



**APPLI**

Appalachian Learning Initiative

# **Adult Literacy Proficiency and Public Health in Appalachia**

## **The Correlations Between Low Literacy Proficiency and Health Outcomes in Appalachian Counties**

**October 6<sup>th</sup>, 2023**

# Appalachian Learning Initiative

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Appendices available separately at the following address:

<https://cutt.ly/literacy-correlations-appendices-oct-23>

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## Disclosures

We know of no existing conflicts to disclose

## Keywords

Adult Literacy, Public Health, Health Interventions, Educational Interventions, Appalachia, Appalachian, Appalachian Region

## Suggested Citation

Hopkins, M.J., Harper, C.D., Morgan, A.G.S., Cox, W.M., Graves, T.B., Peters, A.D., Woodworth, K.L., & McKenna, M.R. (2023, October 06). Adult literacy proficiency and public health in Appalachia: The correlations between low literacy proficiency and health outcomes in Appalachian counties. Morgantown, WV: Appalachian Learning Initiative: Publications.

# Abstract

The Appalachian Region's thirteen states, 423 counties, and eight independent Virginia cities are home to some of the most breathtaking landscapes in the United States. The region is also beset by significant negative public health outcomes, including the incidence, prevalence, and mortality rates of both infectious and non-infectious diseases, as well as mental and physical health conditions.



Considerable research has been dedicated to defining and examining the Social Determinants of Health (SDOH) and the roles they play in negative health outcomes in both urban and rural settings. Few attempts, however, have been made to evaluate the correlative link between adult literacy proficiency and health outcomes.

We explore these links by gathering county-level adult literacy results from Phase 1 of the Program for the International Assessment of Adult Competencies (PIAAC) testing program and using Pearson's Correlation Coefficient to test the linear correlation between public health data gathered from the Behavioral Risk Factor Surveillance System (BRFSS) as presented in the Centers for Disease Control (CDC)'s Population Level Analysis and Community Estimates (PLACES) dataset and the CDC's Wide-ranging ONline Data for Epidemiologic Research (WONDER).

The findings indicate that adult literacy proficiency levels have moderate to strong correlations with several negative health behaviors and public health outcomes in Appalachia, as an entire region, as well as in individual Appalachian states. These findings also indicate the need for cooperative and integrative solutions that incorporate community-led educational and public health interventions.



# Introduction & Background

## Low Adult Literacy Proficiency and Health Outcomes in Appalachian Counties

We demonstrate the correlative links between adult literacy proficiency levels and 25 measures of public health. This requires the establishment of baseline measures of both adult literacy proficiency and the incidence, prevalence, and mortality rates of the selected health behaviors, conditions, and outcomes. It also requires a basic understanding of the Appalachian Region, its people, and the underlying Social Determinants of Health that serve as barriers or facilitators to public health outcomes.

## The Appalachian Region at a Glance

The Appalachian Region comprises 423 counties and eight independent cities in Virginia across thirteen states—Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Virginia, and West Virginia. This region follows the Appalachian Mountain Chain in the eastern United States. This mountainous region is home to 26,300,000 people. 107 (25.3%) of Appalachia’s 423 counties are designated as “rural” by the United States Census Bureau (Pollard, Srygley, & Jacobsen, 2023), and 311 (72.2%) of Appalachia’s 431 jurisdictions have been designated as being “fully rural” by the Federal Office of Rural Health Policy (FORHP):

Due to the fact that entire counties are designated as Metropolitan when, in fact, large parts of many counties may be rural in nature, FORHP has used an alternative method of looking at sub-county units of these Metropolitan counties that would allow sections to be designated rural. [...] On January 12, 2021, FORHP published a final Notice in the Federal Register implementing the modification as proposed to expand its list of rural areas (Health Resources and Services Administration, 2021).

The rurality of Appalachian jurisdictions (Figure 2) negatively impacts several of the Social Determinants of Health (Figure 1) and drives many of the negative educational and health outcomes in the region.

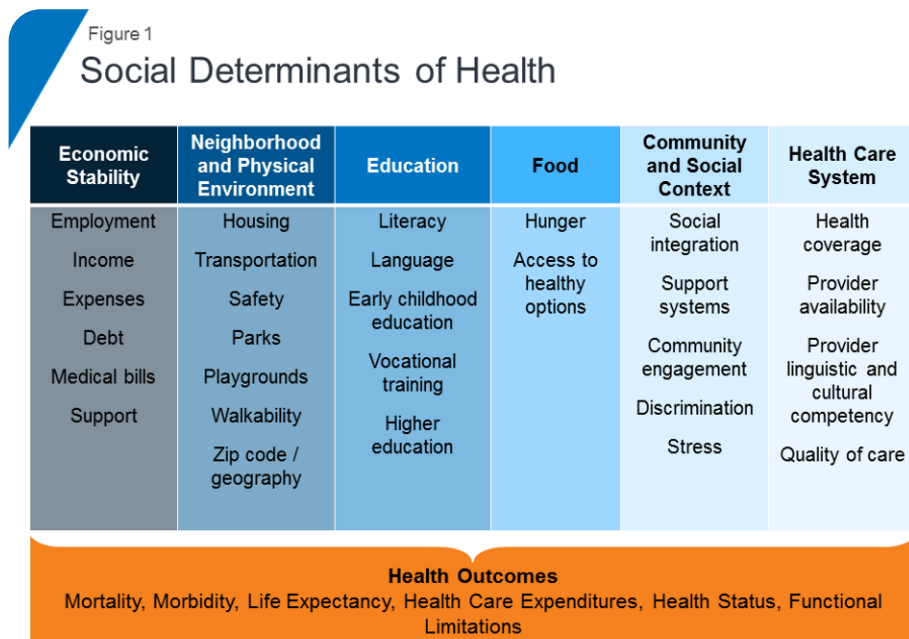
The median age of the population of the Appalachian Region is 2.5 years higher than the United States average, at 41.3 years compared to 38.8 years. The Southern Appalachia subregion has the lowest median age at 39 years, while the Northern Appalachian subregion has the highest median age at 42.7 years. Metro regions boast the lowest median age (40.0) while non-metro adjacent to small metros have the highest median (43.7). In all but one case of states that include both Appalachian and non-Appalachian areas, Appalachian populations hold a higher median age than those of their non-Appalachian counterparts, South Carolina being the only exception (Pollard, Srygley, & Jacobsen, 2023).

The population of the Appalachian Region is predominantly White, with 79.8% of the population identifying as White alone, as compared to the United States as a whole at 59.3%. The makeup of the non-White population differs from the United States average in that Black-identifying people make up the majority of the remainder (10.2%) as opposed to the majority being Hispanic or Latino in the United States (18.9% in the United States as a whole, 5.8% in the Appalachian Region). However, the percentage of White versus non-White population varies widely by subregion. While Central Appalachia has a White population of 94%, Southern Appalachia has only 65.4% of the population identifying as White (Pollard, Srygley, & Jacobsen, 2023).

## The Social Determinants of Health in Appalachia

The Social Determinants of Health (SDOH) are “the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (Artiga & Hinton, 2018). The determinants are separated into six categories: Economic Stability, Neighborhood and Physical Environment, Education, Food, Community and Social Context, and Health Care System

Figure 1 - The Social Determinants of Health



Note. Image retrieved from Artiga & Hinton, 2018.

(Figure 1). The SDOH do not only contribute to health behaviors, conditions, and outcomes; each SDOH is inextricably linked with the others. For example, having insufficient access to food (i.e., being hungry or experiencing food insecurity) has been associated with worse academic and cognitive outcomes (Gallegos, Eivers, Sondergeld, & Pattinson, 2021).

## Economic Stability

While the unemployment rate in Appalachia is comparable to the national average (4.5% in the Appalachian Region compared to 4.6% nationwide), a greater percentage of the population earns less than 200% of the national poverty level (19% in the Appalachian Region compared to 16.6% nationally), and 6.4% of the Appalachian population are below 50% of the poverty level, whereas the national average is 5.8% (Pollard, Srygley, & Jacobsen, 2023). Appalachia's median household income sits nearly \$13,000 below the US median income (\$56,780 in Appalachia, \$69,021 nationwide), with an overall poverty rate of 14.5%, while the nation's overall poverty rate sits at 12.6% (Pollard, Srygley, & Jacobsen, 2023).

With higher unemployment rates and substantially greater poverty rates than the national average, the Appalachian Region also has greater accumulation of debt and higher rate of default on loans and medical bills. Additionally, people in Appalachia are subject to higher interest rates than the national average and are more likely to be denied financing (Liu et al., 2022). For example, in Appalachian Persistent Poverty Counties (PPCs), in 2021 the average mortgage rate was 3.857% and only 3.127% nationally. Additionally, Liu et al. also found that 11% of the Appalachian population (and 20% of those living in PPCs) have mortgages for manufactured housing, compared to the national average of 3%, which means higher interest rates, lot rents, and other fees associated with manufactured housing.

Appalachian households also experience a significantly higher average energy burden—the percentage of a household's median yearly income spent on utilities, including electricity, gas, and/or water—than the national average. People living in Appalachia spend an average of 6.5% of annual income on utility bills compared to the national average of 3.4% (Greenlink Analytics, 2023). While energy burden is not a measure of public health, it does serve an SDOH that often leads households to forego necessities like food and medicine to pay energy bills (United States Energy Information Administration, 2020).

Appalachians also have a much greater likelihood of having medical debt. While nationally 17% of people have delinquent medical debt accounts, 24% of rural Appalachians do. Additionally, rural Appalachians with medical debt have more than double the rates of delinquency for other credit products (Liu et al., 2022).

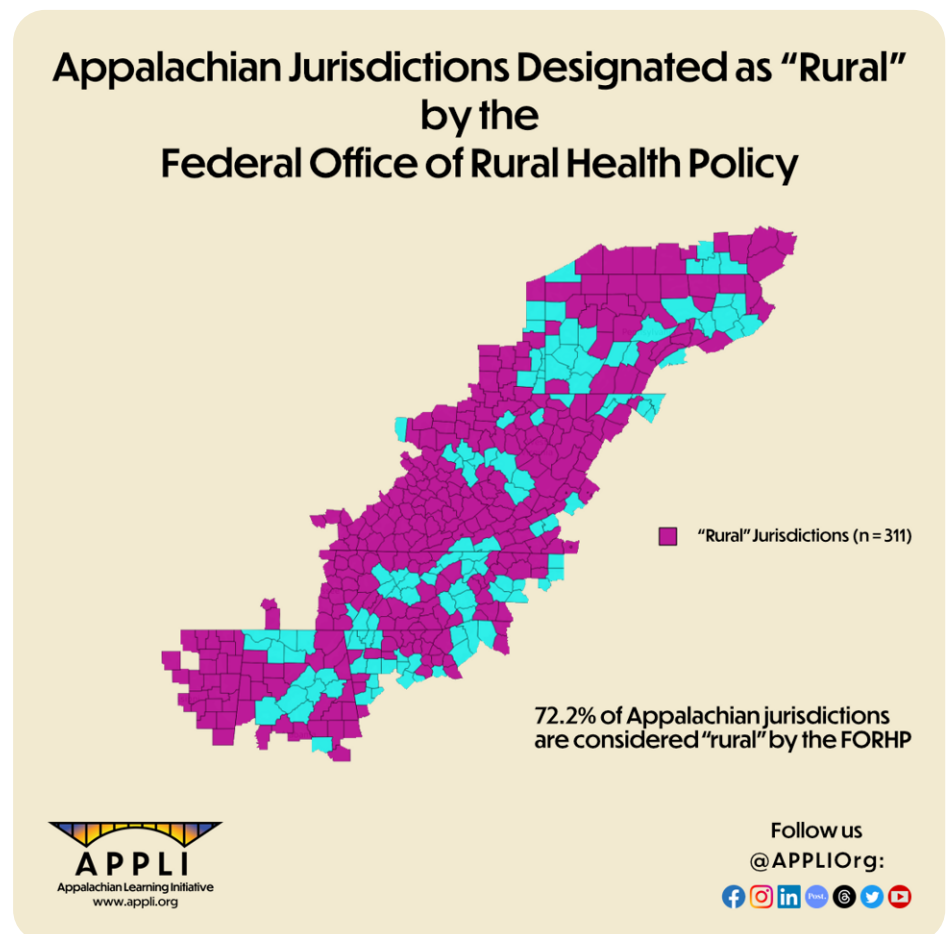
## Neighborhood and Physical Environment

While the Appalachian Mountains are a vast natural landscape, many Appalachians find themselves living in geographically- and topographically-isolated communities. The majority of Appalachian jurisdictions are classified as “rural” by the FORHP (Figure 2), which may lead to the impression that the physical environment is rife with opportunities for physical activity, but rural and geographic isolation increases reliance on personal vehicles for transportation. While personal vehicle use and ridership does not cause obesity, links between the time spent in personal vehicles and the risk of obesity have been examined for over two decades. Each additional hour spent in a car per day is associated with a 6% increase in the likelihood of obesity (Frank, Andreson, & Schmid, 2004), and personal vehicle reliance is significant throughout most Appalachian jurisdictions (Price & Godwin, 2012). Price and Godwin’s mapping of the United States showed that the areas where reliance upon personal vehicles was higher than the national average also had higher rates of obesity and diabetes.

Recent research by Smart Growth America found that there are 292 counties in the United States where at least 10% of households don’t have access to a car, of which 56% (164) are rural counties. Most of those 164 counties are located in Kentucky, West Virginia, North Carolina, South Carolina, Alabama, and Mississippi (as well as South Dakota, Louisiana, and Alaska; Bellis, 2020).

In areas where the topography serves as a physical barrier to accessing educational and healthcare services, reliable public transportation can be equally difficult to access.

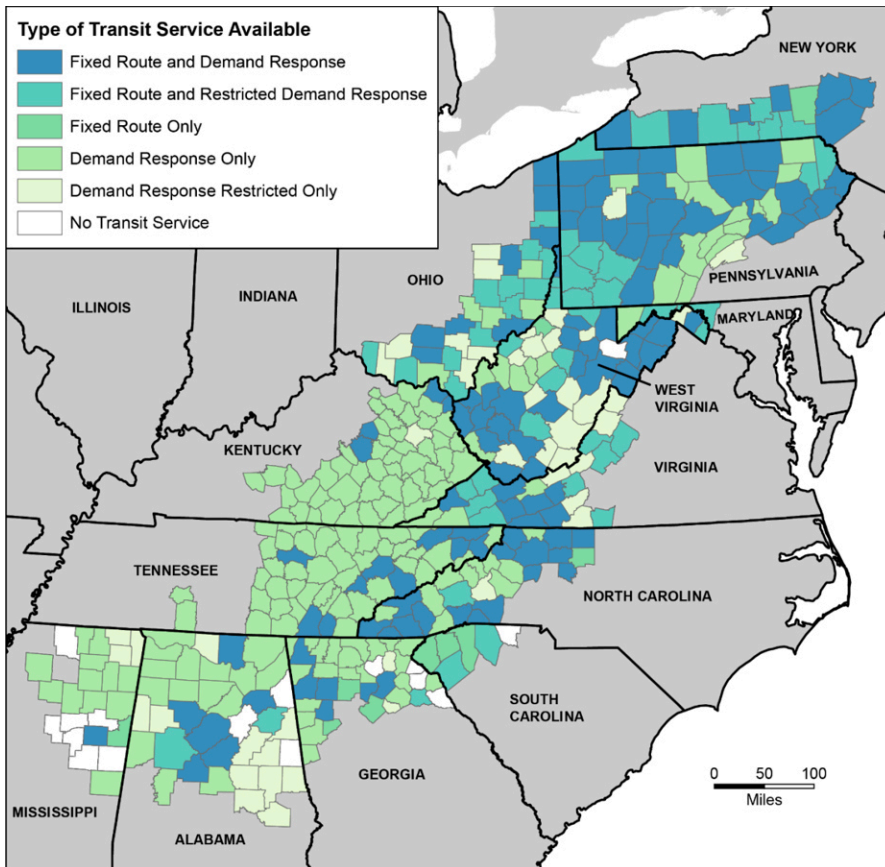
**Figure 2 - Appalachian Jurisdictions Designated as “Rural” by the Federal Office of Rural Health Policy**



Note. Map created from data retrieved from HRSA, 2021.



**Figure 3 - Types of Transit Service Available by County**



Note. Retrieved from Appalachian Regional Commission (ARC), 2020.

healthcare deficits.

## Education

Adults living in the Appalachian Region are less likely to have earned at least a high school diploma than the national average, with 83% of Appalachian adults aged  $\geq 25$  being high school graduates compared to 87.3 in the United States (NCES, 2020a). Appalachia also substantially lags behind when it comes to post-secondary education, with only 44.4% of Appalachian adults aged  $\geq 25$  having obtained some post-secondary education compared to the national average of 60%. In terms of literacy proficiency, 65.1% of Appalachian adults aged 16-74 read at or below an Eighth Grade level is 65.1% compared to the national average of 54.1%, including 23.9% reading at or below a Third Grade level compared to the national average of 21.8% (NCES, 2020a).

While most people living in Appalachian jurisdictions “have” access to public transportation services on paper, that access is often greatly limited by actual availability and the types and frequency of services provided (Figure 3).

Without personal transportation, people living in Appalachia must rely upon either friends, relatives, or public transportation to access both non-virtual educational opportunities and healthcare services. These barriers are likely to contribute both to the decision to seek remedial or further adult education opportunities or to healthcare avoidance (as a result of inconvenience and/or cost), thus potentially exacerbating existing educational and

## Food

The rate of food insecurity in the Appalachian Region is around 14%, approximately 2% higher than the national average (West Virginia University, 2023). 293 (67.8%) of Appalachia's 431 counties and independent Virginia cities have food insecurity rates higher than the national average of 11.8% (Hake, Engelhard, & Dewey, 2022). Economic insecurity and state-level differences in eligibility for social safety programs, such as the Supplemental Nutrition Assistance Program (SNAP), exacerbate the rate of hunger and food insecurity.

## Community and Social Context

People of the Appalachian Region experience worse health outcomes due to the social isolation prevalent in the region. For instance, a significant positive association between social isolation, social disconnectedness, and perceived isolation and a variety of cognitive functions (memory, executive functioning, attention, language, and overall function) in older adults in Appalachia. (DiNapoli, 2013) A study by Douglas Post of Appalachian women in Ohio shows social isolation contributes to a higher rate of depression. (Post, 2013) Women in the Appalachian Region carry concerns regarding social perceptions against mental health that impacts their willingness to seek treatment. Some point to community stigma towards mental health struggles. Others feel a deep shame based on their spiritual beliefs. Still more felt their struggles were ignored by the people in power that provide support and adequate care for mental health issues. (Snell-Rood, 2016)

The isolation continues even outside the confines of Appalachia. By and large, the Appalachian Region is seen as its own distinct area worlds apart from the rest of the United States, and with that belief comes a derision towards it and its people. Appalachians are thought to be poor, uneducated, uncivilized, and "backwards". These stereotypes are often upheld and even embellished by popular media, and many people of the region have stories about being asked if their houses had running water and surprise at their ownership of shoes. (Coyne, 2006)

## Health Care System

In Appalachia, the supply of primary care physicians per 100,000 people is 66.8 compared to the national average of 75.6, approximately 12% lower. Rural counties fare the worst with 55.6 per 100,000, 26% lower than the nation as a whole. The supply of specialty physicians is 28% lower than average, while the supply of mental health providers is 35% lower than the national average. While the uninsured population under 65 is slightly better than average (15.8% compared to 16.8% nationally), in distressed counties, this number swells to 18.7% (Pollard, Srygley, & Jacobsen, 2023).

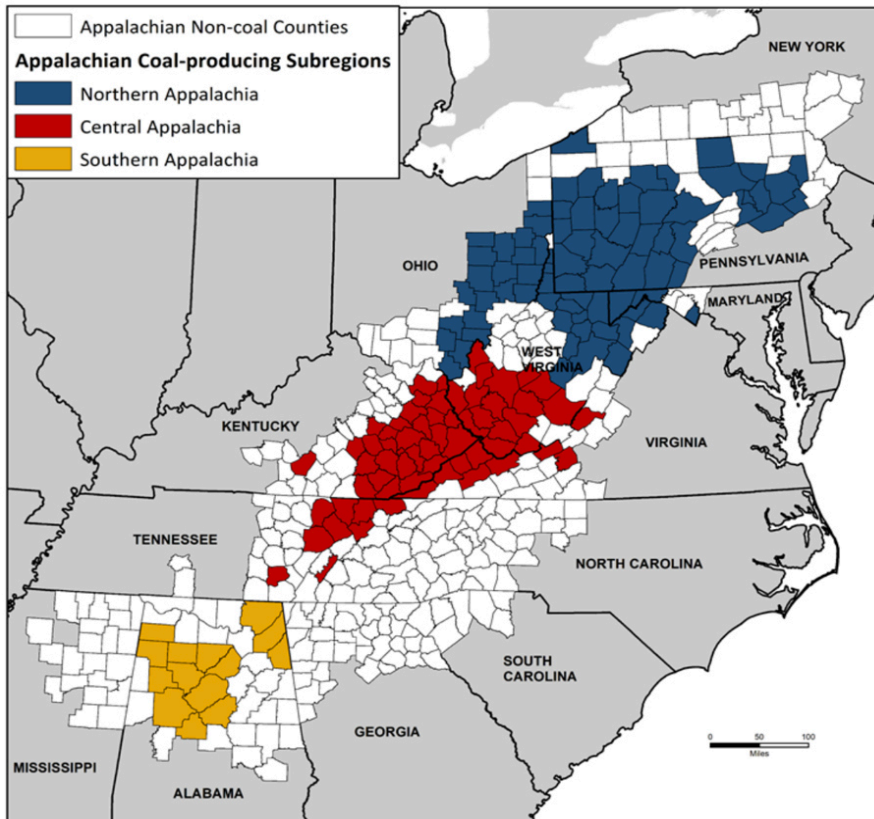
## External Factors That Impact Access to and Outcomes of Education and Healthcare Access

### Figure 4 - Appalachian Coal-Producing Subregions and Appalachian Non-Coal Counties

In addition to the SDOH that impact both education and healthcare

The mountainous terrain makes the development of infrastructure both costly and difficult. Building roads through the Appalachian Mountains requires either cutting or blasting through mountains or building in valleys, both of which increase the cost of construction. The same is true for the expansion of public utilities, such as reliable electricity, centralized water and sewage, gas, and communication technologies, such as cellular towers and broadband Internet. This means that the people living in these jurisdictions are more likely to be both physically and digitally

Figure 1: Appalachian Coal-producing Subregions and Appalachian Non-coal Counties



Source: Appalachian Regional Commission, 2022 and U.S. Energy Information Administration (EIA)  
Note: Appalachian coal-producing subregions include counties within Appalachian region, as defined by EIA, that produced at least one thousand short tons of coal in any year from 2000 through 2021.

Note. Retrieved from ARC, 2022.

isolated from other parts of the state, in general, and from educational opportunities and healthcare services, specifically.

In addition to being isolated, an additional factor exists that either directly or indirectly impacts both educational and health outcomes: coal mining. Central Appalachia is home to the Appalachian coal region which includes a long coal seam that spans Alabama, Eastern Kentucky, Maryland, Ohio, Pennsylvania, Tennessee, Virginia, and West Virginia (United States Energy Information Administration, 2022; Figure 4).

Many counties in Central Appalachia continue to be heavily reliant upon the coal industry to support both employment and local economies despite two decades of steady declines in the production of coal and job losses (ARC, 2022). Historically, jobs in the coal mining sector—specifically in the actual mining of coal and the management thereof—do not require high levels of education in order to earn hourly wages that are at or above the local median incomes. Many of these physical labor jobs do not require even a high school diploma, and the jobs that are available for college graduates in coal-dependent counties—careers in natural resources, education, and social and community services—tend to be in occupations that pay less than the salaries offered for non-college graduates in the coal industry (Douglas & Walker, 2017). This may serve as a disincentive to strive for better educational outcomes or further education beyond a high school diploma.

In the Appalachian Black Belt—counties in Southern Appalachia where Black Appalachian compose a significant percentage or a majority of the population, such as Macon County, Alabama (82.2% Black), and Noxubee County, Mississippi (72.1% Black)—topographic barriers (i.e., mountains) are less prohibitive than barriers related to distance, significant chronic federal and state underfunding of both infrastructure and education, and the impacts of systemic racism on the funding appropriation and allocation processes for increasing the number of, access to, and quality of educational and healthcare facilities.

Eight of the ten Appalachian Black Belt jurisdictions with the largest Black populations are in Alabama and Mississippi, with the eighth in Virginia (Martinsville City) and the ninth in Georgia (Douglas County), and each of those jurisdictions has a significantly high percentage of adults reading at or below an Eighth Grade level, ranging from 61.6% in Douglas County, Georgia, to 86.1% in Noxubee County, Mississippi (NCES, 2020a). In addition to low adult literacy proficiency levels, all ten counties have a prevalence of adult obesity well above the national average of 31.9% (ranging from 37.4% in Douglas County, Georgia, to 47.3% in Macon and Hale Counties, Alabama), extraordinarily high incidence rates of chlamydia and gonorrhea compared to the national rates of 495.5 (per 100,000 residents) and 214.0, respectively, and significantly higher prevalence rates of Chronic Obstructive Pulmonary Disorder (COPD) and Coronary Heart Disease (CHD).

The disproportionate educational and public health impacts in these two Appalachian subregions are so significant, they drive many of the negative education and health rankings for the entirety of their respective states so greatly that offset by higher income, urbanized areas cannot counter their impacts.

## Differentiating Between General Literacy and Health Literacy

It is important to differentiate between general literacy and “health literacy”. Whereas general literacy is the ability to read, write, and comprehend written information, health literacy goes beyond that. Health literacy allows people to read and understand not just the written information, but also know and interpret all aspects of health. Having the ability to just read the information they are given isn’t enough. Health literacy comes in several forms. Personal health literacy allows people to find, use, and understand information about themselves. Organizational health literacy is how health organizations make the information available. Digital health literacy is knowing how to find and evaluate information from electronic sources. Numeracy is the mathematical and problem-solving skills needed to navigate health information or data. By being familiar with these aspects, one can care for themselves and others, make informed decisions regarding health information, and keep themselves and others safe and healthy.

For the purposes of this research, we focused on general literacy rates in Appalachian jurisdictions rather than focusing on health literacy as we looked at the correlation between the proficiency level of adult readers and the correlations between 25 measures of public health.



# Limitations

## The Measurement of Health Literacy

The primary limitation of this research is that the available national, state, and census-level health literacy scoring is based upon data that are 20 years old. While the University of North Carolina at Chapel Hill (UNC-CH) put significant effort into developing this interactive mapping tool in 2014, the health literacy estimates are based on the 2003 National Assessment of Adult Literacy (National Health Literacy Mapping to Inform Health Care Policy, 2014). The data gathered during the three initial PIAAC testing periods utilized a more precise tool to measure adult literacy proficiency and present those findings on a county-level basis. The data from UNC-CH, aside from being outdated, are also more granular in their presentation, going down to the census tract level. This presents an additional limitation when attempting to gather incidence and mortality rates, as census-level data, particularly in tracts with small populations, are more likely to have suppressed data than at the county level.

## Suppressed Data

A secondary limitation of this research is data left unreported by data collection agencies. In epidemiological reporting, when there are too few observations of an outcome within a specific population, demographic group, or geographic area, or if the number otherwise falls under disease-specific privacy policy rules, data are reported as being “Suppressed” (CDC, 2022). Data suppression serves the primary purpose of protecting the identities of patients, particularly in smaller populations where a small incidence or mortality rate may lead to a person being identified as one of only a small number of people who were diagnosed or died.

While the suppression of incidence, prevalence, and mortality data is important to protect patients’ identities, it creates various “blind spots” in epidemiological reporting. We address this limitation by dropping data with a missing variable. For example, in Coosa County, Alabama, 75.0% of adults read at or below an Eighth Grade level, but the rate of lung cancer deaths per 100,000 residents is suppressed. In this case, our analysis will omit the row for Coosa County when calculating the correlation coefficient between Adult Literacy Proficiency and Lung Cancer Mortality (2021).

## Access to and Utilization of Healthcare Services in the Appalachian Region

A third limitation to this research is the potential lack of infectious disease incidence data in rural or underserved Appalachian counties. According to research from GoodRx, a majority of counties in the Appalachian Region are considered to be “Healthcare Deserts,” which are:

...areas where people lack adequate access to six key healthcare services: (1) pharmacies, (2) primary care providers, (3) hospitals, (4) hospital beds, (5) trauma centers, and (6) low-cost health centers (Nguyen et al., 2021).

Beyond just the absence of healthcare services, Appalachian residents are more likely to avoid physicians than non-Appalachians (Vanderpool & Huang, 2010). This means that people living in Appalachia self-report being more likely to avoid their physicians because they “fear having a serious illness,” are less likely to receive diagnostic testing, and are therefore less likely to be diagnosed with both infectious and non-infectious diseases. The difficulty of accessing healthcare services combined with a higher likelihood of physician avoidance makes it more difficult to accurately portray the incidence and prevalence of diseases. As a result, the surveys from which our data are derived may suffer from an undercount of the actual prevalence of specific conditions due to a lack of physician encounters and under-reporting from the population. We are unaware of studies or survey data that have accounted for this issue. Because of this, our analysis is likely conservative and understates some of the relationships we report but to an unknown degree.

### Demographic Homogeneity in the Available Data

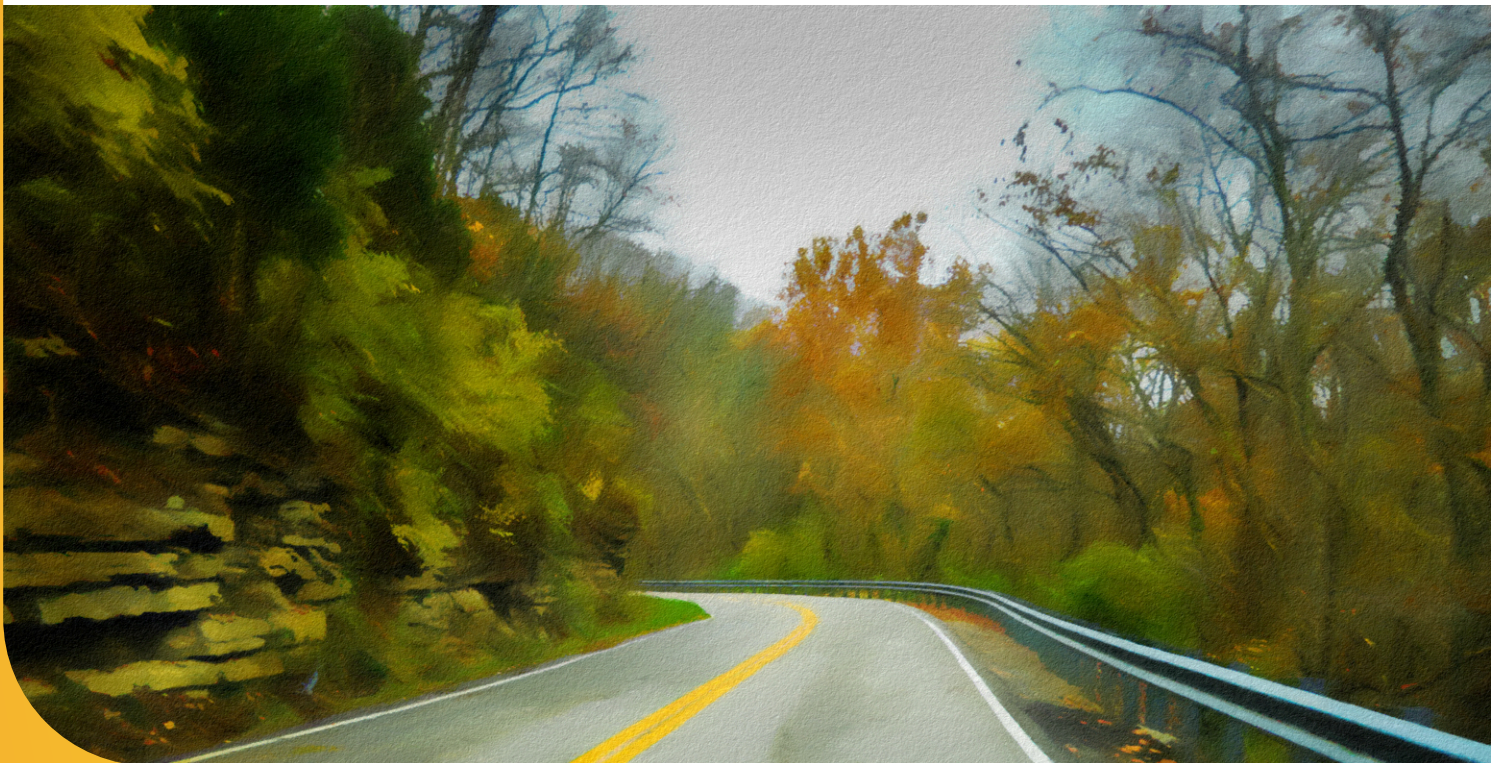
A fourth limitation involves the demographic makeup, cultural identities, and lived experiences of people living in Appalachia. While the portrayal of Appalachia by both media and popular culture tends to be a stereotype of White, lower-income Appalachians, the region is actually home to a racially, ethnically, linguistically, and culturally diverse population that spans from the northeasternmost county of Otsego, New York, to the westernmost county of Panola, Mississippi—a distance of 1,010.5 miles that spans two time zones and numerous topographic landscapes. The Appalachian experience is not monolithic; just as the elevation changes, so do the people who inhabit those areas. The data from PIAAC are, unfortunately, limited in scope, and do not accurately represent literacy proficiency levels by race or ethnicity—only age group and educational attainment level. Additionally, epidemiological data are more likely to be suppressed when broken down into racial and ethnic categories, particularly in Appalachia’s 107 rural counties where a paucity of racial and ethnic diversity would make it easier to identify patients based on demographically delineated incidence, prevalence, and mortality reporting. Beyond this, race as a categorical variable can be subject to misidentification and several confounding errors, complicating its statistical use (Zuberi (Ed.) & Bonilla-Silva (Ed.), 2008). As such, we have chosen to exclude demographic delineation during the data-gathering process.

## Age of Adult Literacy Data

A fifth limitation to this research is that the data for adult literacy proficiency levels are based on data from the 2018 PIAAC findings. Cycle II of testing is underway (Mamedova, Provasnik, & Xie, 2022) and the result will not be released by the Organization for Economic Cooperation and Development (OECD) until 2024. This cycle of PIAAC testing will be the first to include adults aged 16 or older who may have experienced educational interruptions or delays as a result of the COVID-19 global pandemic. It is unknown what impacts those interruptions will have on adult literacy proficiency results. If the results of Cycle II's testing lead to statistically significant shifts in county-level Lit\_P1 and Lit\_P2 percentages, and thus the combination of Lit\_P1 + Lit\_P2 percentages, the corresponding correlation coefficients will likely shift, as well. This will require that the research be repeated in order to update the findings.

## Statistical Assumptions

The final limitation we identified was in our analysis. Our analysis utilizes Pearson correlations as the primary means of exploring the relationship between variables within Appalachia. As a result, our analysis is subject to the constraints of this kind of analysis. For example, it cannot accurately describe nonlinear relationships, does not have the ability to distinguish between dependent and independent variables, to assess or correct for heteroskedasticity, or to control for various factors impacting relationships and outcomes. Since this is our first exploration of these relationships, we also have not connected this data into an explanatory and predictive theoretical construct.





# Methodology

One of APPLI’s primary missions as a non-profit organization is to research, analyze, report on, and advocate for issues related to adult literacy in the Appalachian Region. This requires gathering data from Cycle I of PIAAC testing released by the National Center for Education Statistics (NCES, 2020a), which included the first three rounds of PIAAC data collection (in 2012, 2014, and 2017, respectively).

PIAAC is an international study that measures, analyzes, and compares adults’ basic skills of literacy, numeracy, and digital problem solving across 43 countries, breaking the literacy and numeracy scores into six proficiency categories (Figure 5).

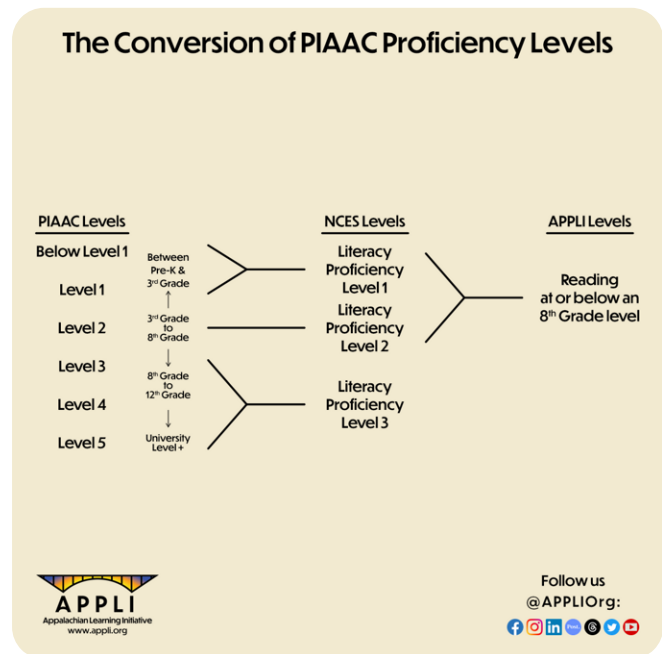
The NCES simplifies the six PIAAC literacy proficiency levels into three proficiency levels. In its research and reporting on adult literacy, APPLI further simplifies these proficiency levels into two categories: (1) Reading at or below an Eighth Grade Level and (2) Reading above an Eighth Grade Level (Figure 6).

**Figure 5 - Literacy Proficiency Levels as Defined by the Program for the International Assessment of Adult Competencies**



Note. Figure created from the National Center for Education Statistics, 2020c.

**Figure 6 - The Simplification of the Program for the International Assessment of Adult Competencies Proficiency Levels**



Note. Figure created from the National Center for Education Statistics, 2020c.

We used Microsoft Excel to organize the data and produce Pearson correlations. Proficiency Levels 1 + 2 were used as Array 1 in every calculation, with a selected measure of public health serving as Array 2. Calculations were performed both for the Appalachian Region—including all 423 counties and eight independent Virginia cities—and for the Appalachian jurisdictions in each of Appalachia’s thirteen states. APPLI then created heat maps for each jurisdiction using Tableau, a visual analytics program, for both Adult Literacy Proficiency Levels 1 + 2 and the individual public health measures.

APPLI gathered data for 25 public health measures, including health behaviors, physical conditions, and disease states gathered from a variety of sources (Table 1). These measures were chosen because of the availability and reliability of current county-level data. We then evaluated them based upon their correlation coefficients to determine which measures were positively, negatively, or not correlated with adult literacy proficiency. Mortality data were gathered from the CDC’s WONDER database using their respective International Classification of Diseases, Tenth Revision (ICD-10) codes (Appendix B).

**Table 1 - List of Selected Public Health Measures and Their Respective Data Years and Sources**

Public Health Measure	Measure Type	Data Year	Data Source
Adult Asthma Prevalence	Percentage (%) of Adult Population	2020	PLACES (CDC, 2023x)
Adult Depression Prevalence	%	2020	PLACES
Adults Diabetes Prevalence	%	2020	PLACES
Adults Obesity Prevalence	%	2020	PLACES
All Cancer Mortality	Rate (per 100,000 persons)	2021	WONDER (CDC, 2023x)
Breast Cancer Mortality	Rate	2021	WONDER

**Table 1 - List of Selected Public Health Measures and Their Respective Data Years and Sources (Cont.)**

<b>Public Health Measure</b>	<b>Measure Type</b>	<b>Data Year</b>	<b>Data Source</b>
Cervical Cancer Mortality	Rate	2021	WONDER
Chlamydia Incidence	Rate	2021	NCHHSTP, 2023
Cocaine Overdose Deaths	Rate	2021	WONDER
Colorectal Cancer Mortality	Rate	2021	WONDER
COPD Prevalence	%	2020	PLACES
Coronary Heart Disease Prevalence	%	2020	PLACES
Current Adult Smoking Behavior	%	2020	PLACES
Drug Overdose Deaths	Rate	2021	NCHS, 2022
Gonorrhea Incidence	Rate	2021	NCHHSTP
HIV Incidence	Rate	2021	NCHHSTP
HIV Prevalence	Rate	2021	NCHHSTP
Lung Cancer Mortality	Rate	2021	WONDER
Methamphetamine Overdose Deaths	Rate	2021	WONDER

**Table 1 - List of Selected Public Health Measures and Their Respective Data Years and Sources (Cont.)**

Public Health Measure	Measure Type	Data Year	Data Source
Opioid Overdose Deaths	Rate	2021	WONDER
Ovarian Cancer Mortality	Rate	2021	WONDER
Pancreatic Cancer Mortality	Rate	2021	WONDER
Prostate Cancer Mortality	Rate	2021	WONDER
Stimulant Overdose Deaths	Rate	2021	WONDER
Syphilis Incidence	Rate	2021	NCHHSTP



# Results

APPLI assessed the correlation between adult literacy proficiency at or below an Eighth Grade Level and each measure of public health.

## Findings for the Appalachian Region

APPLI found that the ability of adults to read at or below an Eighth Grade Level across Appalachia's 423 counties and eight independent Virginia cities had strong correlations ( $r$ ) with the prevalence of adult diabetes ( $r = 0.7$ ), adult obesity ( $r = 0.7$ ), COPD ( $r = 0.7$ ), Coronary Heart Disease (CHD) ( $r = 0.8$ ), and current adult smoking behavior ( $r = 0.8$ ). The data for cervical cancer mortality contained only two data pairs that were not Suppressed or zero values, thus failing to meet a minimum confidence interval to draw an accurate correlation (Figure 7). The full findings, including those for the individual states, can be found in Appendix C.

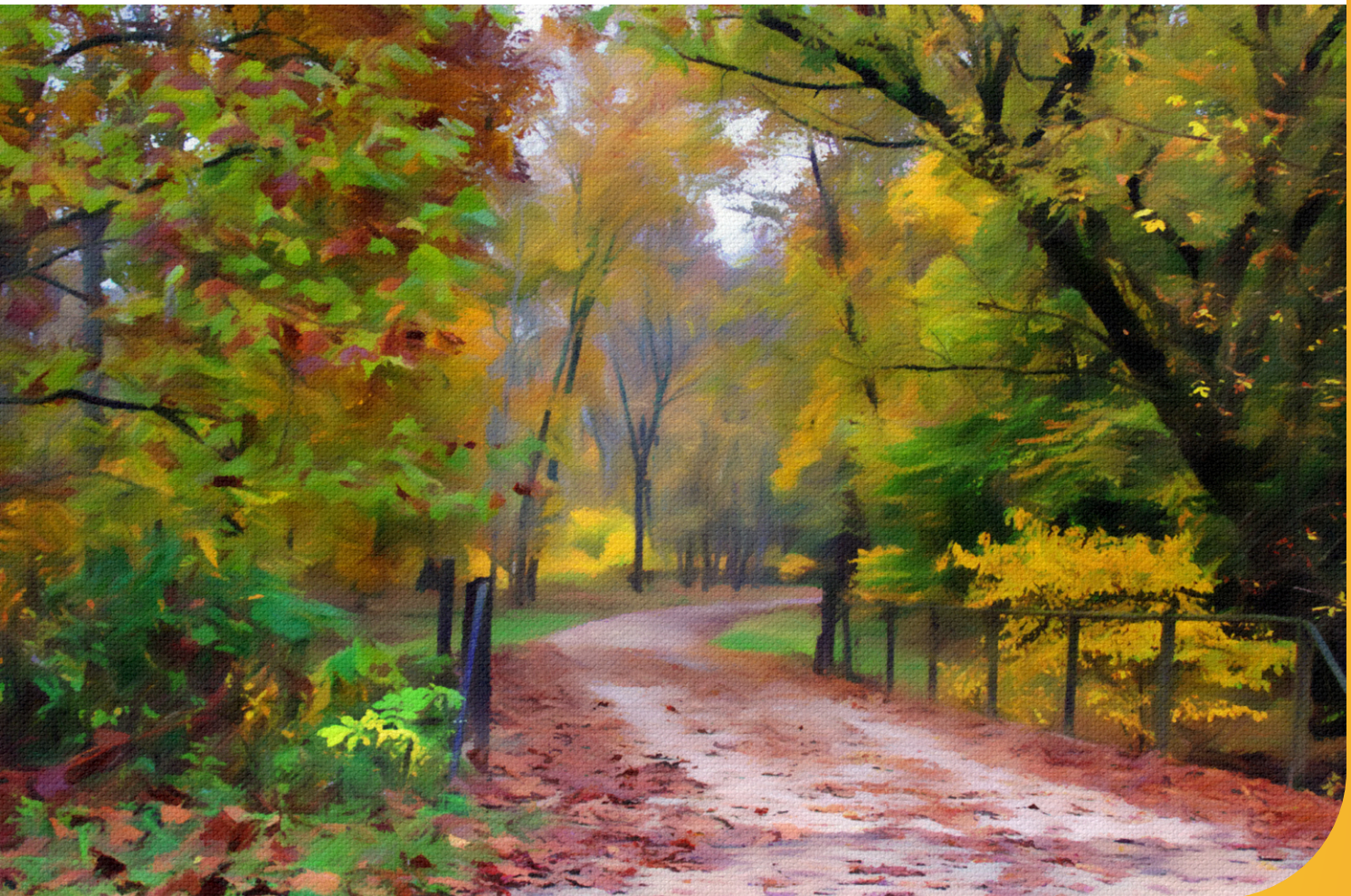
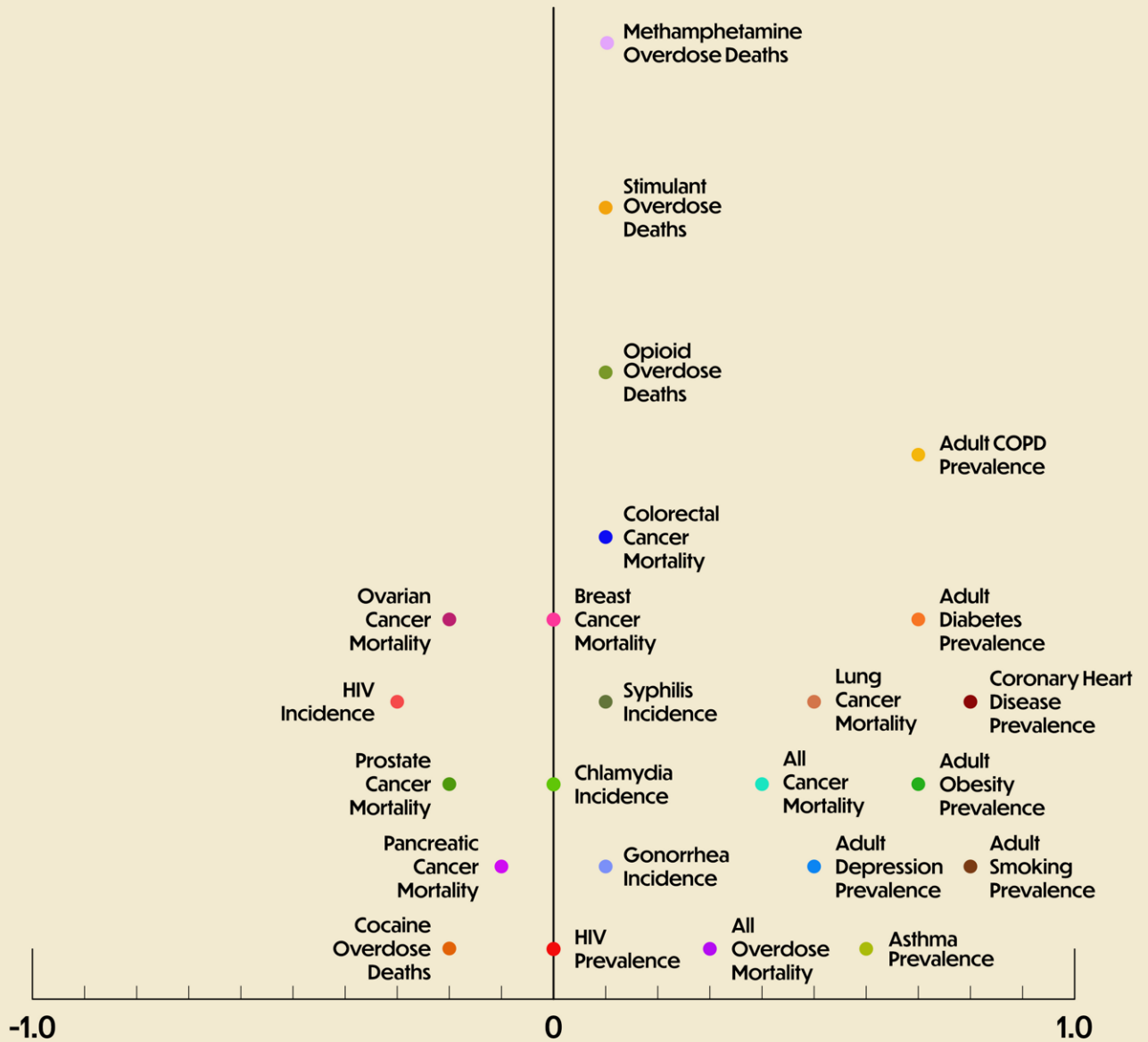


Figure 7 – The Correlation Between the Percentage of Adults Reading At or Below an Eighth Grade Level and 25 Selected Public Health Behaviors, Conditions, and Outcomes in the Appalachian Region

## Pearson Correlation Coefficients Between Adult Literacy and Health Measures in the Appalachian Region



Measure with Insufficient Data Pairs  
 · Cervical Cancer Mortality



## Findings for Alabama's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade Level across Alabama's 37 Appalachian counties had strong positive and negative correlations with the prevalence of adult asthma ( $r = 0.8$ ), adult diabetes ( $r = 0.7$ ), adult obesity ( $r = 0.7$ ), COPD ( $r = 0.8$ ), CHD ( $r = 0.8$ ), current adult smoking behavior ( $r = 0.9$ ), and the mortality rates of ovarian cancer ( $r = -0.9$ ) and prostate cancer ( $r = 0.8$ ). The data for cervical cancer mortality contained only one data pair that was not Suppressed or zero values, thus failing to meet a minimum confidence interval to draw an accurate correlation (Appendix C).

## Findings for Georgia's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade Level across Georgia's 37 Appalachian counties had strong positive and negative correlations with the prevalence of adult asthma ( $r = 0.9$ ), adult diabetes ( $r = 0.8$ ), adult obesity ( $r = 0.8$ ), COPD ( $r = 0.9$ ), CHD ( $r = 0.9$ ), current adult smoking behavior ( $r = 0.9$ ), and the mortality rate of ovarian cancer ( $r = -0.7$ ). The data for cervical cancer mortality, cocaine overdose deaths, and ovarian cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).



## Findings for Kentucky's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade Level across Kentucky's 54 Appalachian counties had strong positive and negative correlations with the prevalence of adult asthma ( $r = 0.7$ ), adult diabetes ( $r = 0.8$ ), COPD ( $r = 0.8$ ), CHD ( $r = 0.8$ ), and current adult smoking behaviors ( $r = 0.9$ ), as well as the mortality rates of breast cancer ( $r = -0.7$ ), lung cancer ( $r = 0.7$ ), and pancreatic cancer ( $r = -0.7$ ). The data for breast cancer mortality, cervical cancer mortality, cocaine overdose deaths, HIV incidence, ovarian cancer mortality, pancreatic cancer mortality, and prostate cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).

## Findings for Maryland's Appalachian Jurisdictions

APPLI found that only eleven of the 25 selected measures of public health contained the three complete points of data sufficient to meet a minimum confidence interval to draw a useful correlation between those measures and adult literacy proficiency for Maryland's three Appalachian counties. The ability of adults to read at or below an Eighth Grade Level had perfect positive ( $r = 1.0$ ) correlations with the prevalence of adult depression, COPD, and CHD. The data for breast cancer mortality, cervical cancer mortality, chlamydia incidence, cocaine overdose deaths, colorectal cancer mortality, gonorrhea incidence, HIV incidence, methamphetamine overdose deaths, opioid overdose deaths, ovarian cancer mortality, pancreatic cancer mortality, prostate cancer mortality, stimulant overdose deaths, and syphilis incidence lacked the three sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).





## Findings for Mississippi's Appalachian Jurisdictions

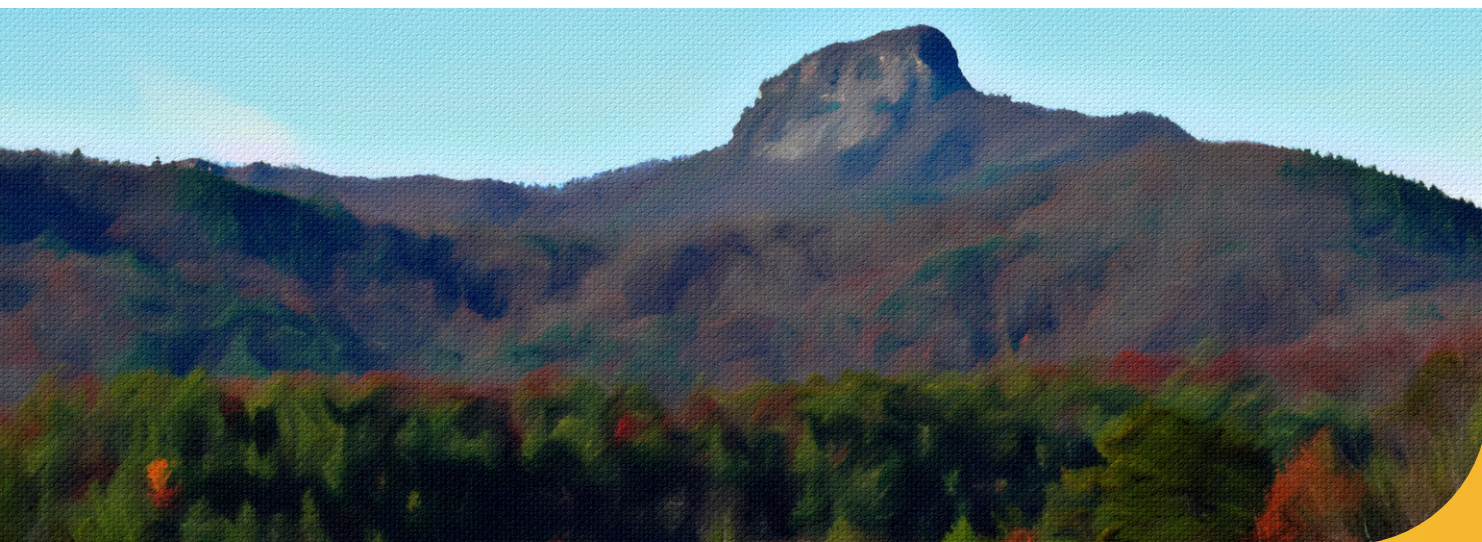
APPLI found that the ability of adults to read at or below an Eighth Grade Level across Mississippi's 24 Appalachian counties had strong positive and negative correlations with the prevalence of adult asthma ( $r = 0.8$ ), adult diabetes ( $r = 0.7$ ), adult obesity ( $r = 0.8$ ), current adult smoking behavior ( $r = 0.8$ ), and the mortality rate of lung cancer ( $r = 0.7$ ). The data for breast cancer mortality, cervical cancer mortality, cocaine overdose deaths, colorectal cancer mortality, HIV incidence, methamphetamine overdose deaths, opioid overdose deaths, ovarian cancer mortality, pancreatic cancer mortality, prostate cancer mortality, and stimulant overdose deaths lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).

## Findings for New York's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade Level across New York's 14 Appalachian counties had strong positive correlations with the prevalence of COPD ( $r = 0.9$ ), CHD ( $r = 0.8$ ), and current adult smoking behavior ( $r = 0.9$ ), and the mortality rates of all cancers ( $r = 0.7$ ) and lung cancer ( $r = 0.7$ ). The data for cervical cancer mortality, cocaine overdose deaths, and ovarian cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).

## Findings for North Carolina's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade Level across North Carolina's 31 Appalachian counties had strong positive correlations with the prevalence of adult asthma ( $r = 0.7$ ), adult diabetes ( $r = 0.7$ ), COPD ( $r = 0.8$ ), CHD ( $r = 0.8$ ), and current adult smoking behavior ( $r = 0.9$ ). The data for cervical cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).



## Findings for Ohio's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade Level across Ohio's 32 Appalachian counties had strong positive and negative correlations with the prevalence of COPD ( $r = 0.7$ ) and current adult smoking behavior ( $r = 0.7$ ), and with the mortality rate of ovarian cancer ( $r = -0.9$ ) and prostate cancer ( $r = 0.8$ ). The data for cervical cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).

## Findings for Pennsylvania's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade level across Pennsylvania's 52 Appalachian counties had strong positive correlations with the prevalence of COPD ( $r = 0.8$ ), CHD ( $r = 0.8$ ), and current adult smoking behavior ( $r = 0.9$ ). The data for cervical cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).

## Findings for South Carolina's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade Level across South Carolina's 7 Appalachian counties had perfect positive correlations ( $r = 1.$ ) with CHD and current adult smoking behaviors. There were also strong positive and negative correlations with the incidence of gonorrhea ( $r = 0.7$ ), the prevalence of adult asthma ( $r = 0.9$ ), adult diabetes ( $r = 0.9$ ), adult obesity ( $r = 0.7$ ), and COPD ( $r = 0.9$ ), and the mortality rates of all cancers ( $r = 0.9$ ), breast cancer ( $r = 0.7$ ), colorectal cancer ( $r = 0.8$ ), all drug overdoses ( $r = -0.8$ ), lung cancer ( $r = 0.8$ ), methamphetamine overdoses ( $r = -0.9$ ), pancreatic cancer ( $r = 0.7$ ), prostate cancer ( $r = 0.8$ ), and stimulant overdoses ( $r = -0.9$ ). The data for cervical cancer mortality, cocaine overdose deaths, and ovarian cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).



## Findings for Tennessee's Appalachian Jurisdictions

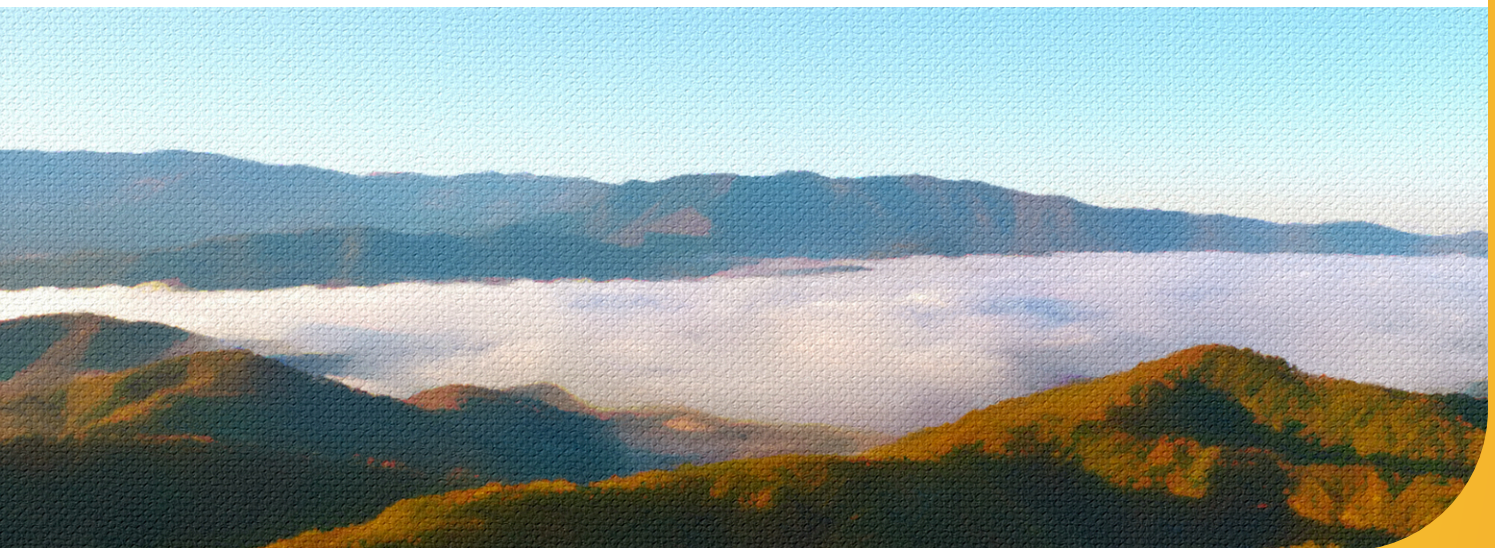
APPLI found that the ability of adults to read at or below an Eighth Grade Level across Tennessee's 52 Appalachian counties had strong positive and negative correlations with the incidence of HIV ( $r = -0.8$ ), the prevalence of adult diabetes ( $r = 0.8$ ), COPD ( $r = 0.9$ ), CHD ( $r = 0.9$ ), and current adult smoking behaviors ( $r = 0.9$ ), and the mortality rates of cocaine overdoses ( $r = -0.7$ ) and ovarian cancer ( $r = -0.9$ ). The data for cervical cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).

## Findings for Virginia's Appalachian Jurisdictions

APPLI found that the ability of adults to read at or below an Eighth Grade Level across Virginia's 25 Appalachian counties and 8 independent Appalachian cities had a strong positive correlation with the prevalence of current adult smoking behavior ( $r = 0.8$ ). The data for cervical cancer mortality, cocaine overdose deaths, HIV incidence, ovarian cancer mortality, pancreatic cancer mortality, and prostate cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).

## Findings for West Virginia

West Virginia was the only state where the entirety of counties lie within the Appalachian Region. APPLI found that the ability of adults to read at or below an Eighth Grade Level in West Virginia had strong positive and negative correlations with the prevalence of adult diabetes ( $r = 0.7$ ), COPD ( $r = 0.8$ ), CHD ( $r = 0.8$ ), and current adult smoking behaviors ( $r = 0.8$ ), and the mortality rates of cocaine overdoses ( $r = -0.7$ ) and prostate cancer ( $r = -0.8$ ). The data for cervical cancer mortality and prostate cancer mortality lacked sufficient data points necessary to meet a minimum confidence interval to draw an accurate correlation (Appendix C).



## Significant Cross Jurisdictional Findings

APPLI found that adult literacy proficiency was strongly correlated with the prevalence of COPD, CHD, and current adult smoking behaviors in almost every state's Appalachian jurisdictions (Table 2). The results for Maryland's three Appalachian jurisdictions should be viewed with caution due to small sample sizes.

**Table 2 - Correlation Findings Between Adult Literacy Proficiency and the Prevalence of COPD, Coronary Heart Disease, and Current Adult Smoking in Appalachian Jurisdictions**

Public Health Measure	Appalachia	AL	GA	KY	MD	MS	NY	NC	OH	PA	SC	TN	VA	WV
COPD Prevalence (2020)	0.7	0.8	0.9	0.8	1.0*	0.5	0.9	0.8	0.7	0.8	0.9	0.9	0.6	0.8
Coronary Heart Disease Prevalence (2020)	0.8	0.8	0.9	0.8	1.0*	0.6	0.8	0.8	0.5	0.8	1.0	0.9	0.6	0.8
Current Adult Smokers (2020)	0.8	0.9	0.9	0.9	0.2*	0.8	0.9	0.9	0.7	0.9	1.0	0.9	0.8	0.8

Note. \* - Data for Maryland's three Appalachian jurisdictions should be viewed with caution due to small sample size

Strong correlations between jurisdictional adult literacy proficiency and the prevalence of COPD were found in every state's Appalachian jurisdictions with the exceptions of Mississippi ( $r = 0.5$ ) and Virginia ( $r = 0.6$ ), where COPD was moderately correlated.

The correlations were similarly strong between adult literacy proficiency and CHD, with a perfect correlation in South Carolina (1.0) and with the exceptions of Mississippi ( $r = 0.6$ ), Ohio ( $r = 0.5$ ), and Virginia ( $r = 0.6$ ).

The correlation between jurisdictional adult literacy proficiency and the prevalence of current adult smoking behaviors was strong in every Appalachian jurisdiction, with a perfect correlation in South Carolina ( $r = 1.0$ ).

In addition to the strong correlations between adult literacy proficiency and the prevalence of COPD, CHD, and current adult smoking behaviors, APPLI also found negative correlations between adult literacy proficiency and the incidence of HIV in almost all jurisdictions (Table 3).

**Table 3 - Correlation Findings Between Adult Literacy Proficiency and the Incidence of HIV in Appalachia**

Public Health Measure	Appalachia	AL	GA	KY	MD	MS	NY	NC	OH	PA	SC	TN	VA	WV
HIV Incidence (20201)	-0.3	0.1	-0.2	*	*	*	-0.2	-0.3	-0.5	-0.6	-0.4	-0.8	*	-0.6

Note. \* – Data for Appalachian jurisdictions in this state are suppressed.



# Discussion

This research attempted to determine if correlations between adult illiteracy and poor public health behaviors and outcomes exist. Little research has been done to examine this correlation in the United States as a whole, with even less research having been done focused on Appalachia. The majority of research heretofore conducted involving healthcare and literacy focuses on “health literacy”—the ability of people to read and understand not just the written information, but to also know and interpret all aspects of health. This focus often results in researchers examining literacy only in the context of healthcare, and ignoring the underlying infrastructural issues that impact literacy proficiency itself.

A 1996 study of patients seen at urban hospitals found that patients with low general literacy had a harder time accessing medical services, understanding medical recommendations, and properly following the instructions of medical professionals (Baker et al., 1996). A more recent study in Great Britain also found that low educational attainment had a negative effect on health literacy, including smoking, nutritional habits, and how each participant viewed their overall health (von Wagner et al., 2007).

## The Role of Adult Literacy Proficiency and its Correlation with the Prevalence of Current Smoking Behaviors, Obesity, and Cardiovascular Health Issues

APPLI examined 25 distinct measures for correlations with adult literacy proficiency. Of these measures, five were shown to have high correlation between low adult literacy proficiency and negative health outcomes. One such finding was in the correlation between low literacy proficiency and obesity ( $r = 0.7$ ), as well as obesity-related or exacerbated conditions. While the correlation between obesity and other poor public health outcomes has been known (CDC, 2022d; Lavie et al., 2009), Appalachian adults with low literacy proficiency are at greater risk of becoming obese. Schenberg et al. found that while there were gaps in knowledge of proper nutrition, many of the study participants also recognized that external factors, including the availability of highly nutritious foods and influences from friends, family, fellow church attendees, and advertisements, played a large part in the way that they ate (2013). Participants suggested activities with social aspects, such as community gardening, cooking classes, and community nutrition coaches, as good ways to help with nutrition education. This presents an excellent opportunity for community-based organizations (CBOs) that focus on providing these types of skills-based learning to partner with those organizations focusing on improving adult literacy, as well as those focusing on improving health outcomes, to develop cross-sectional curricula and linkages to care and treatment to address multiple issues in one setting, with each organization actively referring participants to the other partner organizations.

Another poor public health outcome with high correlation to low adult literacy proficiency was diabetes ( $r = 0.7$ ). While diabetes is prevalent throughout much of the United States, a CDC study showed that residents of counties in Appalachia designated as “distressed” were 1.4 times more likely to be diagnosed with diabetes than those living outside of the Appalachian Region. Distressed counties were those defined as among the worst 10% of counties across the United States when examining poverty, per capita income, and 3-year unemployment rates (Barker et al., 2010). Even though this study was published in 2010, the Appalachian Diabetes Control and Translation Project (ADCTP)—a partnership between the CDC, the ARC, and the Robert C. Byrd Center for Rural Health at Marshall University—began in 2001 (Appalachian Diabetes Network, 2022). The ADCTP increased participation of the community in local events focused on proper nutrition and physical activity from 2011 to 2017, and in 2017, with the aid of local diabetes coalitions, began making it easier for communities to get physical exercise and eat healthier, including cooking classes, walking and running competitions, community gardens, and more (CDC, 2022a). The National Diabetes Prevention Program (NDPP), which was bolstered by ADCTP efforts beginning in 2011, is a national program aimed at stopping prediabetes and Type 2 diabetes (CDC, 2023e). One of the key parts of the NDPP is participation in a lifestyle change program, which often includes diabetes self-management education and support (DSMES) programs (CDC, 2023b). DSMES programs could be combined with community cooking classes that also include literacy education.

A third consistent finding was between low literacy proficiency and COPD ( $r = 0.7$ ). While not as strong a correlation, another lung disease, adult asthma, had a moderate correlation with low literacy proficiency ( $r = 0.6$ ). In 1997, Williams et al. found that knowledge scores of asthma directly correlated with the reading level of research participants with asthma. One recommendation made at the 2016 American Thoracic Society (ATS) Workshop on Education in Pulmonary Rehabilitation for Individuals with COPD included screening COPD patients for learning disorders and other mental health disorders that could disrupt their ability to learn how to manage their disease (Blackstock et al., 2018). Despite this research and recommendations, little has been done to advance screening for low literacy for patients with these chronic lung diseases. Respiratory therapists and other healthcare providers could refer these patients for testing and/or educational intervention.

CHD was another public health outcome that had a strong positive correlation ( $r = 0.8$ ) with adult illiteracy. One study showed that low literacy was associated with a higher risk of CHD in women, but no similar causation was determined in men. This study also recommended that further research be done to determine which literacy skills can best help patients reach their desired health outcomes (Martin et al., 2010). Magnani et al. suggests that patient handouts should be evaluated for not only reading levels, but also comprehension (2018).

Another finding with positive correlations to adult illiteracy was current adult smoking behavior ( $r = 0.8$ ). One factor that may contribute to continued smoking in adults is that many of the written materials for smoking cessation are written at a higher level than that which the smokers are able to read (Meade & Byrd, 1989). More recently, Shang et al. found that a large warning label with graphics as well as written text led to a decrease in smoking prevalence, regardless of literacy level (2017). Creating more patient/consumer information with graphics in addition to written text could help lead to an increase in smoking cessation.

Lung cancer mortality also had a moderate correlation to low literacy proficiency ( $r = 0.5$ ). One study examined websites with lung cancer screening information, determining that the median Reading Level of the 257 websites was at a Tenth Grade Reading Level, with the lowest Reading Level at a Fifth Grade Reading Level. The American Medical Society recommends reading material be at or below a Sixth Grade Reading Level, a goal which only 4 websites out of 257 met. The National Institutes for Health recommends reading be at or below a Seventh or Eighth Grade Reading Level, a goal which only 45 websites met (Gagne et al., 2020). Rudd also highlights the importance of avoiding jargon in patient-facing literature to eliminate issues of reading comprehension (2019).

### Navigating Mental Health Treatment in Appalachia

Cultural sensitivity is recommended when treating mental health conditions in Appalachian Americans, as well as ensuring that depression is actually the culprit for mental health concerns instead of “social suffering.” Adult depression was another finding with a moderate correlation to adult illiteracy ( $r = 0.5$ ). Treatment recommendations include utilizing community support groups where those who have benefitted from mental health treatment can share their stories as well as finding support for mental health treatments from valued community leaders (Elder et al.).

In *Night Comes to the Cumberlands*, Henry Caudill states:

But a deeper tragedy lies in the depression of the spirit, which has fallen upon so many of the people, making them, for the moment at least, listless, hopeless and without ambition.

The region was exploited for natural resources; then, when the companies who were mining those resources left, the area fell into an economic depression. Many of the Appalachians who left did so to pursue better educational opportunities for themselves and their children, leaving behind those who often had little interest in education beyond what could be received at their local schools. From Caudill's description, however, it is hard to determine whether the depression caused the lack of education or the reverse (Caudill, 2015. p. 300). One study in the United States showed that the



participants with depression consisted of more women than men, had lower levels of educational attainment, and often had parents who weren't highly educated, were more impoverished, and had no desire for further education (Cohen et al., 2020.). One international study had similar findings showing that, in Indonesia, the level of education completed helped determine the risk of depression (Patria 2022). Another global study looked at genetic data from across the globe to see if there were any potential genetic causes for the correlation between depression and low educational attainment; this study did not, however, find a positive correlation for a common genetic locus (Peyrot et al., 2015).



## Adult Literacy Proficiency and the Negative Correlations with the Diagnosis of HIV in Appalachia

According to a supplement in the CDC's 2022 HIV Surveillance Supplemental Report, educational attainment (i.e., having a high school diploma or greater) reduces the social and economic factors that may put someone at increased risk of contracting HIV. Their research found that in census districts where 17% or more of the residents had less than a high school diploma accounted for the highest HIV diagnosis rates or percentages (CDC, 2022b).

APPLI's findings in the Appalachian Region seem to contradict that finding. Adult literacy proficiency was found to have negative correlations with the incidence (i.e., diagnosis) of HIV in virtually every Appalachian jurisdiction for which sufficient data were available. A negative correlation, in this case, means that jurisdictions with higher percentages of adults reading at or below an Eighth Grade Level tended to have lower incidence rates of new HIV diagnoses. This finding does not mean that people living in these jurisdictions are less likely to contract HIV, rather that they are less likely to be diagnosed in those jurisdictions. A number of external factors may contribute to this discrepancy:

### The Location of HIV Testing Services in Appalachian Jurisdictions

Jurisdictions with higher literacy proficiency levels tend to be located in more urbanized areas with better economic outcomes. These areas are likelier to have healthcare facilities that provide HIV testing services than areas with lower literacy proficiency levels that tend to be more rural and geographically isolated. People who live in more rural and isolated areas are likely to have to travel to more urban areas in order to access healthcare services, in general, and HIV testing services, specifically.

Moreover, there are relatively few HIV testing, prevention, and treatment providers located in Appalachia's rural or geographically isolated jurisdictions, not because there is no need for those services, but because a variety of economic factors make it difficult for those providers to stay in operation. This means that people living in HIV care deserts are less likely to seek HIV testing services unless they are concerned about having been exposed. The location of HIV testing services in urban areas with higher adult literacy proficiency levels means that more cases are likely to be diagnosed in those jurisdictions than in rural or geographically isolated areas.

### Incomplete HIV Data Collection and Reporting During the Testing Process

In addition to a paucity of HIV services in rural and geographically isolated jurisdictions, additional challenges exist related to the absence of complete HIV reporting data. During the HIV testing process, providers may or may not request information about a patient's

home county. Without the collection and reporting of this data point, any positive test results will automatically be attributed to the county in which they were diagnosed. This attribution combined with the tendency of HIV testing services to be located in urban areas means that, even if a patient who tests positive for HIV lives in a rural county, their diagnosis is likely to be counted in the urban area where they received the positive result.

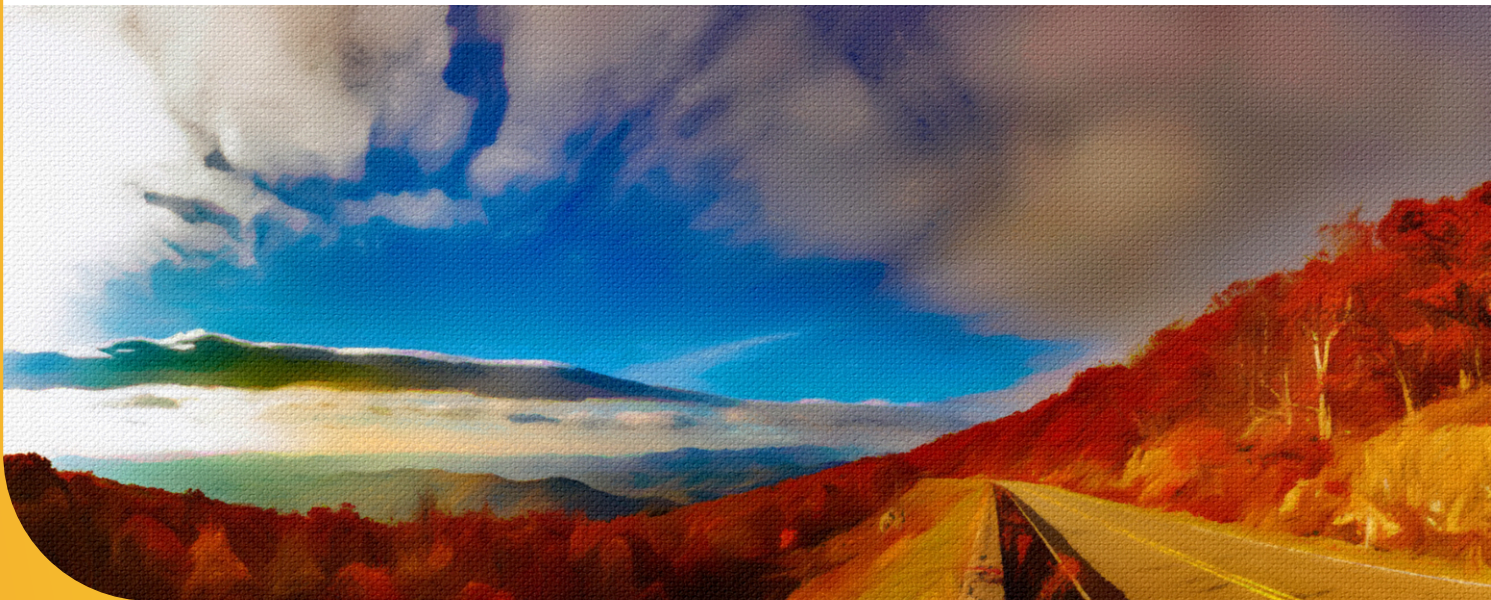
### A Higher Tendency Toward Healthcare Avoidance in Rural Appalachia

People living in Appalachia are significantly more likely to avoid care than non-Appalachians, particularly when it comes to life-changing diagnoses such as cancer or HIV (Vanderpool & Huang, 2010). This tendency is exacerbated both by geographic isolation and by cultural tendencies toward fatalism, particularly in Central Appalachia—West Virginia, Eastern Kentucky, Southwestern Virginia, and Northeastern Tennessee.



Welch breaks Appalachian fatalism down into six primary categories:

- Faith-Based – a belief that a divine being will be involved in any illness or potential recovery;
- Oppositional to Distrust – the mistrust in or distrust of medical professionals and institutions—particularly those run by government agencies—and the quality or types of care or services they provide. This is often driven by personal experiences or the anecdotal experiences of trusted friends or family members;
- Pride Overcoming Poverty – the avoidance or delaying of seeking healthcare services due to a perceived or actual inability to afford them;
- Apathy or Unwillingness to Change – a lack of interest in or willingness to seek diagnostic or follow-up healthcare services, particularly if receiving a diagnosis could potentially require a patient to change long standing behaviors or lifestyle choices in order to survive;
- Based on Ignorance of Potential Health Outcomes – fatalistic behaviors and beliefs informed by mis- or disinformation about healthcare services, health conditions, and their risks; and,
- Upholding a Quality of Life – the belief that a patient’s quality of life will deteriorate if they are diagnosed with and/or seek treatment for a disease (Welch, 2011).
- Each of these types of fatalistic behaviors toward personal health may contribute to the avoidance of HIV testing, particularly in Central Appalachia. Levels of fatalistic beliefs tend to be lower in urban areas and in areas with higher levels of both educational attainment and reading proficiency.



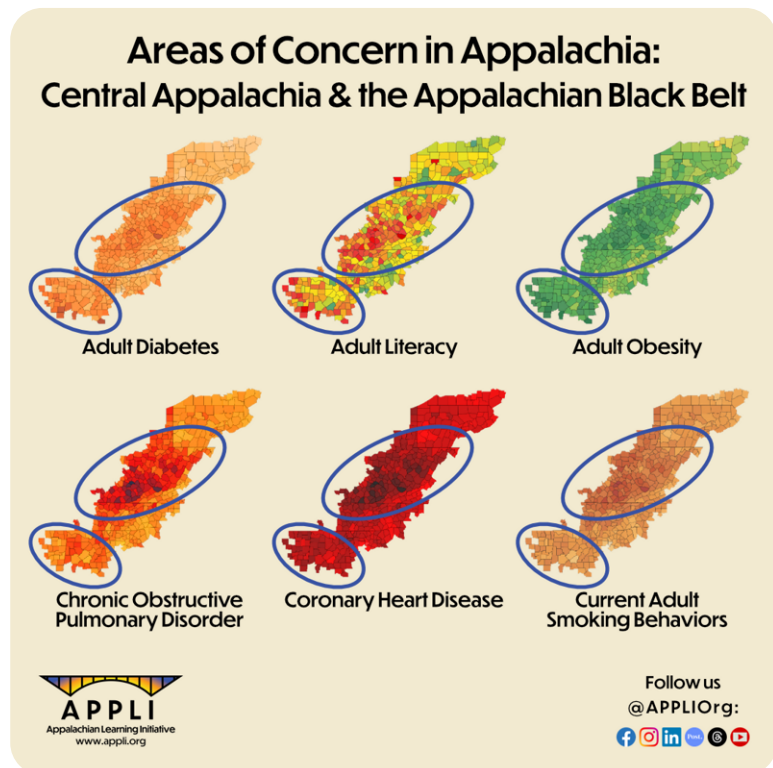
# Recommendations

Additional research is necessary to determine if the correlations between low adult literacy proficiency and these measures of public health are significant enough to warrant requests for large federal, state, and local financial investments. While this research is a good starting point, it is not without its limitations. The number of jurisdictions with suppressed epidemiological data presents a high hurdle to overcome when attempting to measure correlation, particularly as it relates to the mortality rates of individual cancers. Overcoming this hurdle will likely require an organization with greater funding or access to raw data that has not been suppressed to step in and improve upon this process. While we have explored some interesting relationships, the next phase of the research could develop into using more causally-explanatory methodologies and more rigorous statistical modeling techniques.

## Areas of Concern in Appalachia: Central Appalachia and the Appalachian Black Belt

When examining the data points and accompanying heat maps for the five measures of public health with the highest correlation coefficients with adult literacy proficiency (adult diabetes, adult obesity, COPD, CHD, and current smoking behaviors among adults), two specific regions in Appalachia should be areas of concern: Central Appalachia (Kentucky, Northeastern Tennessee, Southwestern Virginia, and West Virginia) and the Appalachian Black Belt (Central Alabama, and Central and Western Mississippi). Jurisdictions in these two regions of Appalachia consistently exhibit high incidence, prevalence, and mortality rates of the 25 selected measures of public health and low levels of adult literacy proficiency (Figure 8).

Figure 8 - Appalachian Jurisdictions of Concern When Planning Educational and Public Health Interventions



Central Appalachian jurisdictions in Kentucky, Northeastern Tennessee, Southwestern Virginia, and West Virginia are of particular interest in no small part because of the intense geographic and topographic isolation of the region, but also because they are home to some of the highest incidence, prevalence, and mortality rates of numerous measures of public health beyond even the 25 measures we examined for this research.

Jurisdictions in Central Appalachia and the Appalachian Black Belt should be examined more closely in order to develop culturally competent and meaningful educational and healthcare interventions.

### Opportunities for Educational and Public Health Interventions

One of the purposes of this research was to not only identify areas of correlation, but also to identify areas where potential solutions exist to address issues related to public health in addition to adult literacy deficiencies. Research has long demonstrated that the co-location of cooperative healthcare services in central or single locations results in better health outcomes if implemented in a thoughtful and meaningful manner (Bonciani et al., 2018; Blackmore et al., 2018). The co-location of services, by itself, has been shown to lead to more initial patient visits, but it is the collaboration, cooperation, and coordination between co-located physicians and other providers that results in better outcomes that go beyond just the initial visit.

When looking at diabetes outcomes and management, active community participation appears to be one of the best ways for Appalachian adults to manage their chronic diseases. With 71 active diabetes coalitions currently participating in the ADCTP, community-based efforts are at the heart of this project (Appalachian Diabetes Network 2022), echoing the results of the 2013 Appalachian obesity study by Schoenberg et al. Community-based participatory research has also been explored for obesity and diabetes, utilizing high school students in Health Sciences and Technology clubs as the facilitators of disease management programs, which not only educates the community, but also gives adolescents a chance to learn about these diseases earlier on so that they can better care for themselves and loved ones sooner after diagnosis (Bardwell et al., 2009). Medical providers should also start screening patients for low literacy, utilizing in-office tests such as the Rapid Estimate of Adult Literacy (REALM), Wide Range Achievement Test (WRAT), the Newest Vital Sign (NVS), or other similar testing modules that can quickly assess a patient's ability to read words and/or reading comprehension (Van Schaik et al., 2017; DeWalt & Pignone). With so many successful and/or requested community programs around chronic disease self management, these types of programs would also be beneficial to the Appalachian Region, especially considering the values placed around community. Being able to see specialists in a local office would also help increase health outcomes.

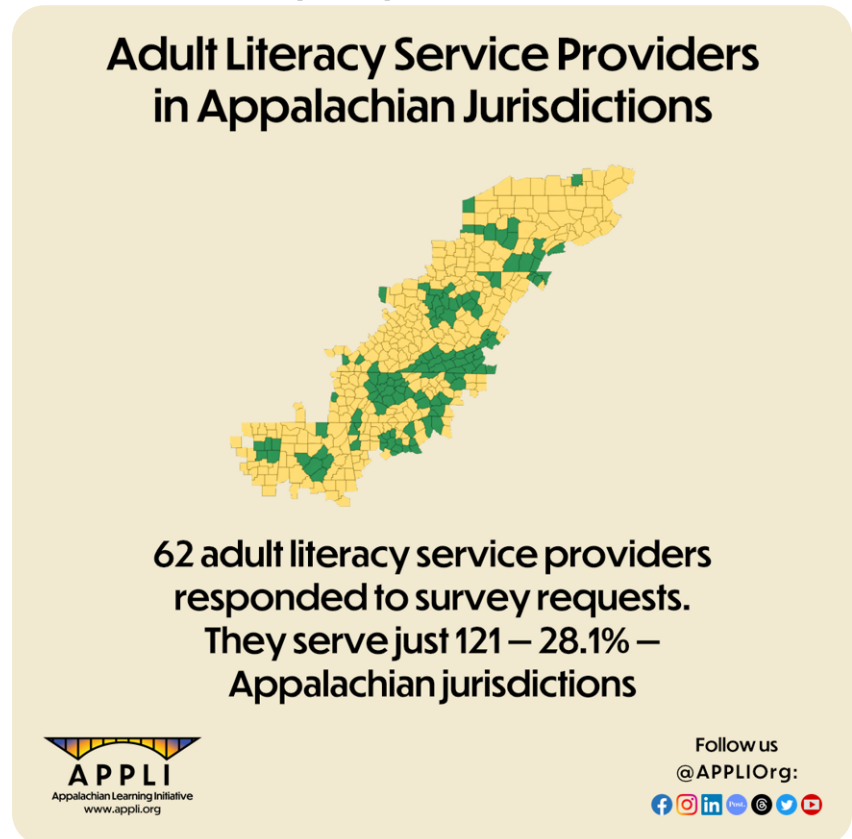
While there are numerous organizations focused on the improvement of health and poverty outcomes, the number of organizations focused on improving adult literacy proficiency is significantly lower. In APPLI’s efforts to build a directory of adult literacy service providers, 71 organizations provided us with directory listings, of which 62 are serving just 121 (28.1%) of Appalachia’s counties and independent Virginia cities (Figure 9). While this does not represent the totality of adult literacy service providers, it does illustrate the need for additional educational opportunities for adults throughout most of Appalachia.

This presents unique opportunities for organizations and institutions providing healthcare services to form collaborative partnerships with the educational organizations that do exist in the Appalachian Region. This could occur in a number of novel ways:

**Establishing Healthcare and Educational Provider Networks with Warm Hand-Off Referrals**

One of the key tools that integrative healthcare models use in an effort to improve the continuity of care in patients who need to see multiple providers is the patient referral. These referrals—and how referrals are conducted—can make the difference between a patient remaining in or falling out of care; between a patient showing up for an appointment or skipping it altogether. These are called “handoffs.” When a handoff is “cold,” patients are referred to another provider or person within an organization without an introduction or conversation between the first provider, the provider to whom the patient is being referred, and the patient themselves. In contrast, a “warm” handoff is one where a patient is introduced to a new provider in person, virtually, or

**Figure 9- Adult Literacy Service Providers Who Responded to the Appalachian Learning Initiative’s Survey Requests, 2023**



Note. Jurisdictions with adult literacy services providers present highlighted in green.

over the phone in an effort to both establish the new relationship and to develop a path of communication between both providers and the patient. Warm handoffs have been shown to improve both patient engagement in care and health outcomes (Young et al., 2020).

Beyond just the meaningful co-location of services and referrals with warm handoffs, we recommend working to develop meaningful partnerships between local and state governments and agencies, healthcare organizations, educational organizations, and educational institutions. We know that breaking down silos (i.e., barriers) in both education and healthcare settings frequently results in better integration of services, better student and patient outcomes, cost savings, and more shared resources (Kelly, Goodwin, Wichmann, & Mendu, 2019; Hartwell, Cole, Donovan, Greene, Burrell Storms, & Williams, 2017).

### Distance, Geographic Isolation, and Infrastructure as Barriers

People living in Appalachia face geographic barriers to accessing treatment; the same holds true for accessing remedial educational services. The jurisdictions with both low literacy proficiency and poor health outcomes tend to be extremely isolated, particularly those jurisdictions located in Central Appalachia (Figure 5). These concurrent barriers mean that adults will struggle to access the services they need to improve either their literacy proficiency or their healthcare issues. These same barriers exist for adults living in rural jurisdictions where topographic barriers (e.g., mountains) are not the primary barriers to access.

Combating barriers related to distance and geographic isolation is no simple task, as many of the solutions are infrastructural. It is not generally feasible, from a financial standpoint, to “just” build a school or build a clinic. Furthermore, many of these jurisdictions lack the underlying broadband Internet infrastructure that would make remote access a viable option. West Virginia schools attempted to overcome the broadband barrier during the COVID-19 pandemic by outfitting school buses in rural counties with portable Wi-Fi routers and using them as mobile hotspots that enabled students to attend virtual classes by parking in vehicles near the buses and logging on using their district-provided Chromebooks (Madden, 2021). This type of innovative thinking expanded into other Appalachian jurisdictions during the course of the COVID-19 pandemic, inspiring similar mobile Wi-Fi operations—a practice that could be refined and applied to improve the accessibility of remedial adult education services.

One potential solution would be for healthcare organizations who already provide mobile medical services to collaborate with adult education providers to establish warm handoffs between the organizations. In this scenario, patients receiving remote healthcare services would be linked to educational opportunities. This would require



mobile healthcare providers to administer REALM, WRAT, or NVS testing modules to rapidly assess the literacy proficiency of adults and connect patients in need of remedial literacy assistance directly to a representative from an educational organization who would be either on-site or attending the event virtually.

Another potential solution would be for education providers to begin linking patients to healthcare providers. In this scenario, educators would provide students with printed or digital literature to students and offer to link students directly to providers via a warm handoff. The downside of this scenario is that it would require adult learners to make the first step—asking for help—which presents a barrier in and of itself.

A third potential solution involves the pooling of resources between networked organizations. When developing collaborative coalitions between organization types, there exists potential for those organizations to cooperatively seek local, state, and federal funding opportunities to either construct new or purchase and renovate existing buildings for mixed purpose use. This would allow organizations to co-locate bases of operation, the provision of services, and to centralize student and patient resources in ways that may be beneficial to Appalachians who are geographically or topographically isolated.

### Final Thoughts

These potential solutions are neither perfect nor prescriptive. APPLI hopes that organizations serving the educational and healthcare needs of Appalachian adults will utilize this correlational research to identify areas of need and develop unique, innovative, and effective solutions that address both literacy proficiency issues and health outcomes. We must think beyond our respective areas of focus—adult education and healthcare—and stretch ourselves in directions that may not, at first, feel natural. APPLI is firm in our belief that, through cross-discipline collaborations and integrative healthcare models, we can create lasting solutions that will provide Appalachian adults with more and better educational and healthcare options regardless of where they live or their ability to pay.



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