveys. Additional research should be done to determine the feasibility and usefulness of adding this item to each survey.
 - b. Work with Maine CDC's Data, Research and Vital Statistics Office to determine how to improve coding for country of origin on birth and death certificates.
 - c. Investigate feasibility of collecting country of birth in hospital discharge and emergency department data.
5. Take a structural and trauma-informed approach to measuring and addressing immigrant health.

Data collection and analysis efforts related to immigrant and refugee health should be informed by a social determinants of health perspective. Instruments should seek to measure upstream factors related to health such as health care practices, labor laws, housing, and economic and health policies. Immigrant communities need to be included in the planning of research and data collection processes.⁵

¹ U.S. Department of Health and Human Services, Office of Refugee Resettlement:

<http://www.acf.hhs.gov/programs/orr/resource/refugee-arrival-data>

² U.S. Census, American Community Survey, Selected Social Characteristics in the United States, 5-year estimates.

http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_14_5YR_DP02&src=pt

³ Catholic Charities Refugee and Immigrant Services.

<http://www.ccmaine.org/refugee-immigration-services>.

⁴ Kandula NR, Kersey M, Lurie N. 2004. Assuring the health of immigrants: what the leading health

indicators tell us. *Annu. Rev. Public Health* 25:357–76.

⁵ Casteneda, H. et al. Immigration as a social determinant of health. *Annual Review of Public Health*. 2015. 36: 375-92.

⁶ Adhikari, S. B., Yotebieng, K., Acharya, J. N., & Kirsch, J. (2015). *Epidemiology of Mental Health, Suicide and Post-Traumatic Stress Disorder among Bhutanese Refugees in Ohio, 2014*. Ohio Department of Mental Health and Addiction Services, Community Refugee and Immigration Services. Columbus, Ohio, USA.

⁷ Ziegahn, I., Ibrahim, S., Al-ansari, B., Mahmood, M., Tawffeq, R., Mughir, M., Hassan, N., DeBondt, D., Mendez, I., Maynes, E., Aguilar-Gaxiola, S., & Xiong, G. (2013). *The Mental and Physical Health of Recent Iraqi Refugees in Sacramento, California*. UC Davis Clinical and Translational Science Center. Sacramento: CA: UC Davis.

⁸ Hekman K, Weir S, Fussman C, Lyon-Callo S. 2015. Health Risk Behaviors Among Arab Adults Within the State of Michigan: 2013 Arab Behavioral Risk Factor Survey. Lansing, MI: Michigan Department of Health and Human Services, Lifecourse Epidemiology and Genomics Division and Health Disparities Reduction and Minority Health Section.

⁹ Markiewicz, B et al. (2009) *Refugee Health and Healthcare Utilization Report*. University of South Florida.

Hispanic/Latino Population in Maine

Background

About Hispanics in Maine

- With over 54 million Hispanic individuals in the U.S., the Hispanic population is the largest racial or ethnic minority in the country, making up more than 17 percent of the total population.¹
- The U.S. Census predicts that the Hispanic population in the United States will grow to nearly 29 percent of the U.S. population by 2060.¹
- In 2014 Hispanic people made up 1.4 percent of the Maine population (18,592 people), compared to 17 percent in the U.S.²
- Cumberland County has the largest Hispanic population, with 5,297 residents (1.8 percent) identifying as Hispanic.²
- Although Maine's Hispanic population is small, it has grown from less than 1.0 percent of the population in 2006 to 1.4 percent today.²
- There are also small pockets of growing Hispanic communities. For example, a population of Hispanic migrant farmworkers settled in Washington County in the early 1990s, where it has continued to grow in the otherwise ethnically homogenous area.

The “Hispanic Paradox” refers to the fact that while most racial and ethnic minorities in the U.S. have higher rates of adverse health outcomes than the non-Hispanic white population, the Hispanic population appears to be healthier in terms of life expectancy, death, and smoking rates.³ However,

Definitions

Hispanic: person of Cuban, Mexican, Puerto Rican, South or Central American origin or other Spanish culture or origin, *regardless of race*.

Latino: includes those who identify as Hispanic, with the addition of persons from non-Spanish Latin American countries (e.g. Brazil).

Hispanics also have higher rates of obesity, diabetes, and liver disease.³ These rates vary widely depending on nativity and country of origin.³

Compared to the U.S. non-Hispanic population, the U.S. Hispanic population has a lower socioeconomic status, including high rates of poverty and low educational attainment. These contextual factors can influence access to care, availability of healthy foods, neighborhood safety, and other important characteristics of a community that contribute to a person's health. Health disparities may also be related to cultural differences, including food culture, social support, and willingness to accept outside help and guidance.^{4,5,6}

Surveillance Challenges

Many of Maine's major public health data systems collect data on Hispanic ethnicity. These include: death and birth certificate data, hospitalization data and surveys such as the MIYHS and BRFSS. Collection and reporting of Hispanic ethnicity is not consistent across these data sources, making

comparisons challenging. In addition, the relatively small population of Hispanics in Maine and their diverse spread geographically can make it difficult to examine health needs and strengths of this population using traditional data sources. For example, the Pew Charitable Trusts created a profile on Hispanics in Maine, but for almost every indicator, data are unavailable for Hispanics due to the small sample size:

<http://www.pewhispanic.org/states/state/me/>.

Assessing the Health of Hispanics in Maine

State-level Population Data

The following section summarizes available data on the Hispanic population in Maine. Hispanic/Non-Hispanic data are included in most data sets, although the validity of these data depends on whether ethnicity is self-reported, as opposed to recorded by someone else based on a visual assessment.

Federal data systems

American Community Survey (ACS)

The ACS is a rich data source with information on population characteristics such as age, sex, educational attainment, employment, and poverty. Data for most indicators are available by Hispanic ethnicity since the ACS produces estimates using three and five years of data for indicators with small numbers.

CDC Wide-ranging Online Data for Epidemiologic Research (WONDER)

CDC WONDER is an online data source that provides a large variety of health data for public health research and practice. Topics include, but are not limited to, AIDS, births, cancer, injury, mortality, and vaccines. Many datasets are available by

Hispanic ethnicity, although individual topics may vary.

CDC Web-based Injury Statistics Query and Reporting System (WISQARS)

CDC WISQARS is an online database providing information on injury, violent death and cost of injury. Some data are available by Hispanic ethnicity, although individual topics vary.

State Data Systems

Birth and Death Certificates

Maine birth and death certificates collect data on Hispanic ethnicity. For more discussion of what is collected and available, please see Chapter 1.

Maine Hospital Discharge and Emergency Department Data

These data are available by Hispanic ethnicity, although the validity of these data depend on the practices of the hospital (whether ethnicity is self-identified or not).

Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS includes a core demographic question on Hispanic ethnicity. This means that all respondents are asked this question. As a result, it can be used to examine health disparities by ethnicity for anything on the BRFSS survey. However, due to the small number of Hispanics that take the survey in a given year (approximately 90 Mainers per year) several years of data must be combined to get valid estimates. In 2011, the BRFSS survey methodology changed significantly, and it is no longer valid to combine current years of data with data collected before 2011. As a result of those changes and the BRFSS suppression rules, it has been difficult to get large enough samples to report on results by Hispanic ethnicity. As of 2016, BRFSS will have collected five years of Hispanic ethnicity using the

new methodology. This may allow for more analyses by Hispanic ethnicity for some health outcomes and behaviors. State-level data are available at:

http://www.cdc.gov/brfss/data_tools.htm

Pregnancy Risk Assessment Monitoring System (PRAMS)

PRAMS is a survey of new mothers in Maine conducted on an annual basis. The PRAMS survey is linked to the birth certificate file. Data on ethnicity for PRAMS come from the birth certificate. About 2,000 PRAMS surveys are completed each year. Since Hispanics represent about one percent of Maine's population, less than 20 Hispanic new mothers complete the survey each year, making analyses by ethnicity challenging. Generally ten years of PRAMS data need to be combined to get reliable estimates by Hispanic ethnicity.

Maine Integrated Youth Health Survey (MIYHS)

The MIYHS includes a question on Hispanic ethnicity. The large sample size of the MIYHS allows for more reliable estimates of risk and protective factors among Hispanic youth compared to other data systems. However, ethnicity is not asked separately from race, as is recommended by OMB standards. Ethnicity is combined with race, which limits the usefulness of the data. MIYHS reports can be found here:

<https://data.mainepublichealth.gov/miyhs/>

Hispanic Health Assessments

Health Status and Needs Assessment of Latinos in Maine: Final Report

In 2002, DHHS produced a report on the health status and needs of Latinos in Maine. This report used population health data (e.g. birth and death certificates, hospital data, Census data), BRFSS, PRAMS and key informant interviews. The report

can be found here:

<https://www1.maine.gov/dhhs/mecdc/phdata/non-dhp-pdf-doc/health-status-needs-assessment-latinos-2002.pdf>

Mano en Mano

Mano en Mano, a nonprofit organization that serves Milbridge's Hispanic population in Washington County, recently conducted a survey for their clients that included a small number of health questions. The survey was administered in spring 2016 and included 75 households. Data are not yet available.

Strengths and Limitations of Existing Data

Strengths

- Most public health data sources in Maine include data on Hispanic ethnicity. Some sources have enough years of data to create adequate sample sizes for examining health disparities among the Hispanic population.

Limitations/Challenges

- While data are collected on this population through typical means (phone surveys, hospital data, etc.), certain subgroups of the Hispanic population can be difficult to reach due to issues like immigration and language. In 2011, more than 75 percent of the 11.5 million undocumented people estimated to be in the U.S. were from Latin American countries, more than 8.5 million individuals.⁷ Though it is possible to survey immigrants without documentation, they may be less likely to respond due to fear of repercussion, lack of valid mailing address, land line, or cell phone, or language barriers.

- Data collection tools must be available in languages other than English in order to fully capture the population's characteristics.
- In states with smaller Hispanic populations, including Maine, it is especially difficult to capture a large enough sample to be representative.
- Since Hispanic status cannot be visually identified, it can be difficult to correctly code a person's status in certain data sets, including death certificates and hospital discharge data.

Recommendations

1. Work with nonprofits and local health organizations to gather health data on Hispanics through existing surveys (e.g. Mano en Mano's survey).

Maine Migrant Health currently collects data through their mobile health clinics, which is a Federally Qualified Health Center.

Approximately 66 percent of those served in 2014 identified as Hispanic.⁸ Additionally, Mano en Mano is conducting a survey of the local Hispanic population in Milbridge that will include some health questions. By partnering with these organizations, it may be possible to collect health data without creating or administering a new measurement tool.

2. Report ethnicity separately on MIYHS detailed tables.

Currently, MIYHS detailed tables divide race/ethnicity data into seven categories: American Indian or Alaskan Native, Asian, Black or African American, Hispanic, Native Hawaiian or Other Pacific Islander, White, and Multiple Races. This categorization excludes Hispanic students from any of the racial categories. The Maine CDC generally uses racial and ethnic

categories separately, so changing the way the MIYHS reports race and ethnicity would align with current practices.

3. Continue to produce standard demographic tables by ethnicity (separate from race) and monitor the growth of the Hispanic population.

Currently, most demographics tables report ethnicity as Hispanic or Non-Hispanic. It will be important to continue this reporting in order to monitor trends over time.

4. Include Hispanic population in any future minority health reports.

The Hispanic community is a growing population in Maine and it will be important to include them in any reports done on racial/ethnic minorities in the future.

¹ Colby S & Ortman J. Projections of the Size and Composition of the U.S. Populations: 2014 to 2060. Population Estimates and Projections. Current Population Reports, Issued March 2015 pp 25-1143. <https://www.census.gov/content/dam/Census/library/publications/2015/demo/p25-1143.pdf>

² Hispanic or Latino Origin by Race. Universe: Total Population. 2010-2014 American Community Survey 5-Year Estimates. American Factfinder.

³ Centers for Disease Control and Prevention. Vital Signs: Leading Causes of Death, Prevalence of Diseases and Risk Factors, and Use of Health Services Among Hispanics in the United States – 2009-2013. Morbidity and Mortality Weekly Report (MMWR). May 8, 2015 / 64 (17); 469-478.

⁴ Thomas S, Fine M, Ibrahim S. Health Disparities: The Importance of Culture and Health Communication. *American Journal of Public Health*. December 2004. 94 (12): 2050.

⁵ Egede L. Race, Ethnicity, Culture, and Disparities in Health Care. *Journal of General Internal Medicine*. June 2006. 21 (6): 667-669. doi: 10.1111/j.1525-1497.2006.0512.x

⁶ Vega W, Rodriguez M, Gruiskin E. Health Disparities in the Latino Population. *Epidemiologic Reviews* 2009. 31 (1): 99-112. doi: 10.1093/epirev/mxp008

⁷ Hoefler M, Rytina N, Baker B. Estimates of the Unauthorized Immigrant Population Residing in the United States: January 2011. Office of Immigration Statistics. U.S. Department of Homeland Security. https://www.dhs.gov/sites/default/files/publications/ois_ill_pe_2011_0.pdf

⁸ 2014 Health Center Profile. Maine Migrant Programs, Inc. Augusta, Maine. HRSA Health Center Program. <http://bphc.hrsa.gov/uds/datacenter.aspx?q=d&bid=010040&state=M&year=2014>

Migrant and Seasonal Farmworker (MSFW) Population

Background

About Migrant and Seasonal Farmworkers in Maine

- The population of MSFWs is constantly changing, and it is difficult to estimate the number of MSFWs in the U.S. at any given time.
- The U.S. Department of Agriculture (USDA) conducts the Census of Agriculture every five years. It estimated that 436,570 migrant workers were hired on U.S. farms in 2012.¹
- According to the USDA Census, 125 Maine farms reported hiring 2,706 migrant workers in 2012.¹
- Maine Migrant Health, an organization that provides affordable healthcare to MSFWs through mobile clinics, says that the population is highest during the warmer months (June-October) and Christmas tree/wreath season (November-December).²
- Maine Migrant Health provides services to approximately 1,200 individuals each year.²

MSFWs are constantly moving, so accessing health care can be challenging. Children and other nonworking family members also sometimes travel with MSFWs, and they face many of the same issues. Continuity of care can be especially difficult, as an MSFW may have a primary care physician or usual provider in their town of permanent residence, but may only live there part of the year.³ Language barriers and cultural differences may also impede access to care, as many MSFWs are not fluent in English or U.S. citizens.³

Definitions

Migrant and Seasonal Farmworker (MSFW): an individual who is required to be absent from a permanent place of residence for the purpose of seeking employment in agricultural work. Some MSFWs may have a permanent home that they leave seasonally, and some may not have one at all.

Additionally, MSFWs often live below the poverty line, making it even more difficult to access care. Health insurance can also be a barrier, and while the number of uninsured Americans has decreased with the Affordable Care Act, many MSFWs cannot afford copays or deductibles even if they do have insurance.³

The physical nature of farm labor puts MSFWs at risk for injury from vehicle rollovers, falls, and hazardous equipment, along with exposure to pesticides, unsanitary conditions, heat illness, and other occupational hazards.^{3,4} Pesticides can be hazardous to both MSFWs and their families, leading to both short and long-term illness.⁴ Exposure can occur during pesticide application, harvest, as well as through the ground water (e.g. bathing, drinking, washing hands, etc.), or the air from nearby fields.⁴



Surveillance Challenges

Data on this population are extremely difficult to capture due to the transient nature of migrant workers and limited access to health care. Additionally, MSFWs are not Maine residents and are not captured by standard surveillance tools (e.g. BRFSS, MIYHS, Census, etc.), as they require a Maine phone number and/or address. Hospitals and medical practices in Maine do not record their patients' occupations, so unless MSFWs are treated at a Maine Migrant Health mobile clinic, there is no way to access health data on this population.

Assessing the Health of MSFWs in Maine

State-level Population Data

The following is a summary of available data on MSFWs in Maine. Few datasets include occupation, and the transient nature of this population excludes them from many that do, such as BRFSS.

Federal data systems

United States Department of Agriculture (USDA) Census of Agriculture

The USDA Census of Agriculture is administered every five years to all U.S. farmers and ranchers, collecting vital information on American agriculture. Topics include farm characteristics, expenses, and hired workers (including migrant and seasonal). This

data source is the only national information available on the number of migrant workers working in the U.S. It does not provide any additional characteristics. The most recent USDA Census of Agriculture was conducted in 2012. State-level reports are available at:

https://www.agcensus.usda.gov/Publications/2012/Full_Report/Census_by_State/Maine/

The National Agricultural Workers Survey (NAWS)

NAWS is a survey of U.S. crop workers that collects demographic, employment, and health data using in-person interviews. Data are collected continuously; 56,976 interviews were conducted between 1989 and 2012. Although data are available by region, they are not available by state. Region 1, which includes Maine, also includes North Carolina, Virginia, Kentucky, Tennessee, West Virginia, Connecticut, Massachusetts, New Hampshire, New York, Rhode Island, Vermont, Delaware, Maryland, New Jersey, and Pennsylvania. Public data files are available at:

<https://www.doleta.gov/agworker/naws.cfm#d-files>

State Data Systems

Maine Migrant Health

The only state-level health data available on this population are collected by Maine Migrant Health, which collects information on those who are treated at one of their mobile health clinics. There are no data on MSFWs that do not need medical treatment, cannot access it, or choose not to seek it (at all or from the mobile clinics). Maine Migrant Health mobile clinics are Federally Qualified Health Centers, and are required to report their data annually. Data collected include age, race, ethnicity, insurance status, services provided, chronic disease, and cost. Data tables are publicly available here:

<http://bphc.hrsa.gov/uds/datacenter.aspx?q=d&bid=010040&state=ME&year=2014>

MSFW Assessments

Maine Migrant and Seasonal Farm Worker Demographic Survey

In 2015, a Maine State Government Summer Internship Program intern conducted a 44 question survey with 52 MSFWs in Maine. The survey covered family composition, living and working, work prior to Maine, work in Maine, and post-Maine plans. Surveys were conducted using in-person interviews in both English and Spanish. The results of this survey are available at:

http://www.maine.gov/labor/labor_laws/migrantworker/summary.html

National Center for Farmworker Health (NCFH)

The NCFH has a variety of fact sheets on the health of migrant farmworkers in the U.S., including demographic, general health, and disease-specific sheets. The majority of their data come from NAWS, although they include some state-specific data sources as well. Fact sheets are available at:

<http://www.ncfh.org/fact-sheets--research.html>

Strengths and Limitations of Existing Data

Strengths

- The USDA Census of Agriculture requires that farms report the number of migrant workers hired during the Census year, and these numbers can be obtained at the state-level.
- Maine Migrant Health serves approximately 1,200 patients per year, which is nearly half (44 percent) of the total number of migrant workers reported by farm owners in 2012.^{1,5} Although the data are only available for those who visited the mobile clinics, they provide information on health status and demographics on a large portion of the population.

Limitations/Challenges

- Maine Migrant Health's dataset does not represent the entire MSFW population in Maine. It is limited to those who need and seek medical care in the mobile clinics, and cannot be considered a representative sample.
- The USDA Census of Agriculture is only conducted every five years, making it difficult to estimate population fluctuation. Additionally, farmers could potentially refrain from reporting hired migrant and seasonal workers if they do not hire them legally, so this estimate may not be accurate.
- NAWS data are only available at the national and regional level; there are no state-level estimates. The number of interviews conducted in Region 1 is relatively small (approximately 200 per year) throughout all 16 states in the region, so the number of interviews conducted in Maine is most likely very low or possibly zero, depending on the year.

Recommendations

1. **Partner with Maine Migrant Health – offer analysis support using data currently collected on mobile health clinics.**

Maine Migrant Health currently collects data through their mobile health clinics, which is a Federally Qualified Health Center. Maine Migrant Health may be interested in having these data analyzed for their own reports or grants.

2. **Partner with Maine Migrant Health – create and administer a health survey (in-person interviews and/or focus groups).**

Although migrant workers were surveyed in summer 2015, the survey did not cover health

topics. Due to Maine’s relatively small MSFW population, it may be feasible to collect data from a substantial portion of the population.

This project may include in-person interviews as well as focus groups in order to best understand the health status and needs of the community.

¹ Table 7. Hired Farm Labor – Workers and Payroll: 2012. Census of Agriculture. Accessed 6-29-16 from: https://www.agcensus.usda.gov/Publications/2012/Full_Report/Volume_1,_Chapter_2_US_State_Level/st99_2_007_007.pdf.

² Our Services. Maine Migrant Health Program. Accessed 6-29-16 from: <http://www.mainemigrant.org/about/our-services/>.

³ Migrant Health Issues. Maine Migrant Health Program. Accessed 6-29-16 from: <http://www.migrantclinician.org/issues/migrant-info/health-problems.html>.

⁴ Hazards and Controls. US Department of Labor. Accessed 6-29-16 from: https://www.osha.gov/dsg/topics/agriculturaloperations/hazards_controls.html

⁵ 2014 Health Center Profile. Maine Migrant Programs, Inc. Augusta, Maine. HRSA Health Center Program. Accessed 6—29-16 from: <http://bphc.hrsa.gov/uds/datacenter.aspx?q=d&bid=010040&state=ME&year=2014>

Gay, Lesbian, Bisexual, and Transgender Mainers

Background

About Gay, Lesbian, Bisexual, and Transgender (GLBT) Mainers

- Between 4.1 and 6.8 percent of men and 4.1 and 4.5 percent of women identify as gay or bisexual. When asked about sexual behavior, between 6.2 and 10.0 percent of men report having same sex partners, and between 10.0 and 11.5 percent of women report having same sex partners.¹
- There are no reliable population estimates for transgender people. Currently no national or Maine surveys allow respondents to identify as transgender.
- GLB youth in Maine are more likely to engage in suicide and suicidal behavior and to experience harassment and violence compared to heterosexual peers.² Maine adults who identify as gay, lesbian or bisexual experience disparities in the areas of health care access, health promotion, substance use, preventive care practices and mental health when compared to the heterosexual population.

GLBT populations experience health disparities as a result of their experiences, behaviors, and living environments. For example, GLBT people may experience worse mental health due to social inequities such as stigma and discrimination. While some of these disparities are well understood, many more questions remain unanswered. The lack of data is a serious challenge to understanding the needs of this population.

Definitions

Bisexual- A person who is sexually attracted to people of their own gender and another gender.

Cisgender- People who identify with the gender they were assigned at birth.

Gay/Lesbian- A person who is sexually attracted to members of the same sex. Although gay can be used for any sex (e.g. gay man, gay woman, gay person), “lesbian” is sometimes the preferred term for women who are attracted to women.

Gender Identity- The sense of being male, female, transgender, genderqueer, etc.

Heterosexual- A person who is sexually attracted to members of a sex different than their own. Also called “straight.”

Sexual Orientation- The type of sexual, romantic, and/or physical attraction someone feels toward others. Often labeled based on the gender identity/expression of the person and who they are attracted to. Common labels: lesbian, gay, bisexual, pansexual, etc.

Transgender- An umbrella term referring to people who do not identify with their assigned gender at birth or the binary gender system.

Source: <https://internationalspectrum.umich.edu/life/definitions>

Surveillance Challenges

Several factors have made it difficult to measure the size or health of the GLBT population with accuracy:

- **Small population size.** Even in large national population based surveys, the total number of people identifying as gay, lesbian and bisexual is limited. Small samples create statistical uncertainty. Often, several years of data must be combined in order to examine disparities by GLB groups.
- **Identities are difficult to measure.** The survey questions used to determine GLBT status are still being developed and tested. Some surveys ask respondents about their sexual or gender identity, others ask about sexual desires, others sexual behaviors, sometimes over a lifetime or over shorter periods of time. Because the methods used to determine GLBT status are not yet consistent, comparisons across datasets or time are difficult to make.

As part of the Affordable Care Act (ACA), the Department of Health and Human Services will be developing recommendations for collecting sexual orientation and gender identity data. Once established, the law will require these data collection standards be used, to the extent practicable, in all national population health surveys.³ The sexual orientation measure testing began in 2013, and results from that test are promising. However, it is not clear when measure testing will be completed or when the gender identity question testing will begin.

- **Stigma and discrimination** associated with GLBT status may discourage people from answering questions about their sexual behavior or gender identity.⁴ Distrust of researchers could also be a barrier. There have been cases in which data were used against the GLBT community (for example, in the AIDS epidemic), and some are wary of giving information to organizations that do not have a history of serving their community.⁵

Being healthy is harder for some.



GLBT people have:

- Less health care access
- More substance use
- Less preventive care
- Worse mental health outcomes
- Higher rates of youth suicide

Assessing the Health of GLBT Mainers

State-level Population Data

There are relatively little population-based health data on the GLBT population available at the national or state level,⁶ and existing data have not been the subject of many published studies.⁷ Smaller convenience sample surveys of GLBT populations have been done in other states; one study of older GLBs has been done in Maine.⁸

Gay, Lesbian and Bisexual Data

Maine's Behavioral Risk Factor Surveillance System (BRFSS)

BRFSS has included sexual orientation as a demographic question since 2004. This annual survey provides Maine with a wide variety of state-level health data on adult gay, lesbian and bisexual populations.

Maine's Integrated Youth Health Survey (MIYHS)

MIYHS has included questions about sexual contact since 1995 and sexual orientation questions since 2007. This biennial survey provides Maine with health risk data on its gay, lesbian and bisexual youth.

Sexual orientation is not currently collected on death records, hospitalization records, emergency department records, or cancer registry records. Clinics that receive federal funding for HIV and STD testing do include questions about sexual behavior, but sexual orientation is generally not included in infectious disease databases.

Transgender Data

In 2015 an analysis of social security administrative data estimated the prevalence of transgender people using name change and gender change records.⁹ It proposed that there were 4.8- 6.0 transgender people per 100,000 in Maine (a total of 62-78 people). This number likely represents a gross underestimation of the transgender population and illustrates the need for better methods of estimation.¹⁰ Not all transgender people change their name, and not everyone who changes their name can legally register the change with the Social Security Administration due to legal and social barriers.

There are currently no state or national surveys that produce reliable prevalence or health data on transgender people. Several states have begun collecting gender identity data, but the data are not yet publicly available. Currently no population-based surveys collect data on transgender people in Maine. However, a question on gender identity will be included on the 2017 MIYHS and 2017 BRFSS as a result of this health equity project.

There are two new studies which may provide some national data in the future:

The U.S. Transgender Population Health Survey, conducted in 2015-2016, will be the first national probability sample of transgender individuals in the U.S. It will be part of a larger Gallup survey of 350,000 U.S. adults, with an estimated 300-500 transgender-identified individuals participating.¹¹ While the study may produce useful national data

Data Availability in Maine		Gay, Lesbian, Bisexual Population	Transgender Population
Population-Based			
	Youth Data (MIYHS)	✓	✗
	Adult Data (BRFSS)	✓	✗
Other Data			
	Death Records	✗	✗
	Small Convenience Samples	✓ Elders only	✗
	Hospitalization and ED Records	✗	✗
	Cancer Database	✗	✗
	Infectious Disease	✓ HIV only	✓ HIV & STD only

on demographics, health outcomes, well-being, and health care needs of transgender people, this sample will not be large enough to produce meaningful state-level data.

The U.S. Trans Survey, a new convenience sample survey of transgender people, was conducted in 2015 but results have not yet been released. That survey will provide more comprehensive demographic and health data and will likely have a larger sample size (in the thousands). This survey is scheduled to be conducted every five years.¹²

Maine GLBT Health Reports and Needs Assessments

There are no reports on transgender people available at the national or state level. The following Maine GLB reports and data tables are available:

Gays, Lesbians and Bisexuals in Maine, 2011

In 2011 the Maine Center for Disease Control and Prevention (Maine CDC) published a report on the

health of gay, lesbian, and bisexual adults and youth in Maine using BRFSS and MIYHS data.

<http://www.maine.gov/dhhs/mecdc/infectious-disease/hiv-std/documents/CDC-SummiReport.pdf>

Maine State Health Assessment (SHA)

The Maine CDC also produces State Health Assessment indicator tables describing the prevalence of risk behaviors, chronic diseases, and health outcomes. These are updated every few years. Many of the tables include sexual orientation (gay/lesbian, bisexual, and other) breakdowns in the demographic sections.

<http://www.maine.gov/dhhs/mecdc/phdata/sha/index.shtml>

Factsheets based on MIYHS or BRFSS

Data focused on GLB populations, produced by divisions within Maine's Department of Health and Human Services:

- **Substance abuse and mental health:**
http://www.maine.gov/dhhs/samhs/osa/prevention/Conferences/Provider-Day/LGBTQ_Youth-SA_MH_Factsheet.pdf
- **Tobacco use**
http://www.tobaccofreemaine.org/explore_facts/documents/25-809%20LGBTFacts.pdf

Convenience sample surveys

- An AARP Task Group conducted a convenience sample survey of older (age 55-69) GLB Mainers in 2013. Four hundred, sixty-three adults answered a variety of survey questions on health care, personal safety, social services and social well-being.
http://www.maine4a.org/image_upload/AARP-SAGE-GLBT-Report-2013-pdf.pdf
- A school climate survey was conducted by the Gay Lesbian and Straight Education Network (GLSEN) in 2013 which surveyed 103 Maine

youth.

<http://www.glsen.org/sites/default/files/GLSEN%202013%20Maine%20State%20Snapshot.pdf>

- A non-profit called Maine Health Equity Alliance is currently conducting **The LGBTQ+ Health & Community Survey** as part of a comprehensive assessment of LGBTQ+ community health. This survey will collect information about demographics, family and community, health care and access to care, health behaviors, health status, mental health and social issues. The survey will close in September 2016. Their goal is to collect 385 responses from a group of LGBTQ Mainers who are geographically and demographically representative of Maine's population. As with many smaller independent surveys, is unclear when or if the data will be made public or shared with public health agencies.

Strengths and Limitations of Existing Data

Strengths

- BRFSS and MIYHS data allow for ongoing tracking GLB adults and adolescents by key demographics and health indicators. Trend data are available for BRFSS after 2011 and for MIYHS after 2007.
- Existing population-based surveys have the capacity to collect data on transgender adults and adolescents.
- Convenience samples have identified some of the challenges faced by GLBT subpopulations.
- Current GLB reports, standard tables and factsheets are publicly available.

Limitations/Challenges

- While population-based data for GLB adults and adolescents are available in Maine, county or district level analyses and subpopulation analyses are still very difficult given the small number of respondents to the population-based surveys.
- No transgender data are currently available. There are plans to collect data on adolescent gender identity on the Maine MIYHS and BRFSS surveys in the future. Even if collected, it could take several years before sample sizes are big enough to analyze with any certainty.
- Many important demographic surveys and forms do not collect GLBT status (U.S. Census, death certificates, hospitalizations). As a result, little or nothing is known about GLB disparities in housing, employment, poverty, mortality, or injury.
- GLBT community members are not often consulted when developing survey instruments. There may be pressing health concerns in the community that surveys do not capture.

Recommendations:

1. Add gender identity question to the BRFSS.

Secure funding to make this a standard demographic question.

2. Develop infrastructure for ongoing reporting of the health of transgender youth in Maine.

Once gender identity data are available from MIYHS (and BRFSS), it will be important to publish prevalence and basic demographic data, as this would be the first of its kind in the state. Basic health data may also be available, though we expect the numbers to be small and statistical certainty to be low.

3. Add questions about sexual orientation and gender identity to forms for hospital discharge, ED visits, cancer, and death records.

The Maine CDC does not currently have any data on the prevalence of GLBT injury, disease, or premature death. While these data collection processes may be resistant to change, it is critical that these fields be added in order to understand disparities.

4. Conduct a convenience sample survey of 1,000+ GLBT adults in Maine in partnership with other nongovernmental organizations like EqualityMaine and MaineTransNet.

In order to understand the health of the GLBT population, it is helpful to ask questions specific to that population. Doing so with a convenience sample is much more cost effective than a probability sample. A survey could help answer questions like:

- What barriers to health care do GLBT people experience? To mental health care? Are barriers more prevalent in certain geographic areas?
- Do GLBT people experience unique adverse childhood experiences? Who is most likely to experience them?
- What level of discrimination or support do GLBT people perceive in their communities?
- What other health problems are unique to the GLBT community?

5. Update the *Gays, Lesbians and Bisexuals in Maine* report from 2011.

This report should be updated at least once every five years. When/if adult transgender data become available, it should be included in this report as well.

¹ Conron, K.J., Mimiaga, M.J., and Landers, S.J. A Population-Based Study of Sexual Orientation Identity and Gender Differences in Adult Health. *American Journal of Public Health*, October 2010, Vol 100, No. 10.

² Maine Center for Disease Control and Prevention. 2011. Gays, Lesbians, and Bisexuals in Maine: A Behavioral and Health Profile 2011.

³ U.S. Department of Health and Human Services. HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. 10/31/2011.

<https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status>.

⁴ Institute of Medicine's Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. The National Academies Press. http://www.nap.edu/catalog.php?record_id=13128.

⁵ Personal conversation with Jayson Hunt from the Maine Viral Hepatitis and HIV Program. 2016.

⁶ Gay and Lesbian Medical Association and LGBT health experts. 2001. *Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health*. San Francisco, CA: Gay and Lesbian Medical Association.

⁷ Conron, K.J., Mimiaga, M.J., and Landers, S.J. A Population-Based Study of Sexual Orientation Identity and Gender Differences in Adult Health. *American Journal of Public Health*, October 2010, Vol 100, No. 10.

⁸ Gay, Lesbian, Bisexual and Transgender (GLBT) Aging in Maine Community Needs Assessment . March 20013. Accessed 2-8-16 from: http://www.maine4a.org/image_upload/AARP-SAGE-GLBT-Report-2013-pdf.pdf

⁹ Harris, Benjamin. Likely Transgender Individuals in U.S. Federal Administrative Records and the 2010 Census. U. S. Census Bureau Center for Administrative Records Research and Applications. Washington, D.C. 20233. Accessed 8-1-16 from: http://www.census.gov/srd/carra/15_03_Likely_Transgender_Individuals_in_ARs_and_2010Census.pdf.

¹⁰ Anecdotally, it is estimated that at least that many transgender people reside in the Portland, Maine area alone.

¹¹ The Williams Institute. TransPop: U.S. Transgender Population Health Survey. Accessed 2-8-16 at:

<http://williamsinstitute.law.ucla.edu/research/transgender-issues/transpop-u-s-transgender-population-health-survey/>

¹² 2015 U.S. Trans Survey . About the Survey. Accessed 2-8-15 at: <http://www.ustranssurvey.org/study/>

Persons with Disabilities in Maine

Background

About Persons with Disabilities in Maine

In 2015 the U.S. Centers for Disease Control and Prevention (CDC) published the results of their analysis of the 2013 Behavioral Risk Factor Surveillance Survey (BRFSS) questions on specific disability types: vision, cognition, mobility, self-care, and independent living. This was the first year these questions were included on the survey.¹ According to this report:

- Overall Maine's rate for any disability was 20.2 percent compared to 22.2 percent for the U.S.¹
- Based on disability type, Maine ranked lower than the U.S. in all areas but cognition (11.2 percent compared to 10.6 percent).¹
- However, according to a 2014 Disability Statistics Report, Maine was one of four states with a high concentration of persons with disabilities.²

In the past two decades some important policies have been created to address the health of persons with disabilities. These include:³

- The Americans with Disabilities Act of 1990
- Healthy People (2000 and 2010) focus on eliminating disparities among persons with and without disabilities
- The Affordable Care Act provision for improving data collection

Definitions

Persons with disabilities are individuals with hearing, vision, mobility, cognition limitations or with emotional or behavioral disorders that limit participating in some activities of daily living without accommodations or assistance.

The World Health Organization (WHO) defines disability as having three dimensions: body function impairment such as loss of vision; activity limitation such as difficulty walking or hearing; and limited participation in normal daily activities such as meal preparation.¹ A disability may occur during a person's lifetime or may be present from birth.

Even with these efforts, people with disabilities continue to experience health disparities.

People with disabilities have fewer years of education, lower rates of employment, higher rates of poverty, and are more likely to experience chronic conditions such as diabetes, physical inactivity, heart disease, and higher rates of smoking. They are more likely to report fair or poor health and to report cost barriers preventing them from accessing a primary care provider.³

Some health disparities of persons with disabilities originated from a long history of institutionalization of children and adults with significant disabilities. This history of discrimination and institutionalization has contributed to the differences in health outcomes.³

Today, barriers to health care utilization have led to higher rates of obesity, diabetes and cardiovascular

disease observed in non-institutionalized persons with disabilities.³ According to the U.S. Department of Health and Human Services' Advisory Committee on Minority Health,

“People with disabilities frequently lack health insurance or coverage for necessary services such as specialty care, long-term care, care coordination, prescription medications, durable medical equipment, and assistive technologies. Persons with disabilities often receive care from multiple providers without adequate coordination of services as well.”⁴

Barriers to health care for persons with disabilities include:

- Health care provider stereotypes
- Lack of provider training
- Lack of specialized services or equipment for persons with disabilities such as sign language interpreters, accessible facilities, and accessible information

In addition, persons with disabilities are more likely to experience inequitable treatment and are often excluded from studies and research on health.⁴

Surveillance Challenges

Persons with disabilities are a diverse group of individuals with a range of needs that can affect their health and well-being. This diversity can pose a challenge to identifying them in traditional public health data sources. However, it is vital that we continue to highlight health disparities faced by this population so that they can get the services and assistance they need within their homes, schools, communities, and medical systems.

Assessing the Health of Persons with Disabilities in Maine

State-level Population Data

Federal data systems

American Community Survey (ACS)

In 1999 the U.S. Census Bureau began including disability questions on the annual ACS. These were modified in 2003 and in 2008 the standard disability questions set forth in Section 4302 of the Affordable Care Act (hearing, vision, cognitive, ambulatory, self-care, and independent living difficulty) were included in the survey. For more detail on the types of disabilities assessed in the ACS, see the Children with Special Health Care Section.

<http://aspe.hhs.gov/dataacnl/standards/aca/4302/index.pdf>

Current Population Survey (CPS)

In June 2008, the CPS added the ACS disability questions to measure employment status of persons with disabilities. The CPS uses a slightly modified version of the ACS questions, as survey respondents answer the questions for everyone in the household 16 years and older.

<http://www.bls.gov/opub/mlr/2014/article/the-development-of-questions-on-disability-for-the-current-population-survey-6.htm>

State Data Systems

Behavioral Risk Factor Surveillance System (BRFSS)

Beginning in 2001, two questions to determine disability were added to the BRFSS. In 2013 the survey began including the following questions on disability type (vision, cognition, mobility, self-care, and independent living; Table 2). Starting in 2016, BRFSS includes a question on deafness or serious

difficulty hearing. State-level data are available at: http://www.cdc.gov/brfss/data_tools.htm

The federal CDC has a Disability and Health Data System that allows anyone to query BRFSS data by disability. This system includes state profiles, maps and economic analyses. <http://dhds.cdc.gov/>

Table 2. BRFSS Questions related to health problems or impairments
Are you limited in any way in any activities because of physical, mental or emotional problems?
Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?
Are you blind or do you have serious difficulty seeing, even when wearing glasses?
Because of a physical, mental or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
Do you have serious difficulty walking or climbing stairs?
Do you have difficulty dressing or bathing?
Because of a physical, mental or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping?
Some people who are deaf or have serious difficulty hearing may or may not use equipment to communicate by phone. Are you deaf or do you have serious difficulty hearing? (added in 2016)

Other Disabilities Assessments

Maine Developmental Disabilities Council

While no reports on Mainers with disabilities have been conducted, annually the Maine Developmental Disabilities Council reports on autism spectrum disorder (ASD) in response to a

legislative directive, The Autism Act of 1984, 34-B M.R.S.A. §6001. The report is available at: <http://www.maineddc.org/uploads/Autism%20Act%20Report%202015%206-152%20sent%20to%20the%20legislature%20wo%20letter.pdf>

In 2010, the Maine Developmental Disabilities Council identified dementia as an emerging concern and released a report in 2015, *Supports & Services for Older Adults with Developmental Disabilities and Dementia in Maine*. <http://www.maineddc.org/resources-publications/>

This report:

- Outlines current service needs of individuals with developmental disabilities and dementia
- Reveals gaps between those service needs and current and future service availability
- Makes recommendations to address the current and future service needs

Maine’s Office of Aging and Disability Services Chartbook

Maine’s Office of Aging and Disability Services recently released a chartbook on Maine adults who use long-term services and supports in nursing facilities, residential, home-based, and community-based care. The populations include: older adults, adults with physical disabilities, adults with intellectual disabilities/autism spectrum disorder or other related conditions, and adults with acquired brain injury. The full report is available at: <http://www.maine.gov/dhhs/oads/trainings-resources/reports.html>

Strengths and Limitations of Existing Data

Strengths

- The ACS and CPS are conducted annually, and have a methodology that is consistent from year to year and across states. This allows the data to be used in making comparisons over time.
- The BRFSS provides population-level data on persons with disabilities and are available online.

Limitations/Challenges

- While the BRFSS includes questions on disability in the annual survey, it is only administered to those individuals 18 years and older and does not include those who may be institutionalized or living in group homes, a population which may be more likely to have a disability. BRFSS data is also self-reported therefore depends on respondent recall.
- The ACS, conducted annually by the U.S. Census Bureau, is also a self-reported survey and may be subject to recall bias.
- There were no objectives related to disabilities included in Healthy Maine 2020; although persons with disabilities were included in the Health Equity chapter as a subset population experiencing health disparities.
- There is little or no data on the deaf or hard of hearing in Maine. Those working with the population can only estimate the number of deaf or hard of hearing in the state by extrapolating from other sources such as Census data.

- Due to relatively small sample sizes, Maine does not report on persons with disabilities at the local or even county level.

Recommendations

1. **Improve the quality of disability data through cross-agency collaboration on data collection/sharing to include standardized questions on disability. Gain a better understanding of the total number of persons with disabilities, disability type, and service needs of the population.**

Conversations with those working with persons with disabilities revealed a need for a primary database where information on persons with disabilities can be stored. Currently there are scattered sources and no standardization of questions across surveys. Collaborations could save state resources, both human and financial.

2. **Create report or data brief summarizing the health of adults with disabilities using BRFSS data.**

Starting in 2013, BRFSS included disability questions, but these questions have not been analyzed to examine the prevalence of disabilities and the health status and risk of individuals with disabilities.

3. **Develop a plan to assess the health needs of individuals with disabilities residing in group homes or institutions using traditional public health surveillance systems (e.g., BRFSS) or conducting a separate assessment.**

Frequently those who need and use services are not invited to participate in surveys and assessments as they reside in facilities such as group homes or nursing care facilities that are not traditionally included. It would be helpful to

determine whether the state can play a role in developing an assessment of these individuals.

The state BRFSS coordinator could reach out to the U.S. CDC to determine the feasibility and cost of including those individuals over the age of 18 that are institutionalized or living in a group home. For the deaf and hard of hearing, make accommodations for them to participate in the survey via video phone application. The call can be routed through a sign language interpreter and the person being interviewed can sign to the interpreter online.

4. Partner with Disability Rights Maine (DRM) to work with all public housing, residential care, and nursing homes to include a check box on intake forms that asks if the person is deaf, has serious difficulty hearing or uses sign language to communicate.

Currently, in those instances where a question is asked, deaf and hard of hearing are combined. Collecting this data will provide information on the exact number of deaf people who sign and may need a sign language interpreter when discussing their daily routine needs or when visiting a health care provider.

¹ Courtney-Long, E., Carroll, D., Zhang, Q.C., et al. Prevalence of Disability and Disability Type Among Adults – United States, 2013 (July, 2015). *MMWR Weekly*. CDC. 64(29); 777-783. Accessed 6-29-16 from: <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6429a2.htm>.

² Disability Statistics Annual Report (2014). Rehabilitation Research and Training Center on Disability Statistics and Demographics. Accessed 6-29-16 from: <http://www.disabilitycompendium.org/docs/default-source/2014-compendium/annual-report.pdf>.

³ Krahn, G.L., Walker, D.K., Correa-De-Araujo, R. Persons with Disabilities as an Unrecognized Health Disparity Population (2015). *American Journal of Public Health*. Supplement 2, Vol 105, No S2; 198-206. Accessed 6-29-16 from: <http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2014.302182>.

⁴ Pamies, R. J., Bonta, D. M., Martinez, E. L., et al. Assuring Health Equity for Minority Persons with Disabilities: A Statement of Principles and Recommendations (July, 2011). US Department of Health and Human Services Office of Minority Health. Accessed 6-29-16 from: <http://minorityhealth.hhs.gov/assets/pdf/checked/1/acmhhealthdisparitiesreport.pdf>.

Children and Youth with Special Health Needs in Maine

Background

About Children with Special Health Needs in Maine

- According to the National Survey of Children's Health (2011-2012), about 1 in every 4 children (23.6 percent) have a special health care need in Maine - over 60,000 children.¹
 - Six percent have a functional limitation.
 - 17.1 percent require a prescription medication for a chronic medical, behavioral or other health condition.
 - 5.5 percent require specialized therapy
 - 12.5 percent require elevated use of medical care, mental health, or educational services.
 - 10 percent have ongoing emotional, developmental or behavioral conditions that require treatment or counseling.
- The types of conditions that require special health care among children are diverse and can include asthma, Attention Deficit/Hyperactivity Disorder (ADHD), mental health conditions such as depression and anxiety, learning disorders, autism and Down syndrome.¹
- Maine has a significantly higher number of children with special health care needs compared to the U.S. (23.6 percent vs. 19.8 percent, respectively).¹

It is critical to monitor the health of children with special health needs. These children are more likely to be obese and less likely to be physically active. They are less likely to be engaged in school and more likely to miss school days. Their parents are more stressed and less likely to be in good health.

Definitions

Children with special health care needs (CSHCN): Children and youth who have/are at increased risk for, a chronic, physical, developmental, behavioral or emotional condition. They require health and related services beyond that required by children generally.

CSHCN encompasses a broad range of conditions and recognizes that all children with a special health need require a well-functioning, community-based system of care.

Identifying Children with Special Health Care Needs:

In surveys such as the National Survey of Children's Health, a five-item screener is used to identify children with special health care needs. This screener has three main definitional domains:

- 1) Dependency on prescription medications
- 2) Service use above that considered usual/routine
- 3) Functional limitations

For each of these domains, a child is considered to have a special health care need if the prescription, service use or functional limitation is due to a medical, behavioral or other health condition and this condition has lasted or is expected to last more than 12 months.

They are more likely to have inadequate health insurance and less likely to have a medical home.² All children benefit from having a medical home, which is defined as comprehensive medical care that is accessible, family-centered, coordinated and culturally effective.³ Having a medical home is especially critical for children with special health needs who often need to see multiple providers.³

Surveillance Challenges

Children with special health care needs are a diverse group of children with a range of needs that can affect their health and well-being. This diversity can pose a challenge to identifying them in traditional public health data sources. However, it is vital that we continue to highlight health disparities faced by this population so that they can get the services and assistance they need within their homes, schools, communities, and medical systems.

Assessing the Health of CSHCN in Maine

State-level Population Data

Data on children with special health care needs are available from several data sources. They are summarized below and in Table 5.

Federal data systems

American Community Survey (ACS)

The ACS is an annual survey conducted by the U.S. Census Bureau that collects data on a wide range of topics, including disability. Data are available at the state-level and multiple years can be combined to get county-level estimates. Several items are included in the ACS to assess concepts related to physical and mental impairment.⁴ The concepts assessed are defined in Table 3.

It is possible to get data on these individual concepts as well as disability status overall. Data are available on children under age five and those ages

5-17 years. It is also possible to find data on disability status by race, health insurance, and poverty.

Table 3. American Community Survey Disability Concepts

Disability	Having vision, hearing, cognitive, ambulatory, self-care, or independent living difficulty
Vision difficulty	Blindness or serious difficulty seeing even when wearing glasses
Hearing difficulty	Deafness or serious difficulty hearing
Cognitive difficulty	Serious difficulty concentrating, remembering, or making decisions
Ambulatory difficulty	Serious difficulty walking or climbing stairs
Self-care difficulty	Difficulty bathing or dressing
Independent living difficulty	Having difficulty going outside the home to shop or visit a doctor's office (status determined for the population 15 years and over)

National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN)

The NSCH and NS-CSHCN are conducted by the U.S. Department of Health and Human Services' Health Resources and Services Administration (HRSA). State-level data are available for most of the survey items.

The NSCH samples non-institutionalized children aged 0-17 years of age. The survey is conducted over the phone with parents/guardians and covers

several topics including: physical and emotional health, medical home, family interactions, parental health, school experiences and safe neighborhoods. Data can be analyzed to compare the health and experiences of CSHCN and non-CSHCN and are available online:

<http://childhealthdata.org/learn/NSCH>.

The NS-CSHCN includes non-institutionalized children aged 0-17 with special health care needs. Similar to the NSCH, the survey is conducted with parents over the phone. The survey is focused on the health of children with special health care needs and includes information on medical home, health insurance adequacy, access to services, care coordination, transition, and shared decision-making. Data are available online:

<http://childhealthdata.org/learn/NS-CSHCN>.

The NSCH and NS-CSHCN are being combined by HRSA into a new National Survey of Children's Health. The new survey is being collected during 2016 with data available in 2017. The survey will be conducted annually and data will be available at the state-level.

State Data Systems

Maine Integrated Youth Health Survey (MIYHS)

The MIYHS is a biennial, representative survey of Maine students in kindergarten, third, and fifth through twelfth grades. The MIYHS was first conducted in 2009 and the most recent year data are available is 2015. The MIYHS has four survey modules: Kindergarten/Third grade; Fifth/Sixth Grade; Middle School; and High School. Questions related to special health needs differ across the survey versions (Table 4).

Table 4. Maine Integrated Youth Health Survey Questions on Special Health Needs by Module	
MIYHS Module	Items related to special health care needs
K/3 and 5/6	<p>Asthma:</p> <ul style="list-style-type: none"> • Has a doctor or nurse ever told you that your child has asthma? • Does your child still have asthma? • Additional items related to symptom severity <p>Diabetes:</p> <ul style="list-style-type: none"> • Has a doctor or nurse ever told you that your child has diabetes?
K/3 only	<p>Autism Spectrum Disorder:</p> <ul style="list-style-type: none"> • Does your child currently have autism, PDD-NOS, Asperger's Disorder, or atypical autism? • Does your child receive special education services for autism, PDD-NOS, Asperger's Disorder, or atypical autism at school?
Middle School and High School	<p>Asthma:</p> <ul style="list-style-type: none"> • Has a doctor or nurse ever told you that your child has asthma? • Does your child still have asthma? • During the past 12 months, about how many days did you miss school because of your asthma? <p>Diabetes:</p> <ul style="list-style-type: none"> • Has a doctor or nurse ever told you that your child has diabetes? <p>Physical Disability</p> <ul style="list-style-type: none"> • Do you have any physical disabilities or long-term health problems lasting or expected to last 6 months or more? • Do you have any long-term emotional or behavioral problems lasting or expected to last 6 months or more? • Would other people consider you to have a disability or long-term health problem, including physical health or emotional or learning problems? • Are you limited in any activities because of a disability or long-term health problem including physical health, emotional or learning problems expected to last 6 months or more?

Data on disability status are only available on one of four versions of the Middle School and High School Surveys. This allows for state-level prevalence to be estimated, but county-level data are not available and these items cannot be examined in relation to other items on different versions of the survey.

ChildLINK

ChildLINK is a linked data system that includes Maine's birth certificate data, Maine Newborn Hearing Screening data, Maine Birth Defects Registry, and Maine's Newborn Screening data. Data are entered into the system on an ongoing basis. Through this system, data are available on children with a birth defect, hearing loss, as well as those who screened positive for a genetic disorder. Many of these children require special health care services during infancy and throughout their lives. The system is maintained by the University of Maine and data are available upon request.

Medicaid Claims Data

Maine's Department of Human Services' Office of MaineCare Services maintains a datasystem of Medicaid claims. These are medical claims submitted to MaineCare for reimbursement. From MaineCare data, it is possible to identify children with chronic health conditions and examine their health care and prescription use. Recently, developmental screenings have become reimbursable by Medicaid and MaineCare data have been used to track the percentage of children enrolled in MaineCare who have received a developmental screening based on recommendations from the American Academy of Pediatrics. These screenings can help identify conditions that require special health care needs. To date, there has not been a concerted effort to systematically examine special health care needs among those enrolled in MaineCare. Currently, Medicaid insures about 40 percent of children in Maine.

Maine Department of Education, Special Education Data

Maine's Department of Education maintains a data warehouse where it is possible to find state and school-level data on children with disabilities who are enrolled in public school. Disability status is

defined by the Individuals with Disabilities Education Act (IDEA). Data on children with disabilities are available by sex, age, exceptionality (e.g., autism, deafness, developmental delay), limited language proficiency, and race and ethnicity. Data are available for children in kindergarten through grade 12 or for children aged 3-21 years. http://dw.education.maine.gov/DirectoryManager/Web/maine_report/MaineLanding.aspx

Maine Department of Education, Child Development Services (CDS)

Maine's CDS provides early intervention services for children from birth through age two, as well as public education for children ages three to five years. They maintain a centralized data system on children served. Data from this system are not publicly available, but aggregated data could be obtained. It may be possible to access individual-level data from CDS if a specific project were identified.

Other CSHCN Assessments

Survey of Children Served by MaineCare

The Office of MaineCare Services contracts with the University of Southern Maine's Muskie School of Public Service to conduct an annual survey of parents of children ensured through MaineCare. The survey is designed to monitor MaineCare service quality. The survey instrument comes from a standardized assessment tool. In 2013, over 1,000 families enrolled in MaineCare were surveyed by phone. Children with special health care needs were identified using the same screening tool as the NSCH and NS-CSHCN. Select analyses are conducted comparing CSHCN and non-CSHCN. The 2012 and 2013 reports are available here:

<http://www.maine.gov/dhhs/oms/provider/ihoc.shtml>

Table 5. Summary of available data sources with information on children with special health care needs

Data Source	Year(s) available	Population Assessed	Type of assessment	Geographic availability
National Survey of Children's Health	2003, 2007, 2011/12, annually as of 2016/17	Non-institutionalized children aged 0-17	Phone survey with parents	State-level only
National Survey of Children with Special Health Care Needs	2001, 2005/06, 2009/10, annually as of 2016/17	Non-institutionalized children with special health care needs aged 0-17	Phone survey with parents	State-level only
Maine Integrated Youth Health Survey	Biennially since 2009	Students in public schools; kindergarten, 3 rd grade, and 5 th -12 th grades	K/3: Parent paper survey 5 th -12 th : Student paper survey	CSHCN data only available at state-level
ChildLINK	Annual data available since 2001	All children born in Maine to Maine residents	Birth certificates; newborn hearing screening results; newborn bloodspot screening results; birth defects registry cases	Data available at any geographic level; limitations on data release may apply due to small numbers
MaineCare claims	Current MIHMS system in place in 2011	Children insured by MaineCare (Medicaid)	MaineCare eligibility information and MaineCare claims submissions	Data available at multiple geographic levels with permission from OMS
Survey of Children Insured through MaineCare	2012 and 2013 available online	Children insured by Medicaid	Phone survey with parents	State-level data on CSHCN only
Maine Department of Education	Data available from 2008-2009	Children with a disability served by special education programs	Data collected by schools	State and school-level

Strengths and Limitations of Existing Data

Strengths

- The NSCH and NS-CSHCN provide population-level data on children with special health care needs and related health outcomes, risk factors, and access and usage of health services. The data are available online using a web-query system.
- The MIYHS is the only source for population-level prevalence data on autism, asthma and diabetes among children and youth in Maine.
- Disability-related questions on the MIYHS high school and middle school surveys can be examined in relation to other youth health behaviors such as substance use, smoking, and physical activity and nutrition to examine whether there are health disparities by disability status.
- ChildLINK contains “real-time” data on children screened for potential special health needs or identified birth defects. It has the potential to be linked to other data systems to track the long-

term health and educational outcomes of children identified with a special health need at birth.

- MaineCare started reimbursing providers for developmental screenings and has seen an increase in the proportion of children who are being screened for developmental disabilities. It is possible to identify children with special health care needs based on specific conditions using MaineCare claims data and monitor health care and prescription utilization among these children.
- Maine Department of Education Data is a source of information on CSHCN that has not been used extensively for public health monitoring, but could be useful as a source of information to determine the number of children who have a special health care need requiring services, where they reside, and where they are being served. It also provides useful data on the types of needs being served by special education programs in the state and the ability to monitor changes in the prevalence of these needs over time.

Limitations/Challenges

- The NSCH and NS-CSHCN have been conducted every four years. This has limited the timeliness of the data for monitoring trends. In addition, sub-state level data are not available from these sources. The survey was revised in 2016 and data will be available in 2017 and annually thereafter. However, the survey methodology has changed and it is unclear when state-level data will be available. In addition, the change in survey collection methods may prevent comparisons with data from prior years.
- The MIYHS disability-related questions are only on one version of the middle school and high school surveys. This means that data are not available at the county-level or sub-county

level. It also limits the risk factors and behaviors that can be examined by disability status. The items identifying a child as having a disability on the MIYHS are not the same as those on the NSCH, NS-CSHCN, or MaineCare Family Survey.

- Medicaid claims data only include those insured through MaineCare. They do not include those with private health insurance and the uninsured.
- There is no centralized data system for developmental screenings in the state, making it difficult to know the percentage of children who are being screened and identified.
- Although Maine CDC's Children with Special Health Needs Program has a comprehensive data system to capture diagnosis and follow-up, the program does not currently collect data on the care coordination services provided. Data from this could inform the reach of this program and the types of help needed by families.

Other Methods of Data Collection on Children with Special Health Care Needs

Face-to-Face or telephone interviews: Maine Parent Federation and the Maine Developmental Disabilities Council work with children with special health needs and their families on an ongoing basis to help support their needs. It may be possible to work with these organizations as well as the Maine CDC's Children with Special Health Needs Program to identify families willing to participate in qualitative data collection efforts to learn more about their needs as they navigate the health system.

Recommendations

1. **Develop a report on children with special health care needs using new NSCH data, which is due to be released in 2017.**

This report would highlight new data on CSHCN from the new National Survey of Children's Health. This information would be used to establish baseline measures for CSHCN-related indicators such as medical home, care coordination and transition to adulthood.

2. **Develop a report on children and youth with disabilities using data from the MIYHS and ACS.**

This report would highlight the prevalence of special health needs among children in Maine and present data on any health disparities related to CSHCN, such as substance use, physical activity, bullying, and mental health.

3. **Include disability questions on more versions of the middle and high school MIYHS survey.**

Currently, items related to disability are only on one version of the high school and middle school MIYHS. This does not allow analysis at the sub-state level, leads to a small sample for analysis and limits the number of health and risk behaviors that can be examined by disability status. It is also critical to re-examine the disability-related questions on the MIYHS to ensure that they accurately reflect the information needed for program planning.

4. **Enhance or increase the utilization of the ChildLINK system to better understand the long-term outcomes of children with special health care needs.**

Several states (e.g., Massachusetts and Rhode Island) have linked data systems similar to ChildLINK, but include other datasets, such as hospitalizations and education data. Having longitudinal data systems is becoming more common in education. Some states receive funding for P20W data systems that track children from preschool through college and into the workforce. Maine's State Agency Interdepartmental Early Learning and Development Team (SAIEL) is working towards linking state-level data systems to better understand how early life experiences impact educational outcomes. This work would be especially useful to understand the trajectories of children with special health care needs. ChildLINK can play an integral role in the development of a longitudinal data system.

Specific recommendations related to ChildLINK include:

- Staff from the Maine CDC's CSHN program continue to attend SAIEL meetings to help move this process forward.
- The Maine CDC should apply for a State Longitudinal Data System Grant from the National Center for Education Statistics.
- Increase number of analyses and reports made available from ChildLINK on the Maine CDC website.
- Conduct analyses that take advantage of the linked data in ChildLINK, such as co-occurring conditions.

5. **Develop a data collection system for use by Maine CDC's CSHN's care coordination specialist to track the number of calls/families served and types of support offered.**

Maine's CSHCN program offers care coordination to families in need. Currently minimal information is collected on these calls

using a paper-based system. We recommend expanding the amount of information collected and converting the system to an electronic system, possibly within ChildLINK, where needs of families can be assessed. This system can provide insight into the types of care coordination needed by families and help grow CSHCN's care coordination services.

6. Use MaineCare claims data to better understand health care utilization patterns of children-specific conditions.

Children with special health care needs can be identified by diagnosis using claims data. It would be useful to conduct more in-depth analyses of the conditions most often found in claims analyses and the health care utilization patterns of these children to determine their needs and potential gaps.

¹ Child and Adolescent Health Measurement Initiative. National Survey of Children's Health 2011-2012. Enhanced Data File. Data Resource Center for Child and Adolescent Health. Retrieved [May 1, 2016] from: <http://childhealthdata.org/learn/NSCH>.

² "Maine Report from the National Survey of Children's Health." NSCH 2007. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [May 4, 2016] from www.childhealthdata.org.

³ American Academy of Pediatrics. Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Policy statement: the Medical Home. *Pediatrics*. 2004;113(5 Suppl):1545-7.

⁴ U.S. Department of Commerce, U.S. Census Bureau. School-age children with disabilities in U.S. Metropolitan Statistical Areas: 2010. American Community Survey Briefs: 2011. Retrieved [June 1, 2016] from <https://www.census.gov/prod/2011pubs/acsbr10-12.pdf>.

Women in Maine

Background

About Women in Maine

- Fifty-one percent of Maine's population is female (about 678,800 women).¹
- The median age of women in Maine is 45 years, compared to 39 years in the U.S.¹
- The median income of women in Maine is \$26,653, compared to \$36,855 for men.² In Maine, 15 percent of women live below the poverty level, compared to 13 percent of men.³

Women today enjoy increased access to care and have better health than many of their predecessors. Despite gains, women still face barriers to health and experience health disparities. Challenges to health may stem from a variety of biological and socio-economic factors that accumulate over a lifetime. Socio-economic factors include adverse childhood experiences, income, differences in access to or utilization of quality health care, and social inequities and discrimination.

A 2011 report on Maine women found that despite gains, women still earn less than men and have higher rates of poverty. Women with lower income and education are more likely to have poor health and less likely to have access to care.⁴

A woman's health has an immense impact on her children's health, and thus on the next generation of Mainers. Understanding disparities among women is the first step towards improving the health of women and children in Maine.

Surveillance Challenges

There are relatively few challenges for collecting health and risk factor data on women. All major public health surveillance systems include a variable allowing examination of risk behaviors and health outcomes by sex. Timely reporting of vital records data is one challenge that can impact routine surveillance. Another challenge is getting sample sizes large enough to do sub-population analysis. It is also important to collect that data on issues pertinent to women and analyze sub-groups of women to identify those who are at greatest risk for health disparities.

Assessing the Health of Women in Maine

State-level Population Data

Nearly all national and state datasets include sex variables which can be used for state, county, and district-level analysis (Table 6).

Federal data systems

- U.S. Census data (decennial), American Community Survey (annual)
- Behavioral Risk Factor Surveillance System (annual)
- Pregnancy Risk Assessment and Monitoring Survey (annual)

State Data Systems

- Maine's hospital and emergency department discharge data sets (annual)
- Maine Vital Records (annual birth and death data)

- Maine Crime Victimization Survey (every three to four years)

Table 6. Selected Data Sources for Women

Topic	Available data	Source
Demographics	Race, ethnicity, disability, age, education, income, poverty, household composition, language, marital status, family type, veteran's status, etc.	U.S. Census, American Community Survey
Health Behaviors	Risk behaviors (smoking, drinking), mental and physical health status, disease prevalence (asthma, diabetes), etc.	Behavioral Risk Factor Surveillance System (BRFSS)
Pregnancy-related Behaviors and Risk Factors	Prenatal care, contraception, breastfeeding, mental health, etc.	Pregnancy Risk Assessment Monitoring System (PRAMS)
Birth and Death Data	Birth rate, pregnancy-related mortality, overall causes of death	Birth and Death Records
Injury	Intentional and unintentional injury	Hospital Discharge and Emergency Department Visit Data

Maine Women Health Reports and Needs Assessments

Maine Women's Health Report

A comprehensive report on women's demographics, health and access to care was published in 2011 by the Maine CDC.

<http://www.maine.gov/dhhs/mecdc/health-equity/womens-health/report.shtml>

2015 Report on the Status of Women & Girls in Maine.

Maine's Permanent Commission on the Status of Women produces this biennial report which describes the results of their survey of Maine women, as well as other available data on Maine women. <http://www.maine.gov/sos/womens-comm/2-2015WCReport.pdf>.

Maine State Health Assessment (SHA). The Maine CDC produces SHA indicator tables describing the prevalence of risk behaviors, chronic diseases, and health outcomes, which are updated every few years (last edition: 2012). Nearly all of the tables include sex in the demographic sections.

<http://www.maine.gov/dhhs/mecdc/phdata/sha/index.shtml>

Maternal and Child Health (MCH) Block Grant

Annual Report. Every year the Maine CDC submits the latest data on a variety of national and state performance measures to the Health Resources Services Administration Maternal and Child Health Bureau. <https://perf-data.hrsa.gov/MCHB/TVISReports/Snapshot/snapshot.aspx?statecode=ME>

MCH Five-Year Comprehensive Strengths and

Needs Assessment. Every five years the Maine CDC produces a comprehensive maternal and child health needs assessment for the Maternal and Child Health Services Block Grant. The assessments are available online:

https://mchb.tvisdata.hrsa.gov/uploadedfiles/2016/submittedFiles/printVersion/ME_TitleV_PrintVersion.pdf

Factsheets, data briefs and infographics on

women's health have been produced by divisions within Maine's Department of Health and Human Services. Below are two examples from the Partnership for Tobacco Free Maine.

http://www.tobaccofreemaine.org/explore_facts/documents/WomenFacts.pdf

http://www.tobaccofreemaine.org/explore_facts/documents/PregnantWomenFacts.pdf

Strengths and Limitations of Existing Data

Strengths

- Nearly all demographic and health surveys record the respondent's sex, and most surveillance products already stratify data by sex in the analysis of risk factors and outcomes.
- For many health indicators, data are available by sex at the county and public health district level.
- Maine participates in monitoring maternal health via the PRAMS survey.
- Reports and assessments are publicly available.

Limitations and Challenges

- **Some topics are not adequately studied.** Maine lacks systematically collected information on several topics that disproportionately affect women, such as hysterectomies, caregiving challenges, eating disorders, illicit substance use and treatment, and social isolation.
- **Getting timely data can be challenging.** While most of these data sets are theoretically available on an annual or biennial basis, many datasets do not become public until years later.
- **More sub-group analysis is needed.** Sex is a variable that is nearly universally collected by health surveys, and there is a relative wealth of data on women in the U.S. . Even with all this data, women are often grouped together, a practice that could mask important differences in health risks and disparities between women of different races, ethnicities, socioeconomic situations, areas of residence and ages.
- There are some instances when **sample size may limit analysis.** It is not always possible to get adequate sample sizes to do subpopulation

analyses for some variables, even when multiple years of data are combined. .

Other Data Collected on Women's Health

A literature search on Maine women's health revealed some additional non-routine surveys and analyses. Some of the data highlight the health and needs of certain disparate subpopulations of women.

In Maine there are several small and large convenience sample surveys that gather data on special topics relevant to women. Some of these surveys include:

- Surveys conducted by Maine's Permanent Commission on the Status of Women
 - <http://www.maine.gov/sos/womens-comm/2-2015WCReport.pdf>
- Gay, Lesbian, Bisexual and Transgender (GLBT) Aging in Maine
 - http://www.maine4a.org/image_upload/ARP-SAGE-GLBT-Report-2013-pdf.pdf

Recommendations

1. **Create data briefs/factsheets each year highlighting important topics or health risks and outcomes of subpopulations of women experiencing disparities.**

These products help the public and policymakers become aware of problems that emerge rapidly and change frequently (e.g., drug use during pregnancy or STDs). These factsheets and data briefs can also be tailored to the needs of programs or advocates (domestic violence or sexual assault) that may have limited resources for surveillance products. Factsheets on subpopulations of

women could help highlight the disparities that occur within this group.

2. Produce a comprehensive women’s health report for public health surveillance at least once every five years.

A large report contains data on all aspects of a women’s health so that connections and comparisons can be made across health indicators and between groups. A comprehensive report of women’s health can be used by many health partners to monitor progress, identify trends, plan, and implement public health interventions and advocacy. The report format was created in 2011; it would simply need to be updated with new data.

3. Advocate for the addition of questions on population-based surveys that will improve the quality and quantity of information gathered on women and girls.

Some issues and conditions that disproportionately affect women are not well studied in Maine. We know little about the prevalence of hysterectomies, caregiving challenges, eating disorders, illicit substance use and treatment, and social isolation. Data on these topics could help identify areas of interest for public health interventions.

⁴ Maine Center for Disease Control and Prevention. 2011 Women’s Health Report. 2011. Accessed 6-14-16 from: <http://www.maine.gov/dhhs/mecdc/health-equity/womens-health/documents/2011-report-ch1-socio.pdf>.

¹ US Census, 2014 Population Estimates. Annual Estimates of the Resident Population for Selected Age Groups by Sex for the United States, States, Counties, and Puerto Rico Commonwealth and Municipios: April 1, 2010 to July 1, 2014. Accessed 6-14-16 from: <http://factfinder.census.gov/bkmk/table/1.0/en/PEP/2014/PEPAGESEX/0100000US|0400000US23?slice=GEO~0100000US>.

² US Census, American Community Survey 5-Year Estimates. OCCUPATION BY SEX AND MEDIAN EARNINGS IN THE PAST 12 MONTHS (IN 2014 INFLATION-ADJUSTED DOLLARS) FOR THE CIVILIAN EMPLOYED POPULATION 16 YEARS AND OVER : 2010-2014 American Community Survey 5-Year Estimates. Accessed 6-14-16 from: http://factfinder.census.gov/bkmk/table/1.0/en/ACS/14_5YR/S2401/0100000US|0400000US23.

³ US Census, 2010-2014 American Community Survey 5-Year Estimates. POVERTY STATUS IN THE PAST 12 MONTHS. Accessed 6-14-16 from: http://factfinder.census.gov/bkmk/table/1.0/en/ACS/14_5YR/S1701/0400000US23.

Older Adults Living in Rural Areas in Maine

Background

About Older Adults Living in Rural Areas in Maine

The U.S. population is aging rapidly. Between 2012 and 2050, the population age 65 and older is expected to almost double (43.1 to 83.7 million).¹

- In 2010, Maine’s median age was the highest in the country at 42.7 years (national median age is 37.2).²
- Maine’s population is also aging at a faster rate than the U.S. During 2000-2010, Maine’s median age rose by 4.1 years, more than twice as fast as the national median of 1.8 years. While the Maine rate of change is projected to slow between 2010 and 2020, Maine’s median age is still projected to rise faster than New England and the U.S.²
- The majority of Maine residents reside in rural towns and small cities. Statewide, 61.3 percent of the population lives in rural areas compared with 19.3 percent of the U.S. population.³

Rurality

According to the Census Bureau “Rural” encompasses all population, housing, and territory not included within an urban area.

There are two types of urban areas:

- Urbanized Areas of 50,000 or more people;
- Urban Clusters of at least 2,500 and less than 50,000 people.

- An aging population can place demands on:
 - Family caregivers
 - Health care and long-term care systems
 - Housing and transportation programs

Maine is gradually becoming more racially diverse and older adults in these groups may experience the effects of health disparities such as language barriers, reduced access to health care, and low socioeconomic status.^{4,5} Studies have shown that rural residents are older, poorer, and have fewer physicians to care for them.⁶ Rural risk factors for health disparities include:

- Geographic isolation
- Lower socio-economic status
- Higher rates of chronic illness such as heart disease, cancer, injury-related deaths (falls), diabetes and depression and poor overall health.⁷

Maine seniors are more likely to be low income compared to the rest of the country (29.0 percent vs 27.4 percent), and are more likely to live alone, 26.0 percent compared to 24.9 percent nationally.⁸

The rural nature of the state presents a challenge for many older residents. Unlike the more populated cities such as Portland and Bangor that have public transportation, those living in rural areas depend on personal vehicles to get to the services they need. Older people who stop driving find themselves more dependent on family members, friends or neighbors for transportation.⁹

Surveillance Challenges

Data on health conditions are readily available by age from most of the main public health administrative (i.e., birth and death certificates, hospital and ED discharges) and survey (BRFSS) data systems. However, elders living in rural and/or isolated areas are often not specifically included in routine public health surveillance reports. More analysis is needed to examine the health and well-being of rural/isolated elders.

While rurality can be defined according to the U.S. Census definition, isolation is harder to measure. It is important to assess factors such as social support, access to care, access to transportation, and distance to health care facilities to truly understand the challenges facing people who live in isolated places. This holds true not only for elders, but other Mainers living in rural communities across the state.

Assessing the Health of Older Adults Living in Rural Areas

State-level Population Data

Reports on rural elders have not been developed using population-based data in Maine, but data are available from national and state surveys and administrative datasets.

Federal data systems

American Community Survey (ACS)

This on-going survey collects data on a range of topics that include; age, race, housing (whether people own or rent their home), educational attainment and employment. It is possible to obtain data on age and rurality by census tract to do additional analyses that go beyond the tables provided by the U.S. Census Bureau's American Factfinder. To access ACS data:

<http://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml>

State Data Systems

Behavioral Risk Factor Surveillance System Survey (BRFSS)

The BRFSS is conducted annually by the Centers for Disease Control and Prevention (CDC), provides health data on a number of topics by age and rurality. It is possible that more prevalent conditions could be examined by age and county, or age and rurality. It would be more difficult to analyze social isolation as a barrier to health care. The survey includes a question on health care access but there are no questions asked about lack of transportation limiting or preventing a person from receiving services. In some years, social support questions have been asked, but it is not consistent. Biennially the survey includes a question specific to falls: "In the past 12 months, how many times have you fallen?" with follow up questions: "Did this fall cause an injury?" and, "How many of these falls caused an injury?" The cognitive impairment module includes questions about confusion and memory loss and whether or not someone has been told by a healthcare professional that they have Alzheimer's disease or a form of dementia. This ten-question module was included in Maine's 2012 BRFSS. In 2015, the federal CDC shortened the module to six questions and restricted it to respondents aged 45 and older. Maine included the new module in 2016. Data should be available in Spring 2018. More information about this module can be found here: <http://www.cdc.gov/aging/healthybrain/brfss-faq-cognitive.htm>.

In 2012 and again in 2015, a caregiver module was included in the BRFSS, which includes nine questions about caregiving for someone with a health problem or disability. Both modules were sponsored by the Maine Chapter of the Alzheimer's Association.

Other Rural Elder Needs Assessments

There have been no reports prepared specific to health disparities of older adults in Maine, however there has been increased interest around the impact of the state's aging population on the health and long-term care system. This demographic shift prompted the Maine Council on Aging (MCOA) in partnership with Maine Speaker of the House, Mark Eves, to convene a series of roundtables in 2013 to explore the impact of this shift and the challenges to the state. The resulting *Blueprint for Action on Aging* laid out a community-centered approach and key legislative steps for improving housing, transportation, health care, public safety and employment opportunities for elderly residents across Maine. Working groups were convened to address each area.

http://www.maine4a.org/image_upload/SummitonAgingReport_FINAL.PDF.

In 2008 the Maine Center for Disease Control and Prevention (Maine CDC) produced a *Maine Injury Report* on intentional and unintentional injury that included data on Maine's elder population related to falls. The report is available at:

<http://www.maine.gov/dhhs/mecdc/population-health/inj/data.html>.

In 2012, Maine's Office of Aging and Disability Services produced a *Chartbook of Population and Service Use Trends of Older Adults and Adults with Physical Disabilities*. The chartbook provides demographic information as well as an overview of the number of older adults living in poverty in rural areas and that have a disability.

<http://muskie.usm.maine.edu/Publications/DA/Long-Term-Services-Supports-Use-Trends-Chartbook-SFY2014.pdf>.

Maine's Shared Health Needs Assessment and Planning Process (SHNAPP), conducted in 2014, includes an unintentional injury-related measure;

emergency department (ED) visits due to falls among adults 65 years and older. As part of the SHNAPP, a survey was administered with stakeholders statewide. Respondents perceived that elder health was a major or critical problem in their area (55 percent) and 78 percent reported that significant health disparities existed among certain groups of elders. When asked which populations experienced health disparities, very rural and/or geographically isolated people were among those identified.

<http://www.maine.gov/dhhs/mecdc/phdata/SHNAPP/>.

Healthy Maine 2020 includes an objective to reduce emergency department visits for unintentional falls for adults aged 65 years or more.

<http://www.maine.gov/dhhs/mecdc/healthy-maine/>.

In 2012 Maine's Office of Aging and Disability Services developed a *State Plan on Aging* (October 1, 2012 – September 30, 2016) outlining goals and objectives to meet the needs of the state's elder population, as well as capitalizing on the knowledge that the "young old" (under 70 years old) can offer to assist the older, more frail. The full plan can be found at: http://statedocs.maine.gov/oads_docs.

Maine's Office of Disability and Aging Services also produced, in 2012, a *State Plan for Alzheimer's Disease and Related Dementias in Maine*. This plan is being used to guide the State in meeting the needs of individuals living with these diseases. The Plan is available at:

http://statedocs.maine.gov/oads_docs

Strengths and Limitations of Existing Data

Strengths

- BRFSS data include questions of interest, and multiple years of data are available for trends. The cognitive decline module was asked in 2012 and 2016, allowing for an examination of cognitive decline and access to support.
- The ACS is mandatory for the households that are selected; therefore the response rate is strong. The ACS collects a wide variety of data providing information on national demographic, social, economic and housing characteristics. Census tract data are available, which can help identify those living in very rural areas.

Limitations/Challenges

- No program in Maine is consistently tracking the number of individuals diagnosed each year with dementia or Alzheimer's. BRFSS ran the Cognitive Impairment Module in 2012 however it was not run again until 2016 (Cognitive Decline), thus making it difficult to obtain trend data on dementia or Alzheimer's. Programs like SeniorsPlus, recently began collecting data on dementia by asking those who contact the program "if they have memory issues".
- Due to potential under reporting or lack of screening, it is unclear how many older adults are victims of abuse. Older adults may be reluctant to report abuse because of fear of retaliation, as the abuser may be a family member. SeniorsPlus, together with several other organizations, have started using an "Elder Abuse Suspicion Index" tool developed by Dr. Mark Yaffe from McGill University in Canada.

<https://www.mcgill.ca/familymed/research-grad/research/projects/elder>.

SeniorsPlus is using the tool with their Meals on Wheels and Money Minder's clients. Clients are asked five questions and SeniorsPlus follows up based on responses.

- There are little data on the number of seniors who experience unsafe conditions at home and who stay because they do not have another place to go.
- There are little to no data on transportation challenges, although it is often cited as a major reason for lack of access to care in Maine. Transportation is a basic need that can be a major challenge for older adults when trying to access services. The travel distance, lack of public transportation and lack of health care providers are all contributing factors to health disparities in rural Maine.
- Among older adults in rural areas who have limited mobility, the inability to leave their homes can lead to feelings of isolation. Many elders find themselves without social networks or the ability to engage in physical activity. Data are lacking on the number of rural elders who do not drive and the number without available transportation (personal or public).
- Due to small population size, many datasets cannot be analyzed at the county or city/town level making it difficult to determine the number of Maine seniors who may have dementia and to identify what prevents seniors from seeking medical care (i.e., transportation, lack of providers).

Recommendations

1. **Produce a brief report on rural elders using data from BRFSS and the ACS.**

This would include analyses of the cognitive decline questions in BRFSS.

2. Partner with the Maine Association of Area Agencies on Aging and SeniorsPlus to convene “Listening Sessions” with seniors in all rural Public Health Districts to learn about the issues that create barriers to health.

Most communities have senior or community centers where elders gather or transportation provided to those who do not have the means to get to on their own to hold listening sessions. Local agencies working with elders could host the sessions.

¹ Ortman, Jennifer M., Velkoff, Victoria A., Hogan, H. An Aging Nation: The Older Population in the United States, Current Population Reports, P25-1140. U.S. Census Bureau, Washington, DC. 2014.

² Fralich, J. et al., Older Adults and Adults with Disabilities; Population and Service Use Trends in Maine, 2012 Edition. (Chartbook). Portland, ME: University of Southern Maine, Muskie School of Public Service; 2012. Available at: <http://muskie.usm.maine.edu/DA/Adults-Disabilities-Maine-Service-Use-Trends-chartbook-2012.pdf>.

³ U.S. Census Bureau, 2010 Census. P2 Urban and Rural. Total Population 2010 Census Summary File 1. Available from: http://factfinder.census.gov/bkmk/table/1.0/en/DEC/10_SF1/P2/010000US10400000US23.

⁴ The State of Aging & Health in America 2013, National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health. Available at: <http://www.cdc.gov/aging/help/DPH-Aging/state-aging-health.html>.

⁵ Mattingly, Marybeth J., Schaefer, Andrew P. Report 1: A Demographic Profile of Maine Highlighting the Distribution of Vulnerable Populations. (June 2012). Final Report to the John T. Gorman Foundation.

⁶ Kaye, Lenard W. “The Demographic Transformation in Maine (and Beyond) Is in Full Swing.” *Maine Policy Review* 24.2 (2015): 10-12, <http://digitalcommons.library.umaine.edu/mpr/vol24/iss2/4>.

⁷ Averill, Jennifer B., Priorities for Action in a Rural Older Adults Study. *Family and Community Health*. October/November (2012): 35 (2): 358-372.

⁸ Schaefer, Andrew, Mattingly, Marybeth J., A Portrait of Wellbeing: The Status of Seniors in Maine. University of New Hampshire, Carsey School of Public Health, John T. Gorman Foundation.

⁹ Freund, K. “Getting From Here to There: Maine’s Elder Transportation Challenge.” *Maine Policy Review*. 24.2 (2015): 49-55. <http://digitalcommons.library.umaine.edu/mpr/vol24/iss2/10>.

Key Findings and Recommendations

Overall Findings and Recommendations

The following is a summary of key findings from this report. These findings are based on data analyses, literature reviews and expert interviews. Following each finding is a set of recommendations to guide action towards improving the understanding of health disparities and inequities in Maine.

Existing systems collecting data on race, ethnicity and language are not collecting data in a consistent and detailed enough manner to adequately describe Maine's populations.

More detailed categories of race and ethnicity data are needed and standard definitions and categories should be collected across data systems.

Recommendations:

1. Reinforce the importance of using the OMB guidelines for collecting and reporting race data by health care providers and in surveys and other data sources.
2. Provide training and education to those who collect data at hospitals, birthing facilities, and coroners to improve the accuracy and completeness of data reporting.
3. Conduct ongoing evaluation of data collected in public health surveillance systems to monitor accuracy and completeness.

Social determinants of health need to be measured and analyzed in public health surveillance systems.

Recommendations:

1. Incorporate questions on factors such as housing, length of time living in Maine, and employment to existing surveys (e.g., BRFSS and PRAMS).
2. Expand data linkages to be able to present the relationship between social determinants of health and health outcomes.
3. Present data by equity stratifiers to better illustrate inequities in health status and health care.
4. Produce community-level analyses and maps of social determinants of health.
5. Geocode surveillance data on an ongoing basis to conduct place-based analyses of health risks and outcomes.

Partnerships between state and local partners and diverse communities can increase understanding and use of data to better address social, economic and demographic factors affecting health, health care, and access to health.

Recommendations:

1. Use community-based participatory research methods as a standard strategy when collecting data.
2. Work with local agencies to help them improve how they collect and disseminate data (e.g., legal aid, schools, non-profits).
3. Once data are collected, work with communities to ensure that data are presented in a meaningful way.
4. Convene a working group of local data users to understand data needs, support data collection efforts, disseminate data and products, and promote a health equity perspective statewide.

Alternative methods of sampling, data collection and analysis are effective means of gaining additional information on population groups with health disparities.

Recommendations:

1. Consider oversampling of specific sub-populations or geographic regions.
2. Methods such as convenience sampling (samples drawn from a group or organization where it is easy to recruit/find participants); snowball sampling (identification of a small number of participants representative of the population of interest who can identify other participants); and sampling from publicly available lists (e.g., tribal rolls, phone books) can be an effective way of recruiting population subgroups to participate in surveys and interviews.
3. Conduct more qualitative data collection on populations not captured by traditional data sources to gather more in-depth information (homeless, LGBT, MaineCare recipients, disabled, uninsured, tribal, refugee, and migrant populations).

More timely data are needed.

Recommendations:

1. Data systems should be evaluated to determine ways they can produce data on a more timely basis.
2. Make more data available online and at a community level.

Innovative methods of linking and presenting data can improve data usefulness.

Recommendations:

1. Link data systems on an ongoing basis to make the link between health and social determinants of health.
2. Analyze data at smaller geographic levels (i.e., town, census tract), and present data using interactive maps to identify communities at highest risk.

Data are needed at a local level.

Recommendations:

1. Consider oversampling certain counties or other geographic units to allow for stratifications at a more local level data.
2. Combine several years of data to get county and sub-county estimates.
3. Promote local data-driven decision-making through the use of community assessments.
 - a. Include the challenges, needs, resources, and strengths of the community
 - b. Include measures of morbidity, mortality, and behavioral factors, but also include social indicator data related to employment, economic and environmental conditions.
4. Support local health departments, agencies and tribes to conduct their own population health surveys.
5. Use respondent-driven sampling to select statistically valid samples of difficult-to-reach groups.
6. Assist local agencies in the analysis, interpretation and application of population health surveys as requested.
7. Promote the use of qualitative data collection methods.
8. Enhance current surveillance systems to ensure that data are available at a local level and the systems include social determinants of health at a local level.
9. Use innovative methods of data analysis to get local-level data (e.g., small area estimation, spatial smoothing).

Continuous training and education on presenting data from a health equity perspective is needed.

Recommendations:

1. Encourage presentation of data by social determinants and demographic characteristics, especially race and ethnicity across public health programs.
2. Train public health and local agency staff on the concepts of health equity and the methods to collect, analyze, report, and apply health equity data findings.

Data-Related Recommendations for Groups with Health Disparities

Below are the recommendations for improving data collection and reporting for groups with health disparities in Maine. For additional details about these recommendations, see the discussion of each population group in Chapter Four.

Tribal Members

1. Update the 2003 race misclassification study.
2. Offer support to the tribes with any upcoming surveys (e.g. upcoming youth survey, next administration of the Wabanaki health assessment).
3. Add tribal affiliation field to existing public health surveillance datasets (e.g. death certificates, hospital discharge, etc.).

Persons of Color

1. Encourage standardization of data collection of race in public health and health care data systems to comply with OMB standards.
2. Produce data briefs on populations of color in Maine to highlight health disparities and social determinants of health.
3. Work with nonprofits and local health organizations that may collect data on minority populations to see if an assessment is already being done that can be amended to collect more health data.
4. Support the work of Portland Public Health as they conduct their Minority Health Assessment.
5. Collect qualitative data on different population groups to learn about health needs and concerns.
6. Conduct more analyses on social determinants of health at a local level to demonstrate the relationship between unequal access and opportunity and health.
7. Continue to produce tables that include race to highlight disparities in health.

Refugee/Immigrant

1. Support the work of Portland’s Public Health Division and Healthy Androscoggin in their continued efforts to collect data on the refugee and immigrant populations in their areas.
2. Develop report on refugees and immigrants in Maine using data from American Community Survey, Current Population Survey, and U.S. Census.
3. Explore the possibility of linking refugee data with MaineCare data to get a sense of refugee health needs and health care utilization.
4. Include immigrant status questions on existing surveys and public health surveillance systems.
5. Take a structural and trauma-informed approach to measuring and addressing immigrant health.

Hispanic/Latino

1. Work with nonprofits and local health organizations to gather health data on Hispanics through existing surveys (e.g. Mano en Mano’s survey).
2. Report ethnicity separately on detailed MIYHS tables.
3. Continue to produce public health surveillance tables by ethnicity (separate from race) and monitor the growth of the Hispanic population.
4. Include Hispanic population in any future minority health reports.

Migrants and Seasonal Farmworkers

1. Partner with Maine Migrant Health to create and administer a health survey (in-person interviews or focus groups) or offer analysis support using data currently collected on mobile health clinics.

LGBTQ

1. Add gender identity question to BRFSS.
2. Develop infrastructure for ongoing reporting on the health of transgender youth in Maine.
3. Add questions about sexual orientation and gender identity to forms for hospital discharge, ED visits, cancer, and death records.
4. Conduct a convenience sample survey of 1,000+ GLBT adults in Maine in partnership with other non-governmental organizations like EqualityMaine and MaineTransNet.
5. Update the *Gays, Lesbians and Bisexuals in Maine* report from 2011.

Persons with Disabilities

1. Improve the quality of disability data using cross-agency collaboration and data collection/sharing. Create standardized questions on disability to gain a better understanding of the total number of persons with disabilities, disability type, and service needs of the population.
2. Develop report on adults with disabilities using BRFSS data.
3. Develop a plan to assess the health needs of individuals with disabilities residing in group homes or institutions using traditional public health surveillance systems (e.g., BRFSS) or conducting a separate assessment.
4. Partner with Disability Rights Maine to work with all public housing, residential care, and nursing homes to include a check box on intake forms that asks if the person is deaf, has serious difficulty hearing or uses sign language to communicate.

Children with Special Health Needs

1. Develop report on children with special health care needs using 2017 NSCH data.
2. Develop a report on children and youth with disabilities using MIYHS and ACS data.
3. Include disability questions on more versions of the middle and high school MIYHS survey.
4. Enhance or increase the utilization of the ChildLINK system to better understand the long-term outcomes of children with special health care needs.
5. Develop a data collection system for use by Maine CDC's CSHN's care coordination specialist to track the number of calls/families served and types of support offered.
6. Use MaineCare claims data to better understand health care utilization patterns of children-specific conditions.

Women

1. Create data briefs or factsheets each year highlighting important topics or disparate populations of women.
2. Produce a comprehensive women's health report for public health surveillance at least once every five years.
3. Advocate for the addition of questions on population-based surveys that will improve the quality and quantity of information gathered on women and girls.

Elder Rural Mainers

1. Produce a brief report on rural elders using data from BRFSS and the ACS.
2. Partner with the Maine Association of Area Agencies on Aging and SeniorsPlus to convene “Listening Sessions” with seniors in all rural Public Health Districts to learn about the issues that create barriers to health.

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