

Prepared by: Michelle Mitchell, MSocSc

Erica Swan, MBA

James Moss

Denise Clark, MPH, CHES

**Partnerships For Health** 

112 State Street Augusta, ME 04330

989 Brighton Avenue Portland, ME 04101



**Prepared for:** 

Melanie Feinberg

Comprehensive Cancer Control Program

Division of Disease Prevention

Office of Disease Control and Prevention

Maine Center for Disease Control and Prevention

Maine Department of Health and Human Services

286 Water Street

State House Station 11 Augusta, ME 04333-0011 www.maine.gov/dhhs/mecdc/



CC:

Sarah Lewis

Maine Access Immigrant Network

237 Oxford Street, Suite 25A

Portland, ME 04101



# CONTENTS

INTRODUCTION	4
CANCER SCREENING HEALTH CARE EXTENDER PROJECT	
EVALUATION METHODOLOGY	6
Theoretical Frameworks	6
Cohort Design	8
Instruments	8
Analysis	9
RESULTS	10
Factors Impacting Cancer Beliefs and Screening Behaviors	10
Perceived Risk of Cancer	10
Cancer-Related Beliefs	10
Effectiveness of the Cancer Screening Health Care Extender Project	12
Impact on Cancer-related Knowledge	12
Impact of Workshops on Cancer-related Behaviors	13
Behavioral Spillover Effect of Workshops	15
CONCLUSION	15
REFERENCES	16

## INTRODUCTION

Promoting cancer screenings. The US Preventive Services Task Force recommends early detection and screening as one of the most effective evidence-based public health strategies for reducing cancer morbidity and mortality, especially for breast, cervical, colorectal, and lung cancers<sup>1</sup>. However, immigrants to the United States of America (US) are often less likely to undergo cancer screenings and tend to experience worse cancer outcomes compared to non-Hispanic whites (US Centers for Disease Control and Prevention, 2016).

Barriers to cancer screenings among immigrants. Barriers to cancer screening for immigrants include lack of familiarity with the US healthcare system, negative healthcare interactions, and overall knowledge gaps (Adegboyega, Aleshire, & Linares, 2017). While these barriers are often addressed programmatically through workshops, educational material, etc., screening rates remain relatively low and literature suggests that cultural beliefs and myths surrounding the root cause of cancer may negate program effectiveness among culturally diverse populations. For example, a common belief is that "everything that happens is God's plan" and that personal faith will protect a person from cancer. Cancer may also be seen as a curse or punishment from God (Morrison, Wieland, Cha, Rahman, & Chaudhry, 2012), so the benefits of early detection are often outweighed by fear of ostracism (Adegboyega, Aleshire, & Linares, 2017). The result may be that the benefits of screening are often outweighed by the fear of being socially excluded or being perceived as not having sufficient faith.

Understanding the relationship between cultural beliefs and cancer prevention, early detection, and screening. Given the increasing number of people from racial and ethnic minorities in Maine, as the Maine Center for Disease Control and Prevention (Maine CDC) considered the design of an educational program about cancer prevention, early detection and screening it was viewed as critical to understand cancer from the lived experience of an immigrant. Beliefs are long-standing and emerge as a result of individual experiences. As such, they can be intrinsic barriers to engaging in cancer-related education and / or screening. Thus, it is important to understand these beliefs in order to create an effective educational program.

Culturally sensitive strategies to improve cancer screening among immigrants in Maine. In 2017, as a component of the federal funding to increase cancer screening rates, Maine CDC contracted with Maine Access Immigrant Network (MAIN) to design and implement the Cancer Screening Health Care Extender Project and with Partnerships For Health (PFH) to undertake formative and program outcome evaluation.

The evaluation served both formative and summative purposes. The formative component focused on quantifying the factors that impacted immigrants' cancer-related beliefs, while the summative component assessed the effectiveness of providing culturally sensitive community workshops and ongoing individual support to improve cancer screening rates among participants. Results from both evaluations are summarized here. Findings may provide insight into how different demographic, cultural, and religious factors may affect individuals' cancer-related beliefs and can help to inform future projects.

<sup>&</sup>lt;sup>1</sup> US Preventative Services Task Force statements can be accessed at: https://www.uspreventiveservicestaskforce.org/uspstf/

# CANCER SCREENING HEALTH CARE EXTENDER PROJECT

In 2017, the Maine CDC Comprehensive Cancer Control Program (MCCCP) and the Maine CDC Breast and Cervical Health Program (MBCHP) were awarded federal funding to increase cancer screening rates. This included the implementation of evidence-based strategies aimed at increasing screening services to uninsured and underinsured people, reducing structural barriers to screening, and encouraging cancer screening. One of the strategies implemented was the Cancer Screening Health Care Extender Project (the Project).

Health care extenders are non-medical professionals who work directly with or on behalf of clients. Examples of health care extenders are pharmacists, community health workers (CHWs), and patient navigators. They typically operate from within a health care system or a community organization (Centers for Disease Control and Prevention, 2017).

Staff from the MCCCP and MAIN worked together to develop the Project. MAIN is an ethnic-based community organization that provides multilingual access to health and social services for immigrants, refugees, and asylees living in Maine. MAIN is staffed by CHWs who serve the needs of African and Middle Eastern immigrants living in the greater Portland area.

The Project focused on encouraging screening for breast, cervical, colorectal, and lung cancers. It consisted of three components: (i) MCCCP and MBCHP staff provided CHWs with

#### **HEALTH CARE EXTENDERS**

"non-physician health care professionals who help people take actions to manage their health conditions"

National Association for Chronic Disease Directors, 2018

training and resources in cancer prevention, screening, and early detection; (ii) community workshops were cofacilitated by CHWs, MCCCP, and MBCHP staff / clinical providers; and (iii) CHWs provided ongoing support to community members after the workshops to overcome cultural, economic, transportation, social, and other barriers to screenings.

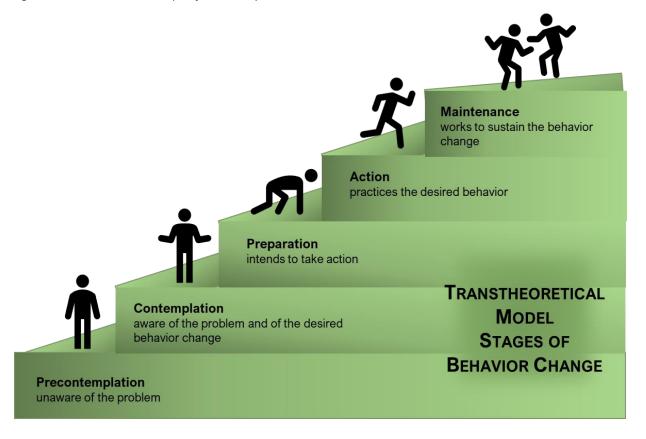
# **EVALUATION METHODOLOGY**

# THEORETICAL FRAMEWORKS

Transtheoretical Model of Health Behavior Change

The evaluation was guided by the Transtheoretical Model of Health Behavior Change (see Figure 1). The Transtheoretical Model focuses on the decision making of the individual (Velicer, et al., 2000). The model describes change as a sequential movement along 5 stages. Understanding a person's current stage of behavior change allows for interventions to be tailored to move people to the next stage of behavior change or maintenance.

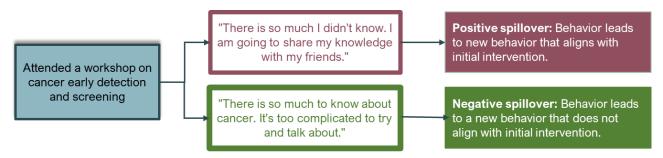
Figure 1: Theoretical Model. Adapted from Grimley 1997 and Prochaska 1992



#### Spillover Effect

The behavioral spillover effect refers to the process where "adoption of one behavior spills over into the adoption of another. Spillover effects are often seen to occur as a result of changes in motivation or preferences at the individual level that result from the adoption of a new behavior and impacts on further behavioral outcomes" (pg 2. Elf, Gatersleben, & Christie, 2019). Spillover effects can occur when individuals adopt a new behavior and, as a result, their motivations or preferences change, and these effects can be positive or negative. Figure 2 provides an example of both positive and negative spillover effects.

Figure 2. Positive and Negative Spillover Effects



Spillover effects are affected by individuals' identities and the support of trusted entity (ibid). People tend to make decisions and take actions that are consistent with their sense of self and the groups they identify with. If an individual takes one type of action that aligns with their individual and/or group identity, they may be more likely to take another action that is in line with the initial behavior. Further, the involvement of trusted entities in behavior change efforts can create relationships and contexts that are sources of awareness of and motivation to undertake specific behaviors.

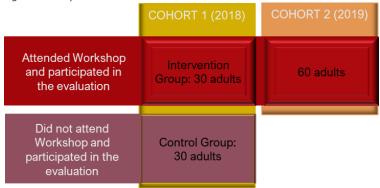
#### Community-Based Participatory Methodology

The evaluation was undertaken using a community-based participatory research methodology. All evaluation materials were translated from English into French, Somali, and Arabic. Consent was obtained using a teach-back methodology to ensure knowledge and understanding of the evaluation. CHWs were trained as data collectors and both completed the initial survey with participants and implemented the follow-up survey three months after the workshops. This process resulted in a high number of responses. This partnership between evaluators and CHWs ensured that the evaluation was culturally sensitive, linguistically appropriate, and comfortable for the community. Additionally, this partnership allowed for community buy-in and evaluation capacity building.

#### **COHORT DESIGN**

The Project was implemented in 2018 and 2019. In Cohort 1 (2018), a group of 30 adults participated in the evaluation and did not participate in the Project. This group formed a control group and were compared with an intervention group of 30 adults who did participate in the Project. In Cohort 2 (2019), 60 adults participated in the Project. The preliminary findings suggested effectiveness of the Project and community members were eager to attend cancer-related workshops, consequently there was no control group in Cohort 2. The resultant sample sizes are shown in Figure 3.





#### **INSTRUMENTS**

Due to the existence of a control group, Cohort 1 was asked to complete two surveys: (i) Knowledge, Beliefs, and Intention Survey, and (ii) the Behavior Survey. The Knowledge, Beliefs, and Intention Survey was developed based on an extensive review of literature and translated into French, Somali, and Arabic. The survey collected demographic data and assessed respondents' knowledge and attitudes about cancer in general as well as their intent to undertake screenings. The Behavior Survey tracked participants' activities in the three months following the workshop. It included activities such as application to programs that cover the costs of cancer-related screenings, completion of screenings, conversations with medical providers, and conversations with friends and family. Only de-identified data was provided to the evaluation team. Due to the absence of a control group in Cohort 2, different components of the Knowledge, Beliefs, and Intention Survey were administered in two time periods. The implementation of the surveys is summarized in Table 1. Completed surveys across both years were combined and statistical analysis undertaken to assess the effectiveness of the workshops.

Table 1: Survey Implementation

		TIME 1 (before workshop)	TIME 2 (immediately after workshop)	TIME 3 (3 months after workshop)
	Control	Knowledge, Beliefs, and		Behavior Survey
Cohort 1	Group Intervention	Intention Survey Knowledge, Beliefs, and		Behavior Survey
	Group	Intention Survey		20
Cohort 2		Knowledge and Beliefs	Knowledge and	Behavior Survey
COHOIT 2		Survey	Intention Survey	

## **ANALYSIS**

Three separate analyses were performed with the data:

- 1. Data from both Cohorts were combined and analyzed to identify overall knowledge, attitudes, and beliefs about cancer among the immigrant population served by MAIN.
- 2. Data from each Cohort were compared and differences in knowledge and intent to undertake screenings were examined.
- 3. Data from each Cohort were analyzed to compare actual screening behaviors at follow-up. Statistical analyses, such as independent sample t-tests, N-1 chi square, and chi-square test of independence, and descriptive data analysis were undertaken using SPSS software.

## **RESULTS**

A total of 120 foreign-born adults living in Maine completed a survey about their cancer-related knowledge and beliefs prior to the start of the Project.

Two-thirds (67%) of respondents were female, below the age of 50 (76%), and practiced Islam (69%). The largest group of respondents identified Somalia as their country of origin (42%), followed by Democratic Republic of Congo (18%) or Sudan (14%). Approximately half of respondents (56%) had completed high school or a lower level of education and had been living in the US for 5 years or less (50%). Figure 4 summarizes demographic characteristics that significantly impacted on perceived risk of cancer and cancer-related beliefs.

# FACTORS IMPACTING CANCER BELIEFS AND SCREENING BEHAVIORS

#### Perceived Risk of Cancer

Country of origin, education, and gender impacted on perceived risk of cancer. Respondents from Sudan were statistically more likely than respondents from other countries to perceive themselves as having a high risk of getting cancer (p<0.05). In addition, post-high school education was associated with a higher

perception of risk (high school: 21% vs post high school: 62%). Women (21%) were more likely than men (16%) to assess their risk of getting cancer as high. Of all age groups, respondents 40-49 years and those older than 60 years were most likely to want to know if they had cancer. The length of time living in the US did not significantly impact personal cancer risk assessment.



Education and religious practices influenced cancer-related beliefs. Women were more likely than men to believe that cancer is caused by having too many children

(women: 10% vs men: 6%) or cancer is part of



God's plan (women: 62% vs men: 50%). While these findings are interesting, there were no statistically significant relationships between gender and each of these beliefs. Similarly, age and length of time living in the US did not have a statistically significant impact on cancer-related beliefs.

However, there was a statistically significant relationship between education levels and beliefs about the causes of cancer. Respondents with lower education levels tended to hold the belief that cancer is caused by having too many children (p<0.05), or that cancer is a curse or punishment from God (p<0.05) more frequently than respondents with higher levels of education.

Respondents from Somalia and Sudan were statistically more likely to agree that cancer is God's will than those from Angola and / or the Democratic Republic of Congo (p<0.05). This may be attributed more to religious affiliation than country of origin as the majority of respondents from Somalia and

Sudan practiced Islam and respondents from Angola and the Democratic Republic of Congo tended to practice Christianity. Respondents who identified as practicing Islam were statistically more likely than respondents practicing Christianity to believe that God would protect them from cancer (p<0.05). However, compared to respondents who practiced Islam, those that practiced Christianity were more likely to not want to know if they had cancer (p<0.05).

The relationship between country of origin and religious practices were not evident in self-assessed risk of cancer. Respondents from Somalia and Democratic Republic of Congo did not believe they had a high risk of getting cancer while respondents from Sudan did assess their personal risk as high. This relationship between county of origin and perception of cancer risk was statistically significant (p<0.05).

Older participants had less knowledge on how to obtain cancer screening. Most respondents (79%), regardless of gender, reported knowing where to go to get a cancer screening test. Respondents aged 40-49 years old were statistically more likely to know where to go for a cancer screening than respondents who were younger or older (p<0.05). This is particularly apparent for respondents aged 50-59 years old who were least likely of any age group to know where to go for a cancer screening.

Figure 4: Demographic Differences in Cancer-Related Beliefs

GENDER	AGE			
WOMEN Perceive the risk of getting cancer as high Believe cancer is caused by having too many children Believe cancer is part of God's plan	<ul> <li>40 - 49 YEAR OLDS</li> <li>Want to know if they have cancer</li> <li>Know where to go for screening*</li> <li>60+ YEAR OLDS</li> <li>Want to know if they have cancer</li> </ul>			
RELIGIOUS PRACTICE				
ISLAM  • Believe God will protect them against cancer*  CHRISTIANITY  • Do not want to know if they have cancer*				
	*			
	* EDUCATION			
Do not want to know if they have cancer				

# EFFECTIVENESS OF THE CANCER SCREENING HEALTH CARE EXTENDER PROJECT

# Impact on Cancer-related Knowledge

Spillover effect as an unintended consequence. While not part of the original evaluation design, the increased sample size in Cohort 2 enabled the assessment of possible knowledge and behavioral spillover effects. In addition to comparing participants who had attended the workshop to those who had not (Cohort 1), analysis was undertaken to determine the extent (if any) of the impact of the workshop on individuals' cancer-related knowledge and behaviors that were not the focus of the topic-specific workshop.

Improved knowledge about cancer risk factors and screening recommendations. Respondents who participated in a workshop expressed an increased understanding of the relationship between age and different lifestyle behaviors (including tobacco use, exercise, and diet) and cancer risk. Respondents also demonstrated increased knowledge about types of cancer screenings as well as increased understanding of the recommended cancer screening ages, frequencies, and tests. Members of the Cohort 1 intervention group attained significantly (t-test = -3.4 and p<0.01) higher overall knowledge scores after participating in a workshop than members of the control group (average overall knowledge scores of 71.3% vs 53.7%).

Figure 5 highlights the change in knowledge in Cohort 2 participants, with the largest improvement being the increase in colorectal cancer-related knowledge among participants who attended the Colorectal and Lung Cancer Workshop. This increase is also evident in participants who attended the Breast and Cervical Cancer Workshop, suggesting a knowledge spillover.

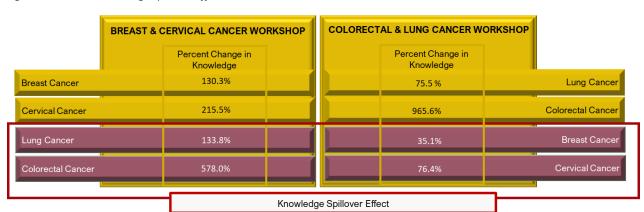
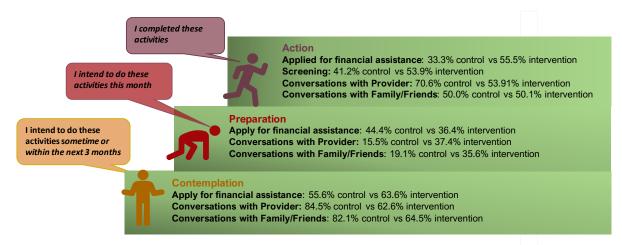


Figure 5: Cohort 2 Knowledge Spillover Effect

#### Impact of Workshops on Cancer-related Behaviors

Workshop participants intended to take action. The Transtheoretical Model was applied to respondents' data to determine if they were in the contemplation or preparation stages of change immediately after attending a workshop. Compared to the control group, workshop participants more frequently reported the intention to act within the month. Respondents who had not participated in a workshop (i.e. the control group) most often reported the intention to undertake activities within the next 3 months suggesting that they were still seeking information and did not intend to engage in cancer-related activities, including cancer screening and conversations about cancer, in the foreseeable future. These differences are shown in Figure 6.

Figure 6: Cohort 1 Differences In Behavioral Intentions and Actions



Respondents applied for financial assistance. In Cohort 1, women from the intervention group appeared more likely than women in the control group to apply to the Maine Breast and Cervical Health Program (MBCHP) for financial assistance (55.5% vs 33.3%). In addition to the MBCHP, the intervention group participants were more likely than individuals in the control group to apply to other programs for assistance in accessing cancer screenings (30.8% vs 11.8%). Participants from both groups who did not apply for assistance self-identified as not eligible due to their gender (men were not eligible for the MBCHP) or insurance status (respondents were currently insured through MaineCare or private insurance).

In Cohort 2, one in ten respondents (9.6%) reported applying to the MBCHP and approximately one in five (18.5%) respondents reported applying to other programs to overcome cost barriers to screening. Ineligibility was the primary reason reported for not applying to assistance programs. Respondents reported ineligibility for multiple reasons including having health insurance (MaineCare or private insurance) or not meeting screening guidelines.

Respondents discussed cancer risk with their medical providers, friends, and family. In Cohort 1, more people from the control group reported having conversations with medical providers (70.6%) than those

in the intervention group (53.9%). Findings from Cohort 2 suggest only a third of participants (39.3%) reported having discussions with their medical providers. Across cohorts, breast cancer and colorectal cancer were the most frequently reported topics of conversation with medical providers. Those that did not speak with a medical provider cited that they were waiting for health insurance or simply that the topic did not come up in conversation.

Approximately half of respondents (49.4%), regardless of group, reported having conversations with family and friends about cancer. Breast cancer appeared to be the most common topic



CANCER CONVERSATIONS

of conversation. Reasons for not discussing cancer with family members included that their family did not live in Maine, they lived alone, or everyone in their family was currently healthy. These were different from reasons for not discussing cancer with friends which included that it did not need to be talked about, the subject did not come up, and that cancer was scary.

Participants undertook cancer screenings. In Cohort 1, a higher portion of participants from the intervention group reported having completed a cancer-related screening than the control group (53.9% vs. 41.2%). Intervention group participants who reported not having completed a cancer-related screening reported that they either were not due for a screening or had recently been screened. In Cohort 2, approximately one-third of respondents (30.8%) reported scheduling or undergoing a cancer screening within three months of the workshop.

# **CANCER SCREENINGS**

- 16 An Breast Cancer
- 23 ååå Cervical Cancer
- 12 🎎
- 1 Lung Cancer

# Behavioral Spillover Effect of Workshops

Figure 7 shows the behavioral spillover for both workshops. A few participants in the Breast and Cervical Cancer Workshop reported having conversations with their providers about colorectal and lung cancer. Approximately 1-in-5 women (20.2%) in the Breast and Cervical Cancer Workshop spoke with friends and family about colorectal and lung cancer. The behavioral spillover was most apparent in Colorectal and Lung Cancer Workshop participants as it appears to have resulted in cervical cancer screening in addition to conversations with providers and family/friends.

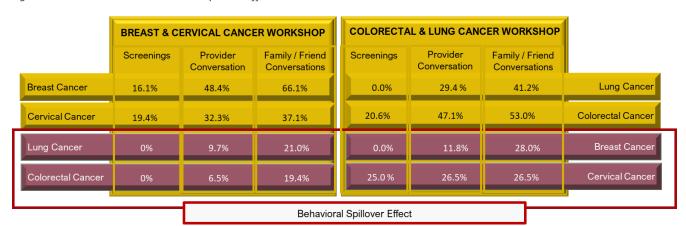


Figure 7: Combined Cohorts Behavioral Spillover Effect

### CONCLUSION

Evaluation findings suggest that cultural myths and / or religious beliefs may impact the extent to which community members engage in cancer screening behaviors. Depending on the country of origin, immigrants may have different perceptions of their risk of developing cancer. Community members with lower educational levels may believe in culturally driven myths. Finally, religious beliefs may result in the belief that cancer is not something that can be prevented. All these factors are important to consider when designing and implementing a culturally informed program to increase cancer screenings.

The Cancer Screening Health Care Extender Project appears to have been effective in debunking myths and misconceptions; increasing knowledge; and encouraging participants to initiate conversations with medical providers, family, and friends. Findings suggest that the Project was effective in increasing participants' application to assistance programs and scheduling or undergoing cancer screenings. Positive spillover effect may explain an exchange of knowledge from one group of workshop participants to another. Group dynamics play an important role in facilitating a sense of efficacy and promoting sustained behavior change and spillover. The support of a trusted entity, such as a CHW, can be critically important. The spillover effect between workshops is an unanticipated outcome and may be useful to explore further.

## REFERENCES

- Adegboyega, A. (2017). Examining Cervical Cancer Screening Utilization Among African Immigrant Women: A Literature Review. *International Journal of Women's Health and Wellness*, 3(1), 46. https://doi.org/10.23937/2474-1353/1510046
- Cancer Screening | Refugee Health Guidelines | Immigrant and Refugee Health | CDC. (2016, June 21).

  US Centers for Disease Control and Prevention.

  https://www.cdc.gov/immigrantrefugeehealth/guidelines/domestic/general/discussion/cancer-screening.html
- Elf, P., Gatersleben, B., & Christie, I. (2019). Facilitating Positive Spillover Effects: New Insights From a Mixed-Methods Approach Exploring Factors Enabling People to Live More Sustainable Lifestyles. *Frontiers in Psychology*, *9*, 2699. https://doi.org/10.3389/fpsyg.2018.02699
- Framework for Program Evaluation CDC. (2017). Https://Www.Cdc.Gov/Eval/Framework/. https://www.cdc.gov/eval/framework/
- Patton, M. Q. (2008). Utilization-Focused Evaluation (4th ed.). SAGE Publications, Inc.
- Patton, M. Q. (2010). *Developmental Evaluation: Applying Complexity Concepts to Enhance Innovation and Use* (Illustrated ed.). The Guilford Press.
- US Centers for Disease Control and Prevention. (2017). *Indicators Spotlight: Health Care Extenders*. https://www.cdc.gov/DHDSP/docs/Health Care Extenders Indicators.pdf
- Velicer, W. F., Prochaska, J. O., Fava, J. L., Rossi, J. S., Redding, C. A., Laforge, R. G., & Robbins, M. L. (2000). Using the Transtheoretical Model for population-based appraoches to health promotion and disease prevention. *Homeostatis in Health and Disease*, 40, 174–195. https://www.uriacc.uri.edu/research/cprc
- Yarbrough, D. B., Shulha, L. M., Hopson, R. K., & Caruthers, F. A. (2010). *The Program Evaluation Standards: A Guide for Evaluators and Evaluation Users* (Third ed.). SAGE Publications, Inc.



The Department of Health and Human Services ("DHHS") does not discriminate on the basis of disability, race, color, sex, gender, sexual orientation, age, national origin, religious or political belief, ancestry, familial or marital status, genetic information, association, previous assertion of a claim or right, or whistleblower activity, in admission or access to, or the operation of its policies, programs, services, or activities, or in hiring or employment practices. This notice is provided as required by and in accordance with Title II of the Americans with Disabilities Act of 1990 ("ADA"); Title VI of the Civil Rights Act of 1964, as amended; Section 504 of the Rehabilitation Act of 1973, as amended; Age Discrimination Act of 1975; Title IX of the Education Amendments of 1972; Section 1557 of the Affordable Care Act; the Maine Human Rights Act; Executive Order Regarding State of Maine Contracts for Services; and all other laws and regulations prohibiting such discrimination. Questions, concerns, complaints or requests for additional information regarding the ADA and hiring or employment practices may be forwarded to the DHHS ADA/EEO Coordinators at 11 State House Station, Augusta, Maine 04333-0011; 207-287-4289 (V); 207-287-1871(V); or Maine Relay 711 (TTY). Questions, concerns, complaints or requests for additional information regarding the ADA and programs, services, or activities may be forwarded to the DHHS ADA/Civil Rights Coordinator, at 11 State House Station, Augusta, Maine 04333-0011; 207-287-5014 (V); Maine Relay 711 (TTY); or ADA-CivilRights.DHHS@maine.gov. Civil rights complaints may also be filed with the U.S. Department of Health and Human Services, Office of Civil Rights, by phone at 800-368-1019 or 800-537-7697 (TDD); by mail to 200 Independence Avenue, SW, Room 509, HHS Building, Washington, D.C. 20201; or electronically at https://ocrportal.hhs.gov/ocr/portal/lobby.jsf. Individuals who need auxiliary aids for effective communication in program and services of DHHS are invited to make their needs and preferences known to the ADA/Civil Rights Coordinator. This notice is available in alternate formats, upon request.