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COST BURDEN OF SOCIAL ISOLATION FOR WHEELCHAIR USERS IN LOUISVILLE, KENTUCKY

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A Dissertation
Submitted to the Faculty of the
School of Public Health and Information Sciences of the
University of Louisville
in Partial Fulfillment of the Requirements
for the Degree of

Doctor of Philosophy in Public Health Science

School of Public Health and Information Sciences
Public Health Management and Systems Sciences
University of Louisville
Louisville, Kentucky

May 2018

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A Dissertation approved on
April 6, 2016

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Scott Lajoie, PHD, MPH

DEDICATION

This dissertation is dedicated to the invisible, so that the world may finally see and welcome them into our workplaces, homes and hearts.

ACKNOWLEDGEMENTS

The Americans with Disabilities Act was signed into law July 26, 1990 by George H.W. Bush. That has been 28 years ago and the United States has still not grown into it.

I have lived in two dichotomous worlds. I have lived as an “upright” RN with a BSN and a Master’s Degree in a barrier free world. This has been constant in the 28 years since the ADA and 33 years for me. Then post-accident I have lived as a “fold” in the tenebrous world of barriers, marginalization, stigma and social isolation. Somehow, I have been erased, I have become invisible. This paper is extremely personal.

I am extremely thankful for Mary Beth Allen, PhD. I met Mary Beth in this PhD program and over the years she learned to speak cogent Connie. I relied heavily on her and those skills to help me develop and present my findings in this paper. Her unparalleled ability to understand the data I needed to access and use for this dissertation and structure my data, allowed me to be here today. She is my sister from another mother.

Michael Mills, PhD is the second person I need to thank. I also met Michael in this PhD program and was wowed by his data wizardry and acumen. Michael’s ability to assess, categorize interrelate and synthesize the data

contained in this paper and coaching me, was also essential to me and this dissertation.

And then there's Susan Olson-Allen. I met Susan in my first PhD program. And if it were not for Susan and her tenacity, understanding and support, I would not be here today. Thank you all for running interference, cajoling, removing impediments and kicking PRN.

Robert Esterhay, MD has always been supportive of my sometimes circuitous agenda. Thank you Dr E.

Scott Lajoie, PhD thank you for your time and attention.

ABSTRACT

COST BURDEN OF SOCIAL ISOLATION FOR WHEELCHAIR USERS IN LOUISVILLE, KENTUCKY

Connie Light

April 6, 2018

Background: Social isolation is an important predictor for poor health status, chronic diseases, and healthcare utilization and costs. There is a growing number of Americans with one or more disabilities, and evidence suggests that many are also socially isolated. This is especially true for those with immobility, as the built environment including housing structures are not universally designed to be accommodating. Immobility describes those who use walkers, canes, or wheelchairs, with the latter suffering the most impact. The cost of social exclusion can be measured by the exacerbation of disease in wheelchair users, whose fragile health status and social networks are interrelated.

Methods: This study estimates the additional cost of healthcare utilization of wheelchair users in Louisville, Kentucky due to social isolation based on assumptions gained from evidence-based literature and compares that cost to the estimated cost of adding visitability features to newly constructed housing

units. This study assumes that visitability policy had been enacted in Louisville, Kentucky in 2004 at an average cost to contractors and owners of \$500. As a result, 34,120 single family, duplex homes and half of all multiplex units built between the years 2004 and 2017 would have visitability features. The assumed impact on the community is a 10% reduction in social isolation of wheelchair users. Population estimates of wheelchair users are derived from novel and unique analysis provided by Cornell University's School of Industrial and Labor Relations (ILR) for this investigation. Aggregations of the drivers of health care cost were derived predominately on data from The Milken Institute. The statistics of new housing built between 2004 and 2017 in Louisville, Kentucky was provided by Louisville Metro Government Archives specifically for this study.

Results: The cost of accommodating in first floor design in newly constructed housing alignment to visitability models is estimates to range from \$0 to \$1000 with overall average of \$500. The cost of modifying newly constructed housing was significantly less than the projected healthcare cost of wheelchair users obtained from the three data sources during the study period.

Conclusion: The cost of healthcare is an important political, social, and economic debate in the US. Allocation of resources in the US for healthcare has increased from 5% of GDP in 1960 to 18.3% in 2016. Public policy has sought to initiate various forms of cost controls and consumer protections, but most of these efforts have failed to make a strong impact on the trajectory of national healthcare spending. Unhealthy populations are responsible for much of the cost, as unhealthy behaviors often facilitated by the absence of choice. For

wheelchair users, there are even fewer choices as many are not only poor, but also physically unable to access key resources in society including public and more so private spaces. The cost of isolation is significant, as facilitating a more accessible and inclusive society could be an important opportunity for savings in healthcare cost.

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INTRODUCTION

Relationships and social connectedness exist as the lifeblood of healthy communities. Social networks strengthen individuals and families, offering support to those with a chronic disease as well as caregivers, family members, and other stakeholders. For these reasons, social isolation has been identified in countless studies as a key factor in determining health status. In fact, the impact of social isolation on health status has been described as both a cause and a consequence.

Given that social networks strengthen individuals, communities and civilizations, it is not surprising that social connectedness also possesses important health implications. As humans access important social resources including their families, faith-based organizations, support groups, professional societies, neighbors and friends as part of daily activities, access to these resources can become critical in the event of hardship or illness. For this reason, a lack of access to social resources has been demonstrated as an important factor in proliferating hardships and has important implications for population health as poor health outcomes secondary to disease states has a proven correlation with social isolation.

There are many reasons for the strong association between social isolation and health status. As health status declines, one's ability to access social resources often becomes diminished. Conversely, loneliness has been shown to exacerbate existing health problems, or cause new conditions to develop. Many illnesses, disabilities, and chronic health conditions have a role in causing individuals to withdraw from their social networks as daily life can become much more challenging. Basic necessities associated with one's ability to live independently with access to transportation can become impossible, undermining a person's ability to participate in professional, social, educational, and leisure activities. Although many health conditions have a role in reducing one's social connectedness, health issues associated with decreased mobility are among the most strongly associated with social isolation.

The definition of mobility has many iterations, but it is generally defined as the ability to move independently, as immobility is the absence of this ability. There are a number of resources that can improve mobility, which include orthotics, canes, walkers and wheelchairs. As much as these resources help restore one's ability to undergo daily tasks, communities are not always designed with these members of our society in mind. This is especially true for wheelchair users, as the smallest step, narrow or uneven sidewalks, inadequate or unenforced designated parking, there are many other barriers wheelchair users must constantly navigate when accessing many public resources and most every private

facility. These obstacles pose significant limitations on a person's ability to visit friends and family, work, and participate in essential functions including accessing healthcare services, and join into leisure activities. Given that social isolation is basically par for the course for wheelchair users, the added cost burden of disease for wheelchair users is difficult to tabulate. Further, the lack of social and political support for wheelchair users, even with public officials representing city planning and new construction, rarely insures the well-planned integration of wheelchair access. These layers of social isolation highlight the persistent marginalization of wheelchair users as unimportant members of our society. Meanwhile, cost effective approaches do exist for mitigating social isolation for this population, which would in turn contribute an important factor to reducing health care costs in the United States. In other words, better integration of this vulnerable population into public and private facilities may equally make as much financial sense as it is our moral obligation as an evolved and inclusive society to do so.

CHAPTER 1: OVERVIEW OF DISABILITY

Disability broadly describes the presence of impairments that impact the daily life of an individual. But, these challenges are not restricted to the individual, as the effect of disability has become an important issue facing modern society. Modern medicine has made it possible to live more functional lives with chronic diseases and consequently adults are living longer. Increased longevity likewise increases the rates of disability because many types of impairments onset and worsen with extended age. The prevalence of chronic disease is high in American society. Because of the availability of healthcare, understanding the complexity of disability is more important than ever, and reducing the impact of disability on the daily life of individuals and families is an important area of research.

Unhealthy America

In order to comprehend the varied reasons the United States is beginning to lag other developed nations in life expectancy and other key indicators, we must recognize the diminished importance placed on those factors that lead to healthy lives. Social Determinants of Health, while well recognized as public health priorities in other nations, take second place in

importance as compared to various healthcare therapies and interventions. This culture of interventional practice neglects priorities that could add to life's quality and lengthen the productive years of US citizens. These practices also neglect to consider end of life care that is not considered medically appropriate in other nations. The narrative that follows establishes that foundation of the factors and trends underpinning health and well-being of United States citizens as contributors to the disability population cohort.

America is known for many things around the world. Unfortunately, health and wellbeing are on the bottom of the list as we lag behind many of our peers in key health indicators. In a monumental study of 4,700 participants in the U.S. National Health and Nutrition Survey collected using positive behavior and lifestyle measures including 1) consistent physical activity, 2) nonsmoking, 3) eating a nutritional diet, and 4) maintaining a normal and healthy body weight, all of which are universally agreed as major drivers of overall health as well as protective against common chronic diseases. The findings of this study revealed that only 2.7% of all respondents met all four of the criteria defined as fundamental healthy lifestyle characteristics. In addition, this study also found a positive correlation between the presences of any healthy lifestyle characteristics with favorable values in the following laboratory studies: C-reactive protein, WBCS, total cholesterol, HDL cholesterol and homocysteine. The study population included a randomly selected

sample from fifteen geographical areas across the US.¹

The deterioration of health in the US is something that is uniquely American as our peers in other industrialized wealthy countries are boasting of superior health status indicators. Average life expectancy at birth, for example, is a measure defined as how long an average newborn can expect to live. This measure assumes that the current death and standard of living measures, such as education, health care quality, and access to care, remain the same. The Organization for Economic Cooperation and Development (OECD) is composed of 35-member countries, which include a consortium of wealthy, industrialized countries committed to democracy and encouraging market economies around the world. These countries look to one another for leadership on policy, leadership in addressing common problems, the identification of successful practices, as well as better coordination of domestic and international policy between members.²

In a 2013 analysis of 35-member countries, the US ranking tied at 26 with Chile with an average life expectancy of 78.8 years. The highest-ranking nations are listed in the table below.³

Table 1: Average Life Expectancy of OECD Countries

Country	Average Life Expectancy
Japan	83.4
Spain	83.4
Switzerland	82.9
Italy	82.8
France	82.3
Australia	82.2
Israel	82.1
Iceland	82.1
Sweden	82
Luxembourg	81.9

A 2016 report published by the World Health Organization (WHO), the US ranked 31 of the 183 surveyed countries in average life expectancy with an average of 79.3 years. The WHO also placed Japan at the top of the list at an average life expectancy, with the top performers listed in the table below.⁴

Table 2: Average Life Expectancy per WHO

Country	Average Life Expectancy
Japan	83.7
Switzerland	83.4
Singapore	83.1
Australia	82.8
Spain	82.8
Iceland	82.7
Italy	82.7
Israel	82.5
Sweden	82.4
France	82.4

A 2015 report compiled by the Population Division of the United Nations Department of Economic and Social Affairs (UN DESA), the US was ranked at 43 with an average life expectancy of 78.88 years. Interestingly, this report included US territories: Virgin Islands, Puerto Rico and Guam separately, with the Virgin Islands and Puerto Rico ranking ahead of the US at 33 and 39, respectively, and Guam close by at 45. A total of 201 nations were measured. See the table below for the top ranking countries in order of average life expectancy.⁵

Table 3: Average Life Expectancy per UN

Country	Average Life Expectancy
Japan	83.74
Italy	83.31
Switzerland	82.84
Singapore	82.66
Israel	82.64
Iceland	82.30
Spain	82.28
Hong Kong	82.07
Sweden	81.93

Life expectancy data published by the Central Intelligence Agency (CIA) from 2016 included a review of 223 countries, ranking the US at number 43 with an average of 79.8 years. The position of the US in this final analysis was similar to other studies, placing the US well below its peer nation of developed, industrialized and wealthy countries. These well researched statistics are a harbinger of healthcare deficiencies in the United States and should be a motivation for action by health policy leaders. See the table below for the top countries in life expectancy according to the CIA.⁶

Table 4: Average Life Expectancy per CIA

Country	Average Life Expectancy
Monaco	89.5
Japan	85
Singapore	85
Macau (China)	84.5
San Marino	83.3
Iceland	83
Hong Kong (China)	82.9
Andorra	82.8
Switzerland	82.6
Guernsey	82.5

Another important population health measure is maternal mortality, which provides insight into the quality of care delivered to expecting and new mothers. This report was created by the CDC along the Maternal Mortality Review Information Application (MMRIA), and the results tell a similar story. In the US, approximately 700 women die each year due to pregnancy or pregnancy-related complications. The impact on minority populations is stronger as African-American women are three to four times more likely to die than non-Hispanic white women. The infant mortality rate, the report stresses, is similarly distributed according to racial features. Almost half of pregnancy-related deaths were caused by

hemorrhage, cardiovascular and coronary conditions, cardiomyopathy, or infection. Other major causes of death varied according to race. For example, African-American women were more likely die as a result of preeclampsia, eclampsia, and embolism. It is interesting to note that during a three-year period, only two deaths occurred in the United Kingdom from preeclampsia and eclampsia. It was the opinion of the committee that over 60% of pregnancy-related deaths were preventable in the US as common issues that contributed to mortality were related to the patient not having the education or ability to access care, treatment failures including misdiagnoses and ineffective management, and healthcare system failures such as a lack of coordination between care providers.⁷

According to a global study using data sources from 186 of 195 countries and territories looking at maternal mortality between the years 1990 and 2015. Causes of death were categorized into eight groups with sub categories that defined timing. A secondary analysis identified trends and measured variables like the availability of reproductive health-care, income per capita, educational attainment, and fertility. Study findings for the US as compared to peers can be seen below, as the maternal death rate for American women is moving in the opposite direction of many of our European peers with a drastically rising trajectory. The study offers a number of suggestion to improve the maternal mortality rate in all settings, which includes improving systems for the collection and timely

dissemination of health information, expanding access and improving quality of family planning services, improving health system capacity, improving access to routine reproductive health care, and collecting data to allow data collection for population health as well as internal system tracking to monitor the performance of interventions on select groups.⁸

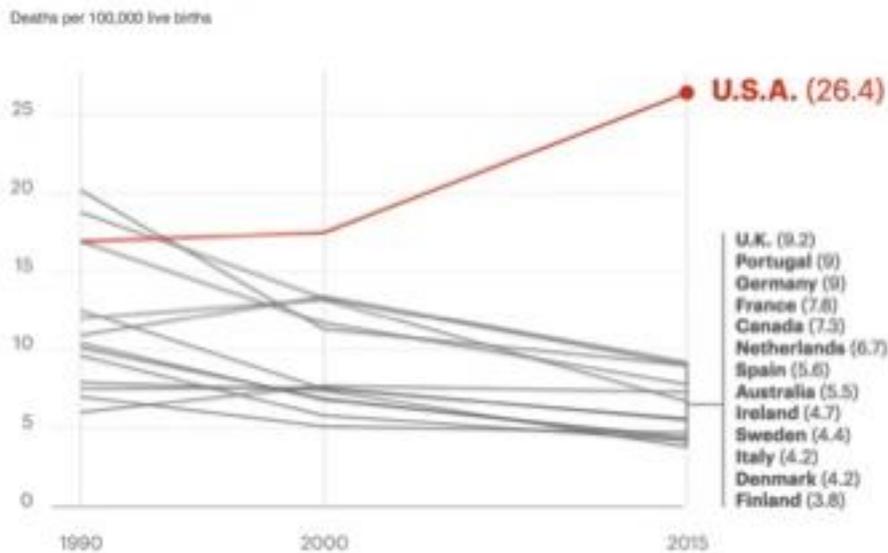


Figure: 1 Maternal Mortality Rates

Infant and child mortality is another important population health status measure. Both represent measures of healthcare quality, access, the health of populations, safety, education, and other important socio-economic measures. A study of OECD measured mortality for children under the age of five years old, noting the average for OECD was 6.9 per 1000 live births in 2016. Of the thirty-five member countries, the US was ranked 32, only beating Chile, Turkey and Mexico.⁹ It is important to note that OECD countries tend to be higher income countries. Infant mortality, as defined by the CDC, is the mortality of an infant within the first year of

life. The CDC notes that infant mortality is a reflection of society health as well as the health of the mother. In 2015, over 23,000 infants died in the United States, which represents an infant mortality rate in the United States of 5.9 deaths per 1,000 live births. The most common causes of death were birth defects, preterm birth and low birth weight, sudden infant death syndrome, maternal pregnancy complications, and injuries such as suffocation.¹⁰ A 2016 analysis of infant mortality published by the CIA placed the US at number of 57 of all countries studied with a rate of 5.8 per 1000 live births. This is in comparison to the lowest rate of 1.8 in Monaco and 2 in Japan.¹¹ Data from the United Nations last updated in 2015 rank the US at forty, directly below Slovakia and Cuba at a rate of 5.97 per 1000.¹² According to the CDC, the infant mortality is much like other poor outcomes as important geographical and racial disparities exist. The geographical distribution of infant mortality in the US using data from 2016 shows a stronger correlation with the south, with Alabama with the highest rate of 9.1, followed closely by Mississippi, Arkansas and Louisiana. The lowest infant mortality in the US is recorded in Vermont at 0 per 1000 births.^{13,14}



Figure 2: Infant Mortality by State, 2016

The CDC also notes important racial disparities. Using 2015 data, racial minorities African-Americans and Native Americans had a disproportionately high incidence of infant mortality. Rates for African-Americans, Native Americans, and Hispanics were all higher than in white populations. See the chart below for a representation of the racial distribution of infant mortality in the US.^{15,16}

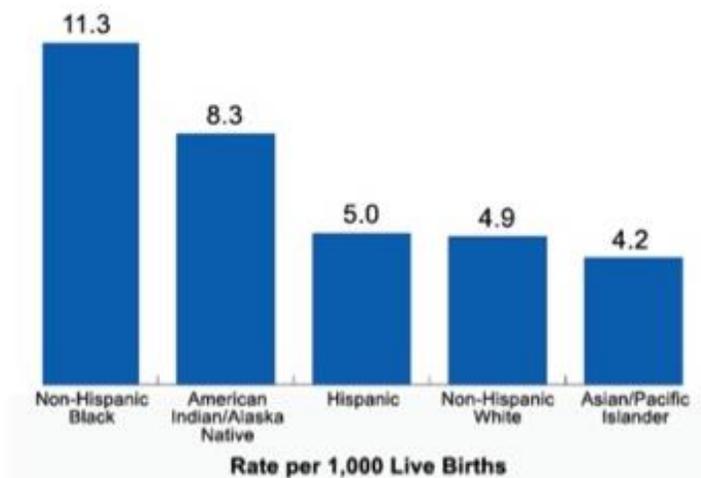


Figure 3: Infant Mortality Rates by Race and Ethnicity, 2015

Several studies in the peer reviewed literature have shown the relationship between infant mortality and race. In 2008, live birth-infant death cohort data from the National Center for Health Statistics' (NCHS) was used for the years 1985-1988 and 1995-2000. This study included singleton live births in the US to mothers with a reported race of white or African-American. The study included 10,620,735 live births from the 1985-1988 birth cohort and 21,687,542 live births from the 1995-2000 birth cohort. The findings of this study include a widening racial disparity in infant mortality despite an increasing incidence of white low birth weight infants. Both white preterm infants and white term infants has a higher likelihood of survival. Further, 3300 more infant deaths per year than expected occurred in the African American cohort.¹⁷

Disease burden is another measure of the health of populations. Just as the US underperforms its peers in life expectancy, such is the case with disease burden. In a 2015 study measuring the burden of disease in the US and comparable countries, despite an overall decrease in all countries in terms of Disability Adjusted Life Years (or DALYs) calculated data from the Institute for Health Metrics and Evaluation, the US lagged behind its peers. Outcomes include a decline in disease burden rate since 1990 by 14% in the US, while comparable countries have seen an average decrease of 18%. Averages included a 15% decline in Canada as the lowest and a 23% decline in Germany as the highest. The authors note that most all countries had improvements in

circulatory diseases since 1990, as the US also demonstrated by a reduction in DALY. However, comparable countries had reduction in DALY that was faster and more significant in the study time frame. The authors note that many of these numbers are impacted by more than medical care, so these numbers are not necessarily a function of health system quality in each country, as socio-economic and behavioral factors also play an important role.¹⁸

There are many variables that can contribute to the eroding health of Americans. First and foremost, health behaviors in the US are strongly tied to health status, and in the US, positive health behaviors are not commonly observed in the population. The western diet has a known association with obesity, and new data indicate that it also supports hyperplasia, or overeating, as excessive sugars and fats impact the peripheral endocannabinoid signaling process. The endocannabinoid system describes the system of many physiological functions in the body, including food intake, energy balance, and reward, which coordinate between the brain and peripheral organs through lipid signaling molecules.¹⁹ Also, the relationship between sedentary lifestyles, generally described as prolonged periods of sitting, laying down, and screen time, is another driver of obesity. According to a 2002 statement published by the WHO, “approximately 2 million deaths per year are attributed to physical inactivity, [prompting] a warning that a sedentary lifestyle could very well be among the 10 leading causes of death and disability in the world.” The

report goes on to emphasize the importance of physical activity, as “sedentary lifestyles increase all causes of mortality, double the risk of cardiovascular diseases, diabetes, and obesity, and increase the risks of colon cancer, high blood pressure, osteoporosis, lipid disorders, depression and anxiety.” The WHO estimates are that between 60% and 85% of the world’s population lead sedentary lifestyles, as well as over 60% of children. The WHO emphasizes that inactivity is an unaddressed population health problem with serious implications for the health of future generations.²⁰ In 2008, the CDC released physical activity guidelines that included recommendations for different age groups and populations segments, which included an update from a previous recommendation to include more flexible options for busy Americans.²¹ According to a 2014 report released by the CDC, only 21% of adults met the 2008 Physical Activity Guidelines, and less than 3 in 10 high school students met the guidelines for children between the ages of 6 and 17 years old. However, younger adults were more likely to meet the guidelines for aerobic activity than older adults. The report also noted important disparities in the results as 23% of non-Hispanic white adults met the guidelines as compared to 18% of African Americans and 16% of Hispanics. Higher income and education attainments was also more strongly associated with the likelihood of meeting physical activity guidelines. Further, the report found that Americans living in the South are less likely to be physically active than Americans living in the West, Northeast and Midwest regions of the

country. The CDC stressed in this report the importance of physical activity and its role in improving the overall health of populations. Also, the CDC noted that physically active people have a reduced risk for heart disease, stroke, type 2 diabetes, depression, and some cancers, and average lifespans are longer. Physical activity has an important role in weight control and has been associated with academic achievement in students.²²

Unhealthy Behaviors, a report updated by the CDC, frequently includes several common behaviors associated with poor health status in the population of resident adults were measures. Statistics related to these behaviors were binge drinking, smoking, low physical activity, obesity, and sleeping less than 7 hours per night. For 2010, of 17.1% of adults reported binge drinking in the past 30 days and of that 17% the highest prevalence of binge drinkers were men, adults in the age group between 18 and 34 years, whites, and with household incomes of less than \$75,000.^{23,24} The CDC notes that alcohol use accounted for an estimated average of 88,000 deaths and represents a risk factor in many health and social problems, including motor-vehicle crashes, violence, suicide, hypertension, acute myocardial infarction, sexually transmitted diseases, unintended pregnancy, fetal alcohol syndrome, and sudden infant death syndrome.^{25,26,27,28,29} For 2011, 19.0% of adults admitted to smoking, with 77.8%, 34.1 million smoking every day, and 22.2%, 9.7 million, smoking on some days. Between the years 2005 and 2011, there

was an overall decline in smoking prevalence, most notably in young adults aged 18–24 years. The rate of smoking in population decreased from 24.4% in 2005 to 18.9% in 2011.^{30,31} Still, there are around 480,000 deaths every year due to cigarette smoking and exposure to tobacco smoke, which makes smoking the leading preventable cause of death in the United States.^{32,33,34} Low amounts of physical activity is another important marker for health status. In 2011, 25.4% of adults participated in no leisure-time physical activity within the month prior to the study. Physical activity has a known impact on health and quality of life of persons regardless of age or the presence of a chronic disease or disability.^{35,36,37} Obesity is another important health status indicator, with prevalence by state ranged from 20.5% to 34.7% based on a CDC survey containing self-reported data.^{38,39} Effective weight management has a proven association with positive health status as overweight and obese weight increases the risk for multiple chronic diseases, including heart disease, stroke, hypertension, type 2 diabetes, osteoarthritis, and certain cancers.^{40,41} Last in the report was the amount of sleep the average American gets in a night. A lack of sleep has been associated with the onset and worsening of numerous chronic diseases and conditions, including but not limited to diabetes, cardiovascular disease, hypertension, obesity, and depression. Insufficient sleep also has important safety and quality of life issues, as motor vehicle crashes and industrial errors have happened, as well as contributed to a reduction in productivity and quality

of life.^{42,43}

In a significant report published by the Milken Institute in 2007, the authors deVol and Dedroussian reported that more than half of Americans suffer from one or more chronic diseases. This financial impact of the burden of the most common chronic diseases was estimated at well over \$1 trillion annually. The chronic diseases that factored into the figure included some of the most common in the US: some types of cancer, diabetes, hypertension, stroke, heart disease, pulmonary conditions, and mental disorders. By 2050, the burden of these diseases alone is expected to reach \$6 trillion. deVol and Dedroussian argue that chronic disease is an underappreciated driver of healthcare costs in the US, which has seen an increase in prevalence rates despite improvements in treatment options for colon, breast, prostate, and lung cancers, with the most dramatic improvements in the treatment and prevention of heart disease. This report warns that the cost and morbidity and mortality associated with chronic diseases are likely to cancel out the benefits of advances in medical care achieved in the last century on a population level.⁴⁴ In a 2014 study, “Health Outcome Disparities among Subgroups of People with Disabilities”, researchers looking at the health status and disease burden of people with disabilities found significant gaps in available research.⁴⁵ Clearly there is opportunity for greater scrutiny of this population cohort beyond the work at Cornell given the impact on spending generated by this population.

As many Americans increasingly struggle with chronic diseases, access to affordable and quality healthcare remains an important challenge. According to the Kaiser Family Foundation National Health Interview Survey, 9% of Americans reported delaying or not accessing care due to cost in 2016, and the majority of those respondents reported poor overall health status. Insurance coverage status was another important factor in accessing care as those without health insurance are more likely to delay or forgo care than those with insurance.⁴⁶ These results are similar across studies, as barriers to care include both financial and nonfinancial. In a 2012 population-based study of 17,797 participants, respondents were asked if they received the medical care they needed or if they had delays in their medical care. If so, the reason for the delay was classified into five distinct dimensions: affordability, accommodation, availability, accessibility, and acceptability. Results in this study were that affordability remained the most important barrier described as respondents expressed concern for cost or the needed intervention representing a non-covered benefit in their health plan.

Accommodation issues were second noting barriers such as flexibility in scheduling, difficulty taking time off work, waiting too long to be seen, and trouble reaching the provider by phone. The next most common reason was availability, which included not being able access timely care or locate the provider office. Accessibility barriers followed, with reports of providers taking too long to access or other transportation challenges.

Acceptability was last with reports of health plans not being accepted or bad interactions with providers. Among notable findings in this study is that 66.8% of the respondents who reported an affordability barrier also reported a nonfinancial barrier. Study findings are outlined on the table below.⁴⁷Table 5: Accessibility Barriers for Healthcare Services

Estimated Unadjusted Prevalence of Barriers That Led to Unmet Need or Delayed Care among U.S. Adults, by Access Dimension

Access Dimension	Estimated Prevalence, % (SE)	
	All Adults (n = 15,197)	Adults with an <i>Affordability Barrier</i> * (n = 2,169)
<i>Affordability</i>	18.5 (0.5)	
<i>Accommodation</i>	17.5 (0.5)	54.3 (1.5)
<i>Availability</i>	8.4 (0.4)	28.6 (1.4)
<i>Accessibility</i>	4.4 (0.3)	15.6 (1.2)
<i>Acceptability</i>	4.0 (0.3)	18.6 (1.2)
<i>Nonfinancial</i> [†]	21.0 (0.5)	66.8 (1.4)

* Any *affordability* barrier that led to unmet need or delayed care in the previous 12 months.

† Any *accommodation, availability, accessibility, or acceptability* barrier that led to unmet need or delayed care in the previous 12 months.

The unhealthiest of Americans also correlate highly with society's most vulnerable population. These factors classified as Social Determinants of Health describe the phenomenon of those who have lowest amount of resources, living in the poorest of communities with low education levels also tend to be the least healthy. There are many contributing factors for this pattern, including low education that drives optimal decisions regarding lifestyle and health, lack of resources that undermines the ability to access resources including grocery stores, and a lack of access to quality healthcare. As important as the latter is, the most important factors driving behavioral and lifestyle factors are the most critical. As a small proportion of healthcare interventions have been shown

to actually impact outcomes, lifestyle remains the most important predictor of health status. In fact, McGinnis and researchers estimate that medical care was responsible for only 10%–15% of preventable mortality in the US.⁴⁸

The situation in the US, relative to other developed countries, is unique. With incredible disparities in access, utilization, outcomes, and health status, the cost of healthcare for everyone is exorbitant. In a comparison using OECD data in order to assess healthcare delivery spending, supply, utilization, pricing, and outcomes relative to thirteen other countries, spending in the US was found to be significantly higher. Also it is important to note that public spending alone in the US was higher than all other countries used in the comparison, with each one having a publicly financed universal health system. Findings include lower numbers of hospital admissions and physician visits in America but use of expensive technologies is much higher. Another explanation for greater health spending is a function of higher pricing in the US. In contrast to other countries, US provides less assistance in social support services like housing assistance, employment programs, disability benefits, and food security, which have a strong impact on health status. Finally, this study revealed, as many others have, the relationship between health spending in the US did not produce superior outcomes as measured by life expectancy and the prevalence of chronic conditions. One exception is cancer, as rates have fallen more quickly in the US as compared to peer

countries, but the case for mortality from ischemic heart disease has risen in the US while rates have fallen elsewhere. The chart below illustrates health spending data used in this study as compared to the 13 other OECD member countries used in this analysis.⁴⁹

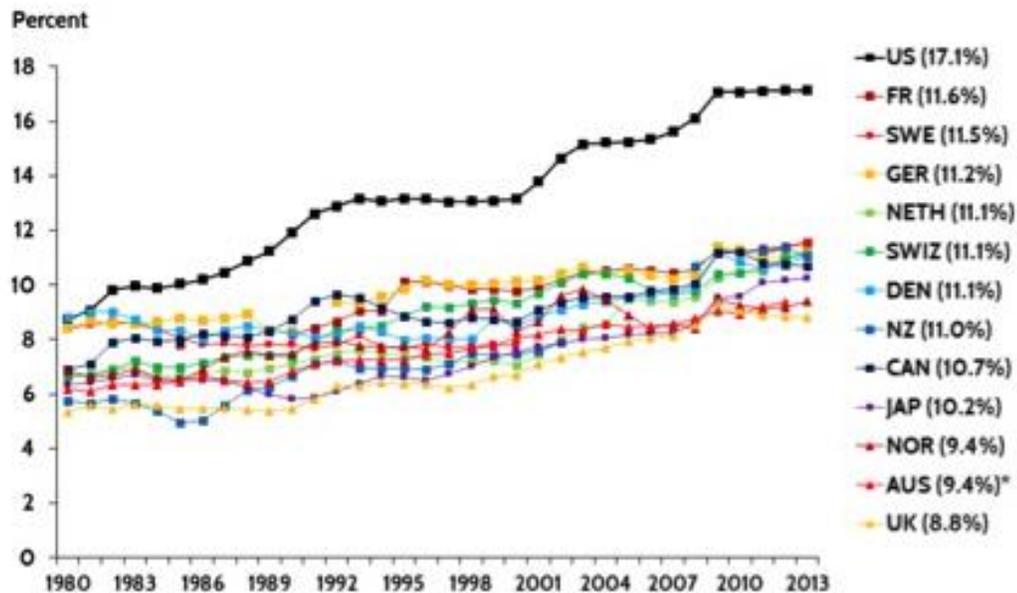


Figure 4: Health Spending as a Percentage of GDP, 1980-2013

There are many reasons health spending in the US remains higher. Explanations for this include imperfect market conditions that limit transparency and undermine competition, high administrative costs, and redundancy, which not only drives up cost for everyone, but also fragments care and leads to poor coordination, medical errors, and bad outcomes. Also, resources in the US tend to not be allocated properly as a high proportion of healthcare dollars are reserved for end of life and futile care.⁵⁰ Meanwhile, over regulation of healthcare and under regulation of the food production market contributes to chronic illness

representing a negative reinforcing feedback loop.

While many Americans lack access to healthcare, other sectors of American population are overly reliant on health resources to treat multiple conditions. For some, the absence of health resource utilization supports the worsening of disease states while for others, over utilization is an equally costly problem in the US. For these populations, over use of healthcare services facilitates low quality and contributes to high costs. In a recent meta-analysis, published by Korenstein et al in 2012, measuring the impact of overuse of therapeutic procedures, diagnostic tests, and medications the extent to which US residents rely upon therapies and their misuse was explored. The meta-analysis study included data published between the years 1978 and 2009 and includes references of 172 articles. Topic breakdowns included 53 studies of therapeutic procedures, 38 included overuses of diagnostic tests, and 81 studies focused on overprescribing of medications. The most common over used services reported in the literature were 59 studies of antibiotics for upper respiratory tract infections, 17 publications for coronary angiography, 13 carotid endarterectomies, and reports of unnecessary coronary artery bypass grafting. The studied trends over time and found the prevalence of over using of carotid endarterectomy and antibiotics for upper respiratory tract infections to be in decline over time. While the meta-analysis authors found reports in the literature of overutilization, reports were limited to select services, most likely as a function of reports in the literature as

opposed to population-based data.⁵¹

The medical concept of polypharmacy is a specific type of healthcare over-utilization that identifies multiple prescriptions for various concomitant conditions, along with other medications to manage a plethora of side effects. Polypharmacy has become an increasingly important challenge, particularly when managing the growing elderly population. In 2002, estimates from the Center for Medicare and Medicaid Services regarding polypharmacy effect was estimated to cost Medicare and Medicaid over \$50 billion, a figure that has likely risen dramatically since this report.⁵² Although medication regimens provide many benefits to patients, prescription overuse has become an increasingly difficult problem to manage, with an increased risk of side effects, drug-drug interaction, and other adverse events.⁵³

Background of Disability

Disability is an increasingly important problem in the US. Many factors contribute to disability, as disability is an outcome of numerous causes and conditions. As Americans are living longer, treatment for many chronic diseases has improved, and medical care has extended the lives of older populations, the prevalence of individuals with one or more disability has increased in recent decades. As a result, disability affects more individuals, families, communities, workplaces, and neighborhoods more than ever. As a result, managing disability in the workplace and in our society is likewise becoming an important part of public policy,

employment policy and contemporary society.

The classification of disability is not universally defined or accepted. The Social Security Program defines disability as “the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.”⁵⁴ This definition exists for the purposes of defining the eligibility of persons for disability benefits through the federal government’s insurance program. In contrast, the Americans with Disabilities Act (ADA) defines a person with a disability as anyone “who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.”⁵⁵ This definition is meant to define a protected population in the US, for which workplace discrimination and a lack of accommodation in select situations is theoretically illegal. These definitions exist for specific policy reasons, as more broad definitions capture greater complexities of disability. The World Health Organization (WHO), for example, notes that disability is an umbrella term that includes “impairments, activity limitations, and participation restrictions.” The WHO defines an impairment as a “problem in body function or structure,” an activity limitation as a “difficulty encountered by an individual in executing a task or action,” and a participation restriction as a “problem experienced

by an individual involvement in life situations.” The WHO goes on to describe disability as not just a health issue, but also a “complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives.” The WHO emphasizes the importance of interventions through public policy that remove barriers to allow participation in society.⁵⁶ The Centers for Disease Control and Prevention (CDC) also address the complexity of disability, offering the definition as “any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).”⁵⁷ This bricolage of definitions is just one example of the disparate measurements that contribute the misunderstanding of what is a disability.

Disability can have many causes. According to the CDC, there are several sources of disability. First, the CDC lists congenital as a cause, which describes any situation in which the person was born with the disability, which may be the cause of an inherited condition, a birth defect, or an injury or health condition that occurred prior to or during the birth process. Another source of disability are developmental conditions diagnosed in childhood, such as autism spectrum disorder and attention-deficit/hyperactivity disorder. Traumatic injury is another important source of disability, with common types of injury noted as traumatic brain injury and spinal cord injury. Also, poor outcomes from chronic diseases can

also facilitate the onset of a disability, such as complication of diabetes mellitus from resulting in limb loss, nerve damage or vision loss. Other health conditions causing a progressive loss in functionality such as cerebral palsy or spina bifida, or intermittent loss associated with multiple sclerosis. See the table below for a listing of CDC's National Center on Birth Defects and Developmental Disabilities identifying specific disability-related health conditions.⁵⁸

Table 6: Birth Defects and Developmental Disabilities Outline

CDC's National Center on Birth Defects and Developmental Disabilities: specific disability-related health conditions:
<ul style="list-style-type: none"> ❖ Attention-Deficit / Hyperactivity Disorder (ADHD) ❖ Autism ❖ Cerebral Palsy ❖ Deep Vein Thrombosis (DVT) ❖ Duchenne/Becker Muscular Dystrophy ❖ Fetal Alcohol Disorders (FASD) ❖ Fragile X ❖ Hearing Loss ❖ Hemophilia ❖ Intellectual Disability ❖ Kernicterus ❖ Spina Bifida ❖ Thalassemia ❖ Tourette Syndrome ❖ Traumatic Brain Injury ❖ Vision Impairment ❖ Von Willebrand Disease

A number of factors are driving an increase attribution of disability. Disability is strongly associated with advanced age. As the population of the US, along with other developed democracies in Europe and Canada, rising population age averages and longevity in the western

world are driving high rates of disability. In the US, the baby boomer cohort describes those born after the Second World War through 1960 at abnormally high rates as compared to subsequent generations, creating a higher than normal number of older Americans vulnerable to age related disability.⁵⁹ The impact of age can be observed by 2013 CDC data that reports that one in three adults over the age of 65 have a disability.⁶⁰ Another important driver of disability is a result in advances in modern medicine that are prolonging lives, but sometimes at a quality of life cost.⁶¹ Finally, unhealthy lifestyles such as poor diet, low levels of activity, and other important drivers of chronic disease, obesity and other poor health status markers also drive the prevalence and severity of disability.⁶² Also, because both disability and poor health behaviors are so strongly associated with low socio-economic measures, the relationship between these three factors is positively associated.⁶³

Cornell University's School of Industrial and Labor Relations (ILR) – and the K. Lisa Yang and Hock E. Tan Institute on Employment and Disability is the premier resource for the study of disability. Cornell has identified six major categories of disability. Each category includes the specific limitation but may be caused by a number of different health conditions, traumatic injuries, or congenital and/or inherited defect. These categories are: 1) hearing, 2) visual, 3) cognitive, 4) self-care, 5) independent living, and 6) ambulatory.⁶⁴ These definitions are in contrast to other sources. For example, Lezzoni and researchers used two major

categories to describe disability in their 2015 study: basic action difficulties and complex activities limitations. Basic action difficulties include subcategories of difficulty in movement, sensory, emotional and cognitive. Complex activities limitations subcategories are limitations in self-care, social and work.⁶⁵

Because disability comes in many forms, the impact of disability on an individual and their ability to participate in society varies. While some disabilities are highly visible in the population, other types may not be obvious or understood. Accommodations in those cases are less likely to be available, while those with more visible types of disability may be more likely to experience social stigma and discrimination. Also common are functional challenges that impact one's ability to carry out daily tasks. That being said, a myriad challenge for the disabled community are common despite the type of disability.

Perhaps the most common social challenge with disability is stigma and marginalization. Stigma is social disgrace, and the presence of disability is among the common sources of stigma. Stigma can be overt, or exist in the form of microaggressions that chip away at the social position of a person slowly but constantly. Overcoming stigma involves education, particularly educating social groups, coworkers, and society at large that the source of stigma is not appropriately applied, or that disgracing members of society is not an acceptable behavior. Despite this, human nature often prevails and treating individuals who are different

poorly is unfortunately an innate part of human behavior. Stigma, however, is not only inappropriate, but it can be illegal if it leads to discrimination. Both stigma and discrimination are common experiences for those in disabled community, and social acceptance remains an important goal for many battling stigma and discrimination often on a daily basis.

The British Equality and Human Rights Commission defined discrimination as any situation, both intentional and unintentional, when a person is treated not as well or placed at a disadvantage that relates to their disability. Examples could include an isolated incident, the global application of a rule or policy, or the placement of barriers, physical or otherwise, that limits communication or access. Referencing the Equality of 2010, the commission describes the classes of disability covered by the act, as well as offering a definition of discrimination as inclusive of the following six categories: direct discrimination, indirect discrimination, failure to make reasonable adjustments, discrimination arising from disability, harassment, and victimization. Direct discrimination may describe a situation in which the best candidate is not chosen for a job due to a disability. Indirect discrimination involves global policies and procedures that impact the ability of a disabled person versus a nondisabled person. The failure to make reasonable adjustments is another form of discrimination, which places the responsibility on employers and organizations to make sure disabled people can access

jobs, education and services as easily as nondisabled people. An obvious example is providing designated parking for disabled employees and customers. Discrimination arising from disability offers an additional layer of protection for a disabled person for reasons connected to one's disability, which may include relying on an assistance dog or accommodating one's schedule for medical care. Of course, harassment can describe any situations in which a person is humiliated by peers. Finally, victimization describes a situation in which one is treated badly as a result of a complaint one has made for any of the reasons already discussed.⁶⁶

In the US, the Americans with Disabilities Act (ADA) offers protections from discrimination for Americans on "the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications." The ADA does not define or list covered disabilities, only offering a broad definition of anyone with a physical or mental impairment that places limitations on one or more major life activities.⁶⁷ In addition to the ADA, specific protections for disabled populations seeking medical services are defined in Access to Medical Care for Individuals with Disabilities. This expectation requires that medical providers offer full and equal access to their health care services and facilities and "reasonable modifications to policies, practices, and procedures when necessary to make health care services fully available to individuals with disabilities, unless the

modifications would fundamentally alter the nature of the services.” The report goes on to define ADA requirements for new construction as well as the reasonable accommodations of existing structures such as the removal of barriers when possible. Further, guidelines state that in situations when this is not possible, providers are required to offer alternative measures or relocation.⁶⁸ Despite the importance of the ADA in highlighting the need for protection for the disabled in the workplace and in society, the reasonable accommodations that are required are very often ignored, the legal burden to enforce is on the plaintiff, and the laws are applied on the local and state level as are the decisions.

Stigma for the disabled is ubiquitous. In a feature, published in the American Academy of Physical Medicine and Rehabilitation (AAPM&R) journal, the authors discussed stigma with key examples in which functional members of society were marginalized and their abilities were devalued. Noting that the ADA has done much to improve access for the disabled, educate society, and move toward equity, the authors emphasize that attitudes and biases persist and have an impact on the way that people with disability are perceived, represented and treated. The authors emphasize the role of disability bioethics, which involves the support and promotion of disability awareness, rights, culture, accessibility, and inclusiveness with health care providers holding a key position.⁶⁹

As consumers of medical care, the disabled experience both stigma

and discrimination. In a news story published by National Public Radio, an attending physician at a teaching hospital describes how residents, nurses and other staff assist a myriad of patients who arrived at the emergency department ahead of the one patient who was a wheelchair user. The story notes that despite 20% of the population have one or more disability, less than 20% of medical schools offer any training on how to relate to disabled patients specifically in order to better understand their needs. The article then describes quality and access to care barriers for disabled Americans. Care quality has been measured relative to the general population, noting that disabled people are less like to be offered preventative and screening studies and providers are more likely to make assumptions involving behaviors including sexual activity.

Disabled patients are also less likely to be accepted as new patients at many providers' offices citing a lack of training of staff and specialized equipment.⁷⁰ In a 2015 study published by University of Louisville faculty members from the J. B. Speed School of Engineering, Department of Internal Medicine and the Department of Physical Medicine and Rehabilitation, wheelchair accessibility was measured in outpatient providers according to ADA guidelines. The sample included 30 primary care and specialty care clinics located within a fifteen-mile radius of Louisville, Kentucky that were affiliated with a statewide Kentucky healthcare network. The study was conducted following a questionnaire completed by clinical managers along with site assessments coordinated

by investigators. Study findings included that 83% of restrooms and 93% of examination rooms were noncompliant with one or more ADA requirements. Surveys found that seventy percent of clinical managers reported the absence of a height-adjustable examination table or wheelchair accessible weight scale and between 70% and 87% of patients were examined in their wheelchair. Clinical managers noted that 30% of the time wheelchair users were asked to bring someone to assist with transfers. Further, patients were also referred elsewhere due to an inaccessible clinic (6%).⁷¹ It is important to note that the ADA addresses all of these scenarios in Access to Medical Care for People with Disabilities in the Commonly Asked Questions portion, noting that all of these practices are unacceptable.⁷²

From a legal perspective, Silvia Lee, a staff attorney for the Disability Rights Education and Defense Fund presented the issue of disability discrimination in healthcare at the Jacobus tenBroek Disability Law Symposium at the Jernigan Institute in Baltimore, Maryland in 2012. Lee provided legal background of disability discrimination in healthcare including the landmark case Metzler v. Kaiser in 2001.⁷³ This landmark case for disability law required Kaiser to modify a range of access barriers at Kaiser's facilities statewide, including architectural barriers, medical equipment, as well as Kaiser's policies and procedures that created access barriers for patients with disabilities. This decision has become a model for the healthcare delivery for the disabled.⁷⁴ Despite this, research

shows the facilities that provide healthcare delivery remain inaccessible, which includes clinic restrooms without grab bars, or reachable faucets. Other limitations include health plans that do not provide benefit documents or notices in media for the blind.

The primary topic of the lecture was to discuss one issue in particular, which was height-adjustable exam and diagnostic equipment. Provider selection of exam tables and diagnostic equipment was based on the most common ambulatory patient presentations. Often the equipment was not designed to accommodate wheelchair users, or if it were designed, proper training in the use of the table for such patients is not provided. Additionally, the bias of providers may lead to erroneous assumptions in the practice of medicine.

The example Lee provided was clinical staff assuming that a woman with a disability was sexually abstinent and would not even need to be on the exam table in an obstetrics and gynecology office. Also, Lee emphasizes that providers that do not have accessible equipment are delivering lower quality to users of wheelchairs as well as other mobility related disabilities. Using data from a California managed care database, Lee shared that only 8.4% of provider sites reported having a height-adjustable exam table and 3.6% reported having an accessible weight scale. Lee emphasized that this data, highlighting low level of readiness of providers to make accommodations, was collected in the state of California, which boasts of some of the longest standing disability laws

and precedent in the US.⁷⁵

Stigma is also not unusual for wheelchair users who also happen to be physicians. In a feature published in the New York Times, Dr. Cheri Blauwet describes the complications of being a wheelchair user, from finding the accommodations and specialized equipment for disabled patients inadequate to managing the reactions from patients who question her functional and cognitive ability to be a physician as a result of her disability, not to mention being mistaken for a patient while visiting the cafeteria for lunch despite the obvious white coat. The author notes that an important source of the stigma she receives is due to the absence of disabled role models in professional positions. Currently, less than three percent of medical school trainees have a disability, a small portion of which have a mobility related disability.⁷⁶

Functional challenges are most strongly associated with disabilities, especially those with specific mobility challenges. The built environment places many barriers for those relying on the use of walkers or wheelchairs in public facilities. Despite public policy dictating that reasonable accommodations are made to improve accessibility in public facilities, changing the built environment in some situations to allow wheelchair access is not possible or cost prohibitive. Also, accessibility for new facilities is not always available or designed properly. Additional barriers to access extend far beyond the availability of wheelchair ramps. Public spaces must also be designed to accommodate the width of

wheelchairs, parking, van accessibility, restrooms, and allow enforcement to prevent resources allocated to wheelchair users are not used by those who are not disabled, in which case preventing wheelchair users from accessing public facilities despite proper accommodations. Further, public policy currently does not allow for enforcement of guidelines without significant legal expense, and court decisions dictating the enforcement of guidelines are restricted to local jurisdiction.^{77,78,79}

In addition to functional challenges in public spaces, those with a disability involving mobility challenges have even more frequent troubles accessing private spaces. Most housing units including single family homes and housing units do not offer wheelchair access. This undermines the ability of those with certain disabilities from being able to participate in social and leisure gatherings including gatherings that take place in people's homes. This is an all too common consequence of disability, as those with immobility find themselves no longer being included in activities involving participation from their social networks. It becomes their normal to politely decline, or not be invited at all. Having dinner with friends, spending down time from family watching movies, or simply dropping in to see someone for a quick visit is no longer a normal or attainable part of daily life for those with immobility. It's also normal to not have ever even seen inside the homes of close friends and family. Efforts to reduce accessibility barriers have included modifications to select units in multi-unit developments so that a mobility disabled person

can live in those designated units. As progressive as this may sound, other parts of that same housing community are often inaccessible making it impossible for a disabled person to visit neighbor's homes. This represents one of many microaggressions that undermines an important part of the goals of accessible living and it represents a failure in many to understand this complex issue.

Literature has defined the relationship between social isolation and the presence and exacerbation of disease. The lonelier one is, the sicker that person becomes, and with the growing and unsustainable cost of healthcare in the US, it is reasonable to say that loneliness is a problem that we cannot afford as a society. In a recent study exploring dichotomy of personal responsibility versus moral obligation, Brown notes the economic impact of disease but explains that unhealthy populations and their unhealthy behaviors that drive their poor health status are not entirely their fault as issues like social determinants of health and psychological mechanisms of behaviors play an important role, emphasizing the need for public policy interventions as unhealthy lifestyles and the often resulting chronic diseases have on both the general welfare and the economy.⁸⁰ The English National Audit Office estimates that obesity costs the National Health Service (NHS) more than half a billion pounds (\$700M) year and probably more than two billion pounds (\$2.7B) to the economy as of 2001, numbers that have likely increased.⁸¹ Also, a meta-analysis of forty studies published between the years 1950 and 2016, the

authors found consistent evidence connecting social isolation and loneliness to poor cardiovascular and mental health outcomes. Although other relationships impact on health spending attributed to social isolation and loneliness were less direct, the authors encourage policy makers, health delivery providers and local governments to consider social isolation and loneliness as important upstream factors impacting health.⁸²

Social isolation has other important economic consequences. Social isolation undermines economic growth by excluding members of society from participating in professional and social roles while simultaneously leading to depression and other medical conditions causing an increase in healthcare resource utilization. This situation is perpetuated by a lack of political support for improvements in accessibility in both public and private facilities.⁸³

Disability in the United States

The scope of disability in the US is not widely measured or understood. Few sources have attempted to capture the degree and types of disabilities common on the population level. Cornell University's ILR School remains the premier resource for the study of disability as it relates to all aspects of one's life. The Cornell viewpoint is that disability is as much a human rights issue as others, and much of the study of disability relates specifically to inequities afforded to the disabled in the workplace and in society. Cornell offers innovative coursework with a goal of supporting the incorporation of disability into personal worldviews as

well as understanding the depth and breadth of disability from a statistical perspective. Cornell's ILR School is regarded as the premier research institution in the collection and analysis of data related to disability.

The mission of the Cornell ILR School is related specifically to workplace and society so the scope of Cornell data focuses on Americans who are not institutionalized. In likely the most extensive study of disability, these 2016 data suggest that a total of 12.8% of all Americans have at least one type of disability, which is distributed comparably between genders at 12.9% for females and 12.7% for males. However, these averages will vary widely across age groups, race, and education. As disability has a strong relationship with aging as medical conditions associated with advanced age exist as a common source, Cornell found that disability is most strongly correlated to the age category over 75 years old. See the table below for a breakdown of disability by age.

Table 7: Disability distribution by age group

Age in years	Disability by age group percentage (%)
Less than 4 years old	0.7
5-15	5.5
16-20	6.2
21-64	10.9
65-74	25.3
75 and over	59.6

Although Cornell represents one of the most important datasets regarding disability in the US, other sources exist that are also measuring disability. The Census Bureau released an estimate in a 2010 report of

around 56.7 million Americans, which represents 19% of the population using broader measures. Also, the Census Bureau included disability severity ratings, with over half of those identified as disabled were defined as severe.⁸⁴ In a study evaluating changes in disability rates and features over time, the rate of disability in the US was defined as 26.5% in 2011.⁸⁵ In a report published by the CDC, findings suggest that 22% of adults, or 53 million people, living in the US currently have a disability. Arguing that disabilities are fluid, the report emphasizes the importance of disability based on the notion that many of us may experience the burden of disability in our lifetime.⁸⁶

Data discrepancies may be explained by differences in study populations definitions, or classifications. Population differences may include institutionalized versus non-institutionalized, which is particularly significant as many severely disabled people rely on institutions including nursing and long term care facilities to carry out basic self-care. Other important distinctions found in data sources are citizen versus resident, adults versus all ages, and enlisted versus civilians. Disabilities are also defined differently, which often includes different categories and severity. Another important consideration is the chronicity of disability, as some limitations are temporary and improve over time, while other disabilities are chronic.⁸⁷ Surveillance discrepancies can also be explained by the lack of standard that exists that defines disability as outlined in the table below.⁸⁸ These numbers, like other data sources, represent disparate

data that is difficult to identify.

Table 8: Disability distribution by Type

Disability by Type	Disability in percentage (%)
<i>Ambulatory</i>	7.1
<i>Independent living</i>	5.7
<i>Cognitive</i>	5.2
<i>Hearing</i>	3.6
<i>Self-care</i>	2.7
<i>Visual</i>	2.4

Data sources also note important changes over time in the prevalence of disability. Lezzoni and others noted that rates changed between the 1998 and 2011. Looking at civilian, non-institutionalized adults living in the US using data from National Health Interview Survey, the findings of this study included an increase in disability rates from 22.6% in 1998 to 26.5% in 2011.⁸⁹ Also, the Census Bureau noted the total number of people with a disability increased by 2.2 million since the 2005 report, but the relative percentage of the overall population was not impacted. However, an increase in the severity of disability between the years 2005 and 2010 was reported by Cornell, which reported the rate of disability to be 11.9% in 2010, rising to 12.6% in 2013, where rates remained consistent through 2015.⁹⁰

An increase in the rates of disability have several explanations. First, the rates of disability increase with age. As of 2015, less than 1% of the population under the age of 5 years has a disability. This number

increases to 5.4% in the population of children between the ages of 5 and 17 years old. The rate for adults under the age of 64 years is 10.5%, increasing to 35.4% in the population of 65 years and older. Given that the population of the US is aging with a disproportionate number of adults in the older age groups, population factors alone amplify the rate of disability. According to Wiener and Tilly, 40.2 Americans were considered elderly in 2010, which will increase to 88.5 million by 2050.⁹¹ Also, disabled Americans tend to not be as healthy as the general population notable in common health status indicators. First, rates of smoking in the disabled were 23.4% as compared to 14.9% of the general population in 2015 and obesity rates in disabled Americans were 39.9% during that same year as opposed to 25.4% in the general population.⁹² The relationship between disability and obesity is particularly well established. A study using data from the Health and Retirement Study along with Behavioral Risk Factor Surveillance Survey shows that if trends in obesity continue, the rate of disability will increase by an additional 1% per year in those between the ages of 50 and 69 years.⁹³ Furthermore, the result of modern medicine has extended the lives of many older, chronically ill, and survivors of traumatic injury but the complexity of their needs cannot be adequately addressed due to constraints in both scientific advancement and the availability of resources.

Other cultural and behavioral factors contribute to the prevalence of disability and manifest disproportionately in the cohort of vulnerable

populations. Vulnerability can be defined as any number of disadvantages which may include economic, education, level of employment, or minority status. Most of these population features can be described as socio-economic factors, which have a particularly strong positive correlation with disability. Although data were not available for the entire US population, Cornell's review of socio economic factors for subset population provides insight in the factors that impacting eventual disability status. Focusing on working age Americans ages 21 years through 64, data indicate that minority status is a strong indicator for disability, which in the US low socio-economic status is also more strongly associated with minority status. Cornell notes the prevalence of disability for the Hispanic population is 8.7%, and this figure actually includes all ages. Further, educational attainment is another important socio-economic indicator as disability is most strongly associated with lower levels of education. The relationship between markers of vulnerability and disability are so strongly entangled that teasing out the cause and effect is not possible. See the tables below for the distribution of disability by race and education:

Table 9: Disability distribution by race

Race	Disability in percentage (%)
<i>White</i>	10.9
<i>Black / African-American</i>	14

<i>Asian</i>	4.4
<i>Native American</i>	18.1
<i>Other</i>	10.1

Table 10: Disability distribution by education level

Educational Attainment	Disability in percentage (%)
<i>High School/GED</i>	34.1
<i>Some college</i>	31.5
<i>Four year degree or more</i>	14.4

Also, Cornell looked at employment status as correlation to an individual being part of the disability milieu. Looking only at employment age persons who are non-institutionalized, Cornell found that 36.2% of this total disabled population are employed, and 23% are at a full-time status.⁹⁴ For the general population, the Observatory of Economic Complexity (OECD) reports that 67.4 of% of the general population of adults between the ages of 15 and 65 are employed.⁹⁵ Also, Cornell noted that of all those actively looking for employment, 7.8% had one or more disabilities.⁹⁶

Cornell also measured income levels for those with a disability. Annual household earnings in 2016 were found to be at an average of \$40,300 for individual and \$43,300 for household.⁹⁷ This is opposed to an average household income of \$56,277 for the general population during the same year.⁹⁸ The poverty rate for the working age disabled is 26.6%,

as 19.2% receive social security benefits.⁹⁹ The average poverty rate for the population as a whole was 12.7%.¹⁰⁰ Further, the percentage of the disabled working age population with health insurance in 2016 was 90.3%.¹⁰¹ For the general population, 2016 numbers show that 64.9% of the general population had employer based health insurance.¹⁰² In 2016, 34.3% of working age disabled adults had employer-based health insurance, 11.1% reported purchasing health insurance through an employer, and 23.9% of working age disabled adults reported Medicare coverage and 42.1% had Medicaid or government provided for low income coverage.¹⁰³

Disability in Kentucky

Disability is a particularly important issue in Kentucky. Kentucky is not universally known for being a healthy state due to high rates of obesity, cancer, tobacco use, sedentary lifestyle, drug abuse, poor diet and health status characteristics and indicators are low uniquely low. Also, Kentucky is regarded as an economically disadvantaged state, as many people living in Kentucky communities represent some of the poorest Americans and with low educational attainment. Economic and community profiles of Kentucky define the majority of the state as rural, which has been shown to often exacerbate the impact of disadvantages on the vulnerable and the disabled. According to the US. Census Bureau, the median household income in Kentucky between the years 2012 and 2016 using 2016-dollar values were 20% less than national averages and

the poverty rate in Kentucky was nearly one third higher. Educational attainment, another important socio-economic indicator was barely short of the national average for high school completion, but college graduates were significantly fewer in Kentucky as compared to the rest of the America.¹⁰⁴ See the table below for a breakdown in comparisons between the US and Kentucky.

Table 11: Socio-economic comparison between US and KY

	US	KY
<i>Average Household Income</i>	\$55,322	\$44,811
<i>Poverty</i>	12.7%	18.5%
<i>High School</i>	87%	84.6%
<i>Bachelor degree or higher</i>	30.3%	22.7%

The relationship between poor socio-economic status and disability is well described. For this reason, it is no surprise that as Kentucky falls below the national average in key socio-economic indicators, that the rate of disability in Kentucky will also be higher. According to the US Census Bureau, the number of adults living in Kentucky with a disability under the age of 65 is nearly double that of the general population of adults in the US in the same age group. See the table below for a representation.^{105,106}

Table 12: Disability rate in Kentucky versus US

	US	Kentucky
Disability rate in adults 18-65	10.9%	17%

As Cornell offers the most comprehensive disability data source in the US, state by state breakdowns of data are also available. As Kentucky underperforms per Census Bureau numbers, the same situation applies from the Cornell dataset as the impact of disability can be observed in most every measure. For example, the table below shows a breakdown of disability in the US versus Kentucky, where Kentucky leads in every category except for children under 5 years old. But, the numbers immediately overcorrect as the age group of 5 to 15 years demonstrate an increase of more than 20% of Kentucky figures over national data. This implies that congenital disabilities present at birth are actually lower as acquired disabilities, often related to health behaviors and the exacerbation of chronic disease most likely have a role in facilitating Kentucky disability rates with age. See the table below.¹⁰⁷

Table 13: Disability distribution by age group in percentage (%)

Age in years	US %	Kentucky %
<i>Less than 4 years old</i>	0.7	0.6
<i>5-15</i>	5.5	7.8
<i>16-20</i>	6.2	8.6
<i>21-64</i>	10.9	17.0
<i>65-74</i>	25.3	33.2
<i>75 and over</i>	59.6	56.0

Disability type is another important measure as Cornell data

provide a breakdown between the six defined categories.¹⁰⁸ As disability has many sources even within categories, which vary between congenital or inherited disabilities, traumatic injury, or outcomes of diseases or other disabilities, it is important to note the Kentucky figures are greater than national figures in every category.¹⁰⁹ See the table below for information.¹¹⁰

Table 14: Disability distribution in percentage (%)

Disability by Type	US %	Kentucky %
<i>Hearing</i>	3.6	5.1
<i>Visual</i>	2.4	3.5
<i>Cognitive</i>	5.2	7.8
<i>Self-care</i>	2.7	3.8
<i>Independent living</i>	5.7	7.9
<i>Ambulatory</i>	7.1	10.6

Race is another important indicator with important socio-economic implications. However, as much of Kentucky's population represents white majorities living in rural areas, one could assume that the relationship between minority populations and disability is not as well defined. In fact, the Census Bureau reports that Kentucky has proportionately many more non-Hispanic whites as compared to the national average, as other minorities tend to be underrepresented. See the table below for a comparison of the general population of Kentucky with the US by race.^{111,112}

Table 15: US versus Kentucky by Race

Race	US	Kentucky
<i>African American</i>	13.3	8.3
<i>Native American</i>	1.3	0.3
<i>Asian</i>	5.7	1.5
<i>Pacific Islander</i>	0.2	0.1
<i>Two or More Races</i>	2.6	1.9
<i>Hispanic</i>	17.8	3.5
<i>Non-Hispanic white</i>	61.3	85

Cornell also uses race as a basis to measure and understand disability. One would expect the results of this comparison to be a disability rate that is heavily weighted with the Kentucky population being 85% versus 61.3% white, but the overall rates were well pronounced for the white population and every other racial category Cornell defined. These data illustrate the universal high rate of disability as a function of the lower socioeconomic status in many Kentuckians. The table below offers a breakdown of these numbers.¹¹³

Table 16: Disability distribution by race in percentage (%)

Race	US %	Kentucky %
<i>White</i>	10.7	16.8
<i>Black / African-American</i>	14	19.1
<i>Asian</i>	4.5	9.0
<i>Native American</i>	18.1	22.5
<i>Other</i>	10.1	20.4

Educational attainment is strongly tied to health status. As education is tied to income, which drives choices, it is likewise tied to the quality of decisions we make regarding our health, from the foods we eat to the medical care we choose to receive, and, in some cases, choose not to receive. Educational attainment in Kentucky is lower than the general population in all categories, especially higher education per Cornell.¹¹⁴

These figures represent one of the few categories in which the disabled population in Kentucky outperforms national averages as a disabled person in Kentucky is more likely to have a completed high school or the equivalency exam.¹¹⁵ In all other measures, Kentuckians with a disability fall short in educational attainment just as the general population of Kentuckians fall short as compared to national averages.^{116,117} See the table below for more details about educational attainment in disabled populations.¹¹⁸

Table 17: Educational attainment in percentage (%)

Educational Attainment	US	Kentucky
<i>High School/GED</i>	34.1	38.1
<i>Some college</i>	31.5	28.3
<i>Four year degree or more</i>	14.4	9.7

Wheelchair Users in the US

Among the several types of disability, immobility represents a particularly important area of study. Immobility undermines one's ability to carry out the most basic of daily tasks as well as limit participation in society. The causes of immobility include chronic disease complications, the worsening of other types of disability, trauma or advanced age. This characterization may include those who walk with a walker, cane, crutches, or have trouble climbing stairs. Immobility is frequently improved with the use of canes, walkers, manual or electric wheelchairs.

Wheelchair users are often included in the broad category of

disability defined as immobility, as this category includes a myriad of mobility challenges and with varying degrees. The purpose of wheelchairs is to restore users to the highest level of activity possible, which varies considerably depending on the nature of the disability or disease. Wheelchairs may provide users a range of possibilities otherwise unattainable such as the ability to maintain employment, participate in social activities, enjoy recreation and leisure, fulfill family obligations, travel, and make healthcare related visits. Because of both physical and policy related barriers, wheelchair users are among the most visible and impacted of the disabled community. While some disabilities are invisible, wheelchair users tend to be the most obviously disabled members of society.

Wheelchair users are most impacted by architectural barriers that limit access to areas where cane and walker using counterparts can more easily access. The shortest step may represent an impenetrable barrier to a wheelchair user, and staircases common in both public and private spaces are off limits to most wheelchair users and in many situations. Sidewalks may represent another important barrier, the absence of, obstructions, or uneven pavement may also limit access. Curb cuts represent critical pathways for wheelchair users to cross streets, access parking, and other necessary movement in public spaces, and the absence of curb cuts, or placement in areas that make movement difficult is another important often daily barrier wheelchair users face. The side-to-

side clearance of many doorways, especially interior doors, in residential homes do not accommodate standard wheelchairs, but other disabled persons with mobility challenges may easily pass through widths that are less than normal size openings. Bathrooms represent another barrier, as doorways must be wide enough, as well as many other details such as ample space, grab bars, toilet seat height, and curb-less showers are all factors. Transportation is an important issue for wheelchair users as most all private vehicles and many public transportation resources are not accessible to wheelchairs, and public resources in many communities are not reliable and have limited availability. Standard width parking spaces are another common issue for wheelchair users. Other less obvious barriers include round doorknobs or door hardware that is difficult to grasp, doors that are too heavy, public aisles too narrow to access, high countertops or narrow checkout aisles at a cash register, and restaurant tables that are too low to accommodate a person using a wheelchair or tables with fixed seats that prevents wheelchair users from accessing.¹¹⁹

Health and public policy efforts continue to address some or parts of physical and functional barriers. For example, commercial health plans and public health insurance programs often provide the wheelchair as a medical necessity without comprehensively addressing other factors that support a person's ability to actually achieve mobility. For example, some wheelchairs have optional seat lifting mechanisms that allow a person to lift in height in order to access basic height countertops and shelves and

there are wheelchairs available that climb stairs. Although these products would greatly improve the activities of daily living for many disabled people within their homes and in other public and private spaces, they are not covered because they are not considered “medically necessary” by the policy. Instead, these barriers are considered by health plans and government payers to be social problems. Also, complementary products like ramps are not provided under health insurance coverage and the lack of such equipment renders the wheelchair useless for those living in inaccessible homes resulting in wheelchair users being confined in small spaces. For those living in rural areas especially, access to transportation is critical and often unavailable. The purchase of accessible transportation is cost prohibitive for even middle-class consumers. Because wheelchair users tend to be economically vulnerable, only a select few are capable of paying the normal cost of a converted van. The national statistics on van conversions demonstrate that the basic cost of just the ramp is \$25,000. That cost does not include the individualized operational equipment, such as hand controls, needed to outfit the vehicle for specialized mobility. These additional costs may be \$25,000 and up. The cost of the van alone, typically \$30,000 for an inexpensive van, is not included in these estimates. Depending on what operational equipment is required, the total cost of modifications to accommodate a person’s needs may range from \$70,000 to \$120,000 or more. In addition, the insurance, maintenance and repair costs for this specialized equipment may total

three times or higher those of a vehicle without modifications. These costs present absolute barriers to acquiring specialized vehicles except for a small percentage of the individuals with the financial means to handle the cost. Braun Corporation is the largest vehicle conversion company in the US responsible for the majority of these conversions. According to Braun, between 18,500 and 20,000 vehicles are converted each year. Due to the complicated nature of conversions, the market for pre-owned conversion vehicles is also limited to fewer than 20,000 each year.¹²⁰ It is important to note that with an estimated 40,000 accessible vehicles available annually, that this figure fails to meet even a fraction of the need for wheelchair users with an estimated population of 3.6 million.¹²¹

Public transportation is an alternative to vehicle ownership given the important cost barrier for most wheelchair users. Public transportation, however, has important barriers of its own. First, the infrastructure in the US does not always provide public transportation resources in middle sized cities and small communities, and some large cities are without strong public transportation options. Assuming public transportation is available, making arrangements for wheelchair users can be particularly difficult to arrange. Disabled transportation often involves accepting long windows (1 to 2 hours) waiting for pick-up which creates an important barrier for wheelchair users who may need to report for employment and other appointments that require punctuality reliably and on time. Also, the availability of such transportation is often limited making

public transportation not a viable option to rely upon.

These barriers are among the many that undermine the function of the wheelchair by preventing users from fully participating in society at the level allowed given their underlying condition. This exclusion of wheelchair users from work, social activities, and other community interaction that many take for granted has an isolating effect, not to mention it undermines feelings of self-worth. Given that many wheelchair users are also battling chronic illnesses that either caused their immobility or exist as a result of their immobility, the isolating effect of exclusion from society has been demonstrated to worsen these disease states. Worsening disease and complications secondary to social isolation have important healthcare and economic cost implications. For this reason, modifying architectural barriers to allow greater accessibility of wheelchair users will likely improve the health of wheelchair users while simultaneously saving healthcare dollars and avoiding additional economic costs.

Although architectural barriers represent an important daily challenge for wheelchair users, almost no one studies the impact of barriers on wheelchair users; however, an internet search reveals numerous discussions of barriers in the form of blogs, commentaries, and other reports. For example, an assessment published on the 1800wheelchair website, (an online seller of wheelchairs, walkers, electric power wheelchairs, and electric mobility scooters, and supplies)

represents one of the few available measures of the impact of architectural barriers. The assessment was conducted in March of 2017 and included 544 Americans who are users of a wheelchair or scooter or live with users of a wheelchair or scooter. First, the survey section identified five major challenges, which include unsafe sidewalks, narrow aisles, non-compliant curbs and crosswalks, blocked wheelchair ramps, and inaccessible buildings. The survey found that 28% of the respondents encounter a barrier to a building, transportation or service once a week and 20% encounter a barrier at least once a day. The survey found also that many suffer barriers within their own homes, noting that 36% live in a home that is not wheelchair accessible. Of the respondents, 70% noted steps leading into the home, 51% had a lack of financial resources to make their homes accessible, and 25% reported that they manage the challenges and inconveniences. And another indicator of factors outside of their control, 16% were unable to make modification due to restrictions from the landlord, homeowner association, or condo board.¹²² It is important to note that this assessment did not appear in a peer-reviewed journal but was included as indicative of the prevalence of these problems, given the paucity of formal studies examining these issues by current researchers. As a result, the study population was not well defined, and the research methods were not internally or externally validated, but the findings still represent an important contribution as they mirror the statements of many individuals and their frustrations. A recent study

published in the Archives of Physical Medicine and Rehabilitation did address another dimension of wheelchair use that no amount of public policy can address, and that is the impact of winter weather in addition to daily barriers. This report found following a cross-sectional assessment of 99 respondents who completed a survey measuring the impact of cold weather issues on a population of urban dwellers in Canada. A total of 42% of respondents admitted to decreasing the frequency of outings during cold winter months, which likewise decreased their community participation. Respondents noted incidents in the winter of slipping on ice and getting stuck in the snow, resulting in the authors calling for better surface maintenance to improve the social participation of wheelchair users. Regarding sampling, the authors did not have a method for measuring the population of wheelchair users in the communities studied, which is also an interesting finding.¹²³

Wheelchair usage data in the US is also not widely available. According to the National Institute of Health, there are a total of 6.5 million people in the US who use a cane, a walker, or crutches and 2.2 million people use a wheelchair.¹²⁴ Other sources of disability statistics also report wheelchair users in the same category of others with mobility related disabilities, with varying degrees as well as temporary and chronic conditions. Among these data sources was Cornell, which is regarded as the premier resource for disability research. For this thesis a special request was made to Cornell, to render an estimate for wheelchair usage

in the United States. A researcher from Cornell used from the 2010 US Census Bureau and from the 2012 American Community Health Survey to estimate the number of wheelchair users based on responses from the mobility disabled group and how they responded to the severity of their condition. Based on how they compared between the two sets and the proportion of the immobility disability category the sample included, these estimates were believed to be conservative, and this number only includes adults and children over the age of 15 years who are non-institutionalized. This figure was estimated at 3,568,000 in the US, which represents 1.4% of the population. See the table below.

Table 18: Wheelchair users in the US

	Estimated Number of wheelchair users ages 15 and older	Estimated % population ages 15 and older using wheelchairs
US	3,568,000	1.4%

Cornell cautioned that these numbers may have reporting errors, as people from different states and regions may report the severity of their condition differently. Estimates included an additional 67,000 wheelchair users under the age of 15 nationally.¹²⁵

Wheelchair Users in Kentucky

As data measuring wheelchair use on a national scale are not easily found, state level estimates were largely unavailable. Per the

special estimation requested from Cornell, their national estimate of wheelchair users was provided with a breakdown for each state. According to estimates, 71,200 people, which represents 2.1% of the adult and child population of Kentuckians over the age of 15 years old living outside of an institution are wheelchair users. The proportion of wheelchair users in Kentucky is significantly higher than the percentage estimate for the US population at large. See the table below for a comparison of Kentucky with national data.

Table 19: Wheelchair users in Kentucky and the US

	Estimated Number of wheelchair users ages 15 and older	Estimated % population ages 15 and older using wheelchairs
US	3,568,000	1.4%
Kentucky	71,800	2.1%

Cornell also provided a breakdown of estimated wheelchair users by state. Please note that the proportion of wheelchair users is among the highest in Kentucky as compared to other states. In fact, only two states have a higher proportion: West Virginia and Mississippi. Also, percentages for Alabama and Arkansas are tied with Kentucky at 2.1%. Every other state has lower percentages of wheelchair users. See the breakdown below for more information. ¹²⁶

Table 20: Estimated wheelchair Users by state

State	Estimated Number of wheelchair users ages 15 and older	Estimated % population ages 15 and older using wheelchairs	State	Estimated Number of wheelchair users ages 15 and older	Estimated % population ages 15 and older using wheelchairs
AK	6,500	1.10%	MT	11,700	1.40%
AL	81,900	2.10%	NC	121,600	1.60%
AR	49,300	2.10%	ND	6,100	1.10%
AZ	72,400	1.40%	NE	16,000	1.10%
CA	362,200	1.20%	NH	13,600	1.30%
CO	44,700	1.10%	NJ	85,700	1.20%
CT	33,100	1.10%	NM	28,800	1.80%
DC	7,100	1.30%	NV	31,300	1.40%
DE	10,900	1.50%	NY	206,500	1.30%
FL	242,700	1.50%	OH	145,900	1.60%
GA	114,000	1.50%	OK	55,500	1.90%
HI	14,600	1.30%	OR	45,900	1.50%
IA	30,200	1.20%	PA	153,500	1.50%
ID	16,000	1.30%	RI	11,500	1.30%
IL	131,700	1.30%	SC	66,100	1.80%
IN	75,100	1.50%	SD	8,400	1.30%
KS	31,800	1.40%	TN	98,400	1.90%
KY	71,800	2.10%	TX	280,500	1.40%
LA	66,000	1.80%	UT	22,100	1.10%
MA	65,400	1.20%	VA	82,300	1.30%
MD	55,300	1.20%	VT	6,900	1.30%
ME	16,100	1.50%	WA	70,100	1.30%
MI	124,200	1.60%	WI	56,600	1.20%
MN	46,300	1.10%	WV	35,500	2.40%
MO	81,100	1.70%	WY	6,000	1.30%
MS	51,100	2.20%	Total	3,568,000	1.40%

CHAPTER 2: STATEMENT OF THE PROBLEM AND LITERATURE REVIEW

Disability is an increasingly important problem in the US. Many factors contribute to disability, whether it be congenital conditions, behavioral and lifestyle issues that are becoming increasingly common, or the consequence of Americans living longer coupled with population aging, all of these factors are driving the increasingly common incidence of disability in the US. Disability also has a strong association with poverty, as the relationship between disability and low socio-economic status is both a predictor and an outcome. A lack of economic resources has driven many of the choices, or lack thereof, which may include important factors like healthcare, transportation, employment options, and the economic power that it takes to maintain social connectedness when doing so is likely much more expensive as compared to the general population. Based on the rising costs of healthcare and the high healthcare costs associated with disability, we as a society may not be able to continue the ever-escalating funding required under current models.

Disability in the US is a complex issue. Due to its relationship with socio-economic factors, social connectedness, public policy, population health drivers, and moral and ethical drivers, the complete picture of

disability might be represented by a discussion of several important components. First are the social determinants of health, or the socio-economic distinctions of different groups in the US and their very specific relationship with behaviors and decisions that drive health status. As those with a disability tend to be clustered to lower-end socioeconomic classifications, researchers have asked if this relationship exists because of disability or is a cause of disability. Also, a conversation about social capital describes the strength of social networks and their ability to improve or dismantle the health status of individuals, with the impact amplified for the medically fragile. Public policy interplays with institutional and societal barriers, and overcoming those barriers through policy initiatives. One example of these types of initiatives is visitability, or the notion that wheelchair users' access into newly constructed homes be legislated. Research discussed previously and continuing below highlights the relative cost of this type of intervention is minimal cost impact outweighed by the potentially economic and societal cost of disability, given assumptions of baseline disease burden. Also, inclusion our most vulnerable members of society is order to improve health equity also represents fair resource distribution.

Social Determinants of Health

Social determinants of health describe the “dynamic, multi-dimensional processes driven by unequal power relationships interacting across four main dimensions - economic, political, social and cultural - and

at different levels including individual, household, group, community, country and global levels. It results in a continuum of inclusion/exclusion characterized by unequal access to resources, capabilities and rights which leads to health inequalities.”¹²⁷ Social determinants of health affect everyone from the wealthiest who have the power and education to make quality health and lifestyle choices to the poorest members of our society whose absence of choice has important consequences. For this reason, the role of social determinants of health has become an important area of research for experts and policy makers in population health. This has represented an important shift in the last century, where the prevailing focus of public health and policy was communicable infectious diseases and vaccine policy. Now, communicable diseases are those that exist in exchanged behaviors that are embedded in cultural norms, socio-economic indicators, race, education, regional differences, access to transportation and food choices, and behavioral and often culturally embedded risks such as alcohol, drug and tobacco use. In vulnerable populations, behavioral and lifestyle related conditions are the most common drivers of outcomes. Policy makers, health care providers, public health workers, researchers, teachers, and many others have sought to offer solutions, but the multifaceted problem persists and health spending continues to skyrocket as a result.

Research demonstrating the critical role of social determinants of health was popularized by Michael Marmot’s series of studies evaluating

over 18,000 British civil servants beginning in 1967 with phases ongoing. The Whitehall studies, named for the geographical area of London where the studies were conducted, sought to investigate the relationship between stress levels on health, particularly cardiovascular health. The Whitehall studies looked specifically at professional positions as a marker for socio-economic indicators and found that lower employment positions were a predictor for mortality. Subsequent phases of the Whitehall studies looked at other health status indicators and included females with similar outcomes.^{128,129,130} Since then, many studies have looked at the impact of social determinants of health on various health status measures, chronic diseases, and communicable diseases in communities across the world. In 1999, one of the earliest epidemiological studies looking at the social environment. This was defined as “the groups to which we belong, the neighborhoods in which we live, the organization of our workplaces, and the policies we create to order our lives.” The authors were among the first to identify the role of the physical environment has on population health, urging more research in identifying community socio-economic status, social structural issues, and quality of environment.¹³¹ In a 2001 critical review, Pickett and Pearl published a systematic method early in the conversation. Using terminology like “social factors” and “ecology,” the authors found consistent evidence of “neighborhood effects” on health outcomes across studies and communities.¹³² In a 2002 publication, Macintyre and colleagues examined social determinants of health from a

social science perspective using the terminology “place effects.”¹³³ By 2004, social determinants of health were being described as the relationship between socio-economic status and health outcomes, defined on the individual level and the neighborhood and group level. Also, the impact of socio-economic status was being studied on specific disease states such as common lifestyle and behavioral chronic conditions like cardiovascular disease.¹³⁴

As medical care is estimated to account for between ten and twenty percent of the modifiable drivers of positive health outcomes on the population level, the remaining factors impacting health status and outcomes are health-related behaviors, socioeconomic factors, and environmental factors.¹³⁵ Despite this, health services including population based policy has been largely driven by intervention focused on access and quality medical care.¹³⁶ But, the role of social determinants of health is an established area of research. In a recent meta-analysis that included data published between the years 2010 and 2017 collected from 26 published studies looked at income inequality and health status, noting the importance of income distribution as it relates to the differences in social status.¹³⁷ In an article published in the Environment and Urbanization Journal, the role of social determinants of health was emphasized as part of comprehensive public policy. As health inequities are amplified in the populations of the urban poor, policies that create “supportive social and physical environments” that support health is critical

in today's cities for populations at all income levels.¹³⁸ Policy implications are also addressed by Schrecker, who argues that social determinants of health have a less defined pathway than other environmental risks. Results in terms of outcome measures like average life expectancy and health status may not represent reality, and some results, such as life expectancy, may take decades before producing measurable data. Despite this, Schrecker argues for a focus on policy that focuses upstream despite what the scientific evidence may show as part of public health ethics.¹³⁹

The importance of social determinants of health form of policy and population health aspect is also an important area of interest. Population health organizations such as the World Health Organization (WHO) and Centers for Disease Control and Prevention (CDC) have initiatives looking specifically at social determinants of health. The WHO describes social determinants of health as “the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels.”¹⁴⁰ The CDC defines social determinants of health as the conditions and the places where people live, learn, work, and play affect a wide range of health risks and outcomes. Paramount to the role of the CDC in managing population health in the US is to provide access to data and other resources as a means of supporting the public health community and other organizations involved in population health, medical care delivery,

community organizations, social support services, and health policy. The CDC is also interested in implication of social and economic impact on society of health policy as well as economics of investment in scientifically based policy, to promote awareness of policy utilizing the knowledge of the root causes illness such as inequality, social disadvantages and poverty.¹⁴¹ The CDC also emphasized the importance of social determinants of health in Healthy People 2020. The report offers several suggestions for improving health inequities including the creation of social and physical environments that promote good health for all as one of the four main goals for improving health on the national level.¹⁴²

In a comprehensive community level study, the Data Set Directory of Social Determinants of Health at the Local Level identified twelve dimensions of the social environment that exist as drivers of health. The first dimension is the economy, which includes a host of economic factors including income, cost of living factors, taxes, and other economic drivers that affect one's economic stability and choices. The second dimension is employment, which refers to the position one holds in the labor market, access, stability and security, professional characteristics, access, security and occupational safety. The third dimension is education, which refers to quality public education as measured by facility quality, teacher quality, faculty to student ratios, racial segregation, graduation rates, literacy rates school funding, private school resources, and physical environment and safety. The fourth dimension in the report is described as political, which

includes civic involvement activities like voting and political party membership, community organizations and other power groups, as well as the political characteristics of the community. The fifth dimension identified is environmental, which include air and water quality, physical safety, and land use policy. The sixth dimension is housing, which describes the characteristics of local housing such as the quality and age of resources, property values, rental versus owner occupied, mortgage lending patters, neighborhood segregation, gentrification, low income and subsidized housing policies, homelessness and community housing policy and initiatives. The seventh dimension is medical, access to all care categories including primary care, specialty care, emergency services, mental health, long term care, oral health based on payer status and affordability of utilization. The eighth dimension is government, which describes the funding of local resources by government sources, government policy that affects income such as minimum wage requirements, labor union policy, and local taxes, government services, and local government power. The ninth dimension is public health data sets, which include the quality of common population health programs like disease screening, nutrition, family planning, chronic disease control, school-based education programs, substance abuse prevention, domestic violence prevention, mental health services, and immunization. Local public health is also involved in the regulation of sanitation, food safety and the enforcement of other important health standards. The quality of

these programs is dependent on the funding available for public health programs. The tenth dimension is described as psychosocial, which describes the interest of individuals in social life, group formation, and other social events. The report highlights the impact of social structure on health status and describes the presence of key community social organizations as having an impact on health. These organizations include political based which may include parties, advocacy or special interest groups. Volunteer organizations and charitable groups represent another key community resource and source of social involvement. Labor unions and professional organizations connect coworkers and colleagues across organizations. The eleventh dimension is behavioral, which describes population characteristics as they relate to health outcomes. Common behaviors may include tobacco use, physical activity, diet, substance use, and violence, which are driven by access to healthy food options, economic opportunity, neighborhood safety, and education. The twelfth and final dimension identified in the report is transportation, which relates to the availability of all resources present within a community to move people to and from work, social activities, medical services, and other important resources. Important factors include safety, which may include highway safety, neighborhood safety, and the presence of law enforcement. Other infrastructure issues may include the presence and quality of roads, traffic volume, the availability of carpooling, and the layout of the community in terms of residential and work locations. Other key

resources include access to vehicles, the affordability of transportation, and public resources.¹⁴³

Social Capital

Humans are by nature a social species with a long history characterized by the formation of communities. Social networks strengthened the earliest prehistoric communities, fostered their survival, supported reproduction, and ensured long term sustainability. Modern communities continue to rely on social networks, as the framework of connectedness remains an important construct influencing self-actualization. Among the many aspects of one's ability to reach their full potential is their health status, which has been found to be influenced by the strength of their social networks.

The importance of social capital has long been described as an important framework for communities. In the nineteenth century, French political scholar Alexis de Tocqueville traveled to the US to observe the establishment of democracy based on European ideals that represented a rebellion against century old absolutism. In his book, "Democracy in America," Tocqueville described the concept of social capital as observed in the newly formed US as a notion of friendship and social connectedness of all people. He described that apparent in the US was this phenomena of "habits of the heart" where citizens within communities looked out for another, and they did so without cause. They just did.

“Habits of the heart” was a cultural artifact of the American story that persisted, seemingly until after the turn of the nineteenth century.¹⁴⁴ Tocqueville was clearly ahead of his time as social science research did not emphasize the importance of social capital until recent decades. Further, the connectedness of communities noted a measurable decline as described by Robert Putnam. In 2000, Putnam cited the decline of bowling leagues, one of the many groups Americans tended to join, as a proxy of the loss of social capital in American communities.¹⁴⁵

Meanwhile, the creation of the Hierarchy of Needs framework emphasized the role of social connectedness akin to basic physical needs such as food, water, shelter and safety as necessary in the pathway to self-actualization. First introduced by Abraham Maslow in his 1943 paper titled, “A Theory in Human Motivation,”¹⁴⁶ Maslow introduced a groundbreaking framework that has since been explored by a number of disciplines in the social sciences.¹⁴⁷ The basic premise of the framework argues that the ability of individuals to reach their full potential hinges on the satisfaction of basic needs. In the model, basic needs are ranked, and individuals move up the pyramid as they approach their ideal self: a state Maslow refers to as self-actualization. At the bottom of Maslow’s pyramid exists physiological needs. Maslow describes this position as the basic physical requirements for survival. The basic elements of human survival include food, water and shelter. Once a person is sheltered and nourished, Maslow argues they become positioned to pursue safety and

sustainability. In contemporary society, safety needs manifest in many forms of personal security or financial security. Once an individual has met this need, Maslow argues that individuals move to the social belonging position where they feel empowered to pursue and nurture relationships. Humans have the need to love others and to be loved, and the failure to do so results in loneliness, isolation, and depression. Following this level, Maslow asserts that humans who achieve this feeling of belonging then want to feel esteemed or respected by those in their social network. Maslow acknowledged these are two separate but often interrelated steps.^{148,149}



Figure 5: Hierarchy of Needs

The Hierarchy of Needs have been widely explored, discussed, and even disputed by researchers in a variety of fields. Critics have expressed a number of questions and objections, including the basic needs Maslow

identified as well as the simple step wise pathway one navigates through in order to self-actualize. The most common objections to the model is the questioning of the existence of a hierarchy as needs seem to be expressed in varying orders depending on circumstance. Also, human behavior often does not seem to be defined by the hierarchy as needs regarded as basic may be disregarded in pursuit of self-actualizing goals. In short, human behavior is complex and drivers of human behavior are interrelated and varying depending on circumstance and sphere. However, the contributions of Maslow to understanding human behavior is not questioned, even by those suggesting alternative or more complex frameworks.¹⁵⁰

Over the past 25 years researchers have been looking closely at the potency of social capital on health and happiness. Study after study have been conclusive that the more social capital an individual has, the less sick days and sad days they experience. A study conducted in Alameda County California found that healthy adults who were more socially integrated with deeper forms of social capital such as wives/husbands/partners as well as with close friends and associates were more likely to still be living nine years post study than others who were less connected.¹⁵¹ Twenty years later Berkman and Glass found that the more social capital the greater the survival from heart attacks, less risk for cancer recurrence, less depression/anxiety, and less severe cognitive decline with aging.¹⁵²

The impact of social capital on health is an important field of study, as a causal relationship between social connections and mortality was observed following a review of five large studies nearly three decades ago. Since then, many studies have emphasized the role of interpersonal relationships on a reduction of risk for chronic disease and mortality in many populations and conditions. In a meta-analysis that included data from 148 studies and 308,849 study participants, there was a 50% increased likelihood of survival found in participants with stronger social relationships, a finding that remained consistent across age, sex, initial health status, cause of death, and follow-up period.¹⁵³ Social capital is not a unique strengthening mechanism for humans, as the social connectedness has also been widely studied as an important factor driving the survivability and thriving of many animal models. In a primate model, the strengthening of social connectedness was observed as a key driver for improving the health and lifespans as a translational model with implications for humans.¹⁵⁴ The importance of social connectedness is also being recognized on a political level. On January 17, 2018, the United Kingdom announced that Tracey Crouch would serve as the first Minister of Loneliness. This position was created following findings from a 2017 British survey seemed to indicate the known challenge of many Europeans with loneliness was seemingly worse for the British with over nine million people admitting to feeling lonely most or all of the time. The impact of loneliness was described as worse than smoking fifteen

cigarettes per day by a British charity that works primarily with older people.¹⁵⁵

Visitability

Many aspects of modern life drive the formation of social networks. Among the most important factors, the mobility of people exists as the most critical as it facilitates human interaction, and a lack thereof undermines the natural inclination of humans to seek relationships with one another. Access to resources available in many modern communities can be critical to facilitating social networks, which may impact human interaction. This includes but is not limited to transportation, mobility technology, and a built environment that allows the free movement of all inhabitants to public facilities and private residences. All of these factors drive a number of critically important aspects of quality of life, including the ability to work, access to resources such as grocery stores, restaurants, entertainment, healthcare and the homes of friends and family.

The built environment is a key area of interest in public health research as the structure of cities, public parks, sidewalks, and other public highways define daily activities. This is especially true for urban communities as sidewalks are often an important mode of transportation to and from work, school, and social activities, family interaction and other interpersonal obligations. In a study evaluating the role of the built

environment on disability following a national sample of American adults over the age of 45 during a 15 year time period, the authors found that older age groups were more noticeably impacted as well as those with chronic health conditions and mobility related disabilities, suggesting that the built environment can exacerbate mobility difficulties for older adults. The authors also note that upgrades to the built environment such as level, unbroken sidewalks or adding curb cuts may be a simpler intervention than influencing risk factors at the individual level.¹⁵⁶

Transportation is another factor impacting human interaction as it facilitates the movement of people to workplaces, businesses, friends and family. Transportation describes a number of resources, including private vehicles, car services, and public transportation systems present in many cities that are available for short distance and daily access. A lack of availability of transportation has consequently proven an important factor for many aspects of low health status including access to fresh and healthy foods, healthcare resources as well as critical social networks. In a meta-analysis which compiled data from 61 peer-reviewed studies on transportation barriers to healthcare access, the meta-analysis authors noted the impact of transportation barriers on the burden of disease. Access to healthcare was impacted by a wide range within the sample, from 3% of the study population to 67% and 25% of the sample reported having missed an appointment due to transportation uses. Access to a car was also an important driver of access to healthcare resources. The

authors concluded that access to transportation represents a common barrier for many, especially in those with low socio-economic status, and the lack of access to safe, quality and reliable transportation exacerbates the health status of key populations.¹⁵⁷

It is not surprising that vulnerable populations, especially those with a disability, have limited choices in transportation. Many cannot afford to own or lease a vehicle, which makes them dependent on public transit, which is not common or reliable in many communities, or they must rely on friends and family. For those with accessibility needs, transportation option may be less limited or nonexistent, which severely undermines one's ability to build social capital, as well as accumulate resources in order to build social capital. If you cannot access transportation to a worksite, then you cannot work.¹⁵⁸

Another important barrier for those with disability is housing. Choices may be limited for a number of reasons including accessibility, affordability, safety and discrimination. In fact, housing has become an increasingly important focus in public health research due to the aging of the population. The notion of aging in place describes the ability to live and remain in the housing of choice over a lifetime with all the necessary support services, which is of increasing importance given the aging of the American population. Unfortunately, aging alone is often reason enough that housing choices are threatened.¹⁵⁹ It is also not uncommon for older Americans to have a disability, which creates additional limitations,

restrictions, and requires additional support services. Disability in Americans of all ages, however, is an important factor in housing. As those with disability are more likely to be economically vulnerable, it results in a disproportionately high number of disabled Americans living in sub-standard housing, often in undesirable, unsafe, and low-income areas of cities, with the worst school systems, low access to healthcare resources, low access to quality food, and poor social networks. In the most severe situations, disabled people are confined to their homes unable to leave due to their limitation, or their homes are so unsuitable they end up homeless or on the streets.

Social justice advocates who have recognized the impact of social networks on healthy communities have endorsed the concept of visitability, which describes a movement that involves the creation of barrier free homes accessible to wheelchairs. Even though visitability is a policy that deals specifically with residential homes, the overarching goal of facilitating their inclusion into society by allowing them access to both public spaces that should be subject to ADA guideline and private spaces. Visitability involves functional changes to new construction that will eventually transform the built environment along with a related cultural goal that facilitates education, acceptance and inclusion.

Visitability has been implemented on the city and community level as both a promotion and compulsory form of public policy. Visitability as a public policy has the following very clear definition:

- one zero-step entrance, and
- doors with 32 inches of clear passage space, and
- one bathroom on the main floor accessible by a wheelchair.¹⁶⁰

Visitability has been a national movement with growing political support, and several local communities have passed local ordinances that have modified local building codes to allow for the low cost and minor changes to new construction to allow disabled friends and neighbors access to private homes for social activities and support.¹⁶¹ Visitability policies have been enacted in many communities including those in Arizona, Texas, Georgia, New York, Ohio, Iowa, and Illinois.¹⁶²

The literature studying visitability is limited. One of the few studies currently available measure impressions and attitudes regarding the presence of visitability features in new houses in a cross-sectional survey that included images of real homes meeting criteria for visitability against those that did not. The study was conducted in an Ohio community with a study population of 96 homeowners and 107 homebuyers. Despite the belief that disability features are unwanted by housing developers, the results indicated favorable impressions in both populations, noting a perceived increase in value as well an improvement in marketability. These results were consistent across younger and older aged respondents and following review of different price points.¹⁶³

Burden of Disease

Chronic disease is another increasingly common challenge facing modern society, particularly in developed industrialized nations. In addition to our aging population, chronic disease is also driven by lifestyle and behavioral factors. In 2001, an international study calculating the mortality, incidence, prevalence, and disability adjusted life years (DALYs) for the global disease burden as well as relevant risk factors for 136 diseases and injuries in relative to seven groups of countries by income and geography during the study period beginning in 1990 through 2001. The study offered a number of key findings. First this study found a 20% reduction in the global disease burden as a result of communicable, maternal, perinatal, and nutritional conditions as an increasing number of non-communication diseases are affecting worldwide populations. For low to middle income countries, this figure was half. Also, this study noted substantial gains in health in most populations, with exceptions due to the HIV/AIDS epidemic in Sub-Saharan Africa and setbacks in adult mortality in the former Soviet Union states. Finally, this study identified ten leading diseases for global disease burden were perinatal conditions, lower respiratory infections, ischemic heart disease, cerebrovascular disease, HIV/AIDS, diarrheal diseases, unipolar major depression, malaria, chronic obstructive pulmonary disease, and tuberculosis.¹⁶⁴

The relationship between social isolation and disease is

multifaceted. First, social networks have a proven role in the survivability of human and nonhuman species, as isolation facilitates exposure to invasion from predators and other threats as well as facilitates biological changes such as decreasing inflammatory control, undermined immunity, sleep regulation, and adrenal process including glucocorticoid responses.¹⁶⁵ In human studies, much of the evidence focuses on perceived social isolation, otherwise known as loneliness. In a cross sectional study evaluating clinical and biological measures in 89 college students and 25 older adults, researchers found significant differences in cardiovascular activation and sleep dysfunction between study participants who were socially connected versus lonely.¹⁶⁶ In a population-based study of 229 adults between the ages of 50-68 years, loneliness and psychosocial factors including depressive symptoms, perceived stress, social support, and hostility were evaluated in relation to cardiovascular and endocrine function measures. Findings in this study include an association between loneliness and elevated systolic blood pressure (SBP) and age-related increases in SBP.¹⁶⁷ Literature also indicates that perceived social isolation may play a role in cortisol regulation. In an analysis of 156 older adults, prior day feelings of loneliness, sadness, threat, and lack of control were associated with a higher cortisol awakening response the next day as determined by diary reports of respondents measured against salivary cortisol levels obtained three times daily during the study period.¹⁶⁸ Perceived social isolation has

also been associated with a reduction in physical activity. A study of 229 older adults over a three year time period reports that loneliness was associated with a significantly reduced odds of physical activity, adjusted for age, gender, socioeconomic status psychosocial variables, and self-reported health status.¹⁶⁹ Another important finding is that loneliness was found to be associated with an increase in mortality following an evaluation of 6,500 men and women aged 52 and older who participated in the English Longitudinal Study of Ageing in 2004–2005. Mortality in this study was all-cause and usually was a result of natural causes, which was higher among more socially isolated and lonelier participants.¹⁷⁰ In a study of social isolation and mortality in a nationally representative US sample, data from 16,849 adults were compared and the predictive power of social isolation was measured against traditional clinical risk factors. Socially isolated adults were found to predict mortality for both men and women.¹⁷¹ Emerging data indicate that social isolation also plays a role in gene expression. Data from an animal model indicate that social isolation decreases dopamine, which is a neurotransmitter that affects behavior including impulse control and increases the likelihood of dementia.¹⁷² Countless studies have already connected that impulse control and obesity due to overeating, and social isolation seems to represent an additional risk factor. Given these data, it is no surprise that a strong association exists between social isolation and disease, especially chronic disease. In the US, chronic diseases remain an important social and

economic burden.

There is no question that disability is having an important impact on local communities, state budgets and the nation as a whole. As local economies and national healthcare budgets are all strongly impacted, little is being done to address one of the most important drivers of poor health status in the disabled community: creating accessible communities and enforcing acceptance of disabled family members, neighbors, friends, colleagues, teachers, public figures, role models, and professionals.

Health Equity

Health equity is a complicated construct that describes fairness related to health which involves the equitable distribution of health resources, health status, and the availability of choices that drive health. Health equity describes a society without social determinants of health, health disparities, unequal access to healthcare, education, or any other resource that impacts one's ability to achieve a healthy state. According to the CDC, "health equity is achieved when every person has the opportunity to attain his or her full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined consequences." Among the goals of the CDC in improving population health involves specific health disparity challenges associated with social challenges.¹⁷³ As the relationship between social

networks and health status becomes more defined, health equity will also depend on one's ability to pursue relationships and build social capital.

Health inequality is not isolated to the United States. In a 2008 report, the WHO stated that social justice is a matter of life and death as it impacts the way people live and well as their risk of illness and premature death. As population measures like life expectancy are extending in some parts of the world, they are shortening in others. This is a reflection of the social advantages present in some places that influence the health of populations, that are simply not a factor in other places and the health of those populations is diminished. The goal of public policy is to mediate the factors that cause these levels of disparities between places. The WHO notes that issues surrounding health and health equity may not be the goal in most social policy initiatives, but health will always be impacted. Overarching recommendations from the report include improving the conditions of daily life, reduce the inequitable distribution of power, money, and resources on a global, national and local level and incorporate proven program and policy evaluation methodologies to measure problems and interventions while educating the populous about social determinants of health.¹⁷⁴

Literature Gap

Disability is an important challenge that is growing in local communities and on the national scale. But truly understanding the

complexity of disability is a major challenge as many factors feed and exacerbate the impact on our societies, our infrastructure and our budgets. The discussion of disability can very easily begin with a discussion of poverty, as disability is strongly associated with those with low socio-economic status. A lack of economic resources has driven many of the choices, which may include important factors like healthcare, transportation, employment options, and the economic power that it takes to maintain social connectedness when doing so is likely much more expensive as compared to the general population.

When examining key issues surrounding disability in the US, perhaps one of the most common challenges is social inclusion. The challenges associated with consciously including some of the most vulnerable members of our society is multifaceted. For wheelchair users specifically, these issues revolve around themes of social acceptance coupled with functional barriers, and the public policy and community values that drive both.

Ample literature is available that identifies the importance of social connectedness along with the negative health consequences of social isolation. The majority of these studies look specifically at economically vulnerable populations including the poor, immigrants, and minorities, and policy discussions looking at health equity focus specifically on these populations. Few data are available that look at the impact of social isolation on anyone in the disabled community, with even less emphasis

on wheelchair users with functional challenges undertaking daily tasks that most of us take for granted. The impact of being excluded from major segments of society has barely been described, much less studied and the economic implications from both a productivity, public resource consumption and health care utilization has not been studied.

CHAPTER 3: RESEARCH METHODS

Social capital has a proven association with many aspects of our lives, including overall happiness, behaviors that impact health, health status and life expectancy. This relationship has been observed in human society and animal models and the importance of social capital has implications for public policy and cultural forces that drive behaviors, attitudes, and acceptance. This is particularly important for the disabled community. As one in five Americans have a disability with higher prevalence anticipated in the future as our population ages, the importance of social inclusion for this growing number of people can have a particularly strong impact on the health of our population, the cost of healthcare in the US, and our culture. Many motivators can exist as drivers of culture and others can exist as barriers to culture change.

Barriers have important physical and psychological consequences as they illustrate the ideals and values within society. Physical barriers may be the most influential as they send subconscious but powerful messages to all of us describing who is welcome in spaces and who is not. Wheelchair users are among the most vulnerable to these messages as physical barriers represent constant impediments during daily life. These barriers not only make it impossible for wheelchair users to access

many public and private spaces, but they also send a message that certain stigmatized people are simply not important and not welcome. Public policy is supposed to support the disabled accessing public spaces, but cultural forces along with enforcement challenges of ADA legislation has resulted in remaining barriers. Private spaces almost always have barriers as, with the exception of scattered city-wide policies affecting only select communities, no legislation exists to support access of private residences for wheelchair users. The outcome is social exclusion as wheelchair users often cannot leave their inaccessible homes or visit the homes of others, and social exclusion is known to make people sick.

Countless studies have emphasized the connections between social forces with health and lifespan, emphasizing both economic and moral consequences. But, just as disability has been largely disregarded in society, it has been understudied in academic literature. This is especially true for wheelchair users. The purpose of this study is to prove the impact of social exclusion on wheelchair users and measure the cost.

Study Goals

The primary goal of this study is to measure and understand the impact of policy interventions related to new housing units that increases the supply of accessible housing in the city of Louisville will strengthen the social capital of wheelchair users. The secondary goal of this study is to learn how the availability of accessible housing will normalize disability on the society level, reducing stigma and discrimination toward wheelchair

users specifically.

Specific Aims

The aim of this study is to provide mathematical and scientific evidence to support visitability as a public policy that promotes the availability of accessible housing in Louisville, Kentucky.

Hypothesis

Current published literature from a myriad of disciplines including medicine, population health, social science, health economics, and other related fields have established the growing challenges associated with disease burden in the US from both an economic and health equity perspective. Also, literature from various perspectives establish the relationship between social determinants of health and health status and outcomes in the disabled, especially those with a mobility challenging disability as social interaction becomes impossible in many situations. By increasing the supply of accessible housing through enacting visitability as a public policy, one of the many barriers present in the built environment will be reduced, which would facilitate the interaction of our medically and socially vulnerable populations with friends, families, and providing net economic benefit to society.

Methods

This is a comparison study measuring the cost of healthcare utilization of wheelchair users in Louisville, Kentucky to the projected cost assuming lower healthcare utilization and higher health status, providing that the first floor of new housing units built during the last twenty years had been in compliance with the requirements of visitability. The cost to eliminate barriers for visitability and the resulting decrease in social isolation was compared against the value of life extension of being more socially integrated. Population estimates of wheelchair users are derived from an analysis provided by Cornell University's School of Industrial and Labor Relations (ILR) at our request for the purposes of this study. Aggregations of the drivers of health care cost were derived from The Milken Institute. The statistics of new housing built between 1996 and 2016 in Louisville, Kentucky was provided by Louisville Metro Government Archives at our request for the purposes of this study.

Visitability describes the policy of implementing low-cost modifications to all new homes that allow basic access of wheelchair users into private residence. Visitability supports low barrier living so that wheelchair users have housing options for themselves that are not confining as many wheelchair users do not live in accessible housing due to low availability and cost constraints. Visitability also promotes more open communities as wheelchair users are able to enhance the quality of life given increased ability to access the homes of others. Visitability is a

concept that promotes openness and a public policy with the following definition:

- one zero-step entrance, and
- doors with 32 inches of clear passage space, and
- one bathroom on the main floor accessible by a wheelchair.^{175,176}

Meeting visitability criteria outlined above is a low-cost option when planned into newly constructed homes. In homes built on a concrete slab, for example, the cost can be in a range of between \$0 and \$100. For homes with a basement or a crawl space, the typical cost is between \$300 and \$500. In atypical circumstances, these costs can be higher. It is important to note that these figures represent an insignificant expense when considering the total average cost of constructing new homes. According to conservative estimates, between 25% and 60% of new homes will have an occupant with severe and chronic mobility disability.¹⁷⁷

Visitability policy focuses on new construction given the low-cost burden relative to results. Renovation costs for existing homes can be much higher. For example, the cost of renovating one interior door is estimated at \$700 and the cost of modifying one exterior entrance with steps is \$3300.¹⁷⁸ Also, visitability is understood as a long-term policy interventions as real estate markets change over time. Old homes are replaced with new homes as neighborhoods change, property values increase, and most existing homes undergo renovation at some point.

With visitability policy in place, it is foreseeable that homes, neighborhoods, and consumer demands and attitudes will fundamentally change over time.

The impact of the Louisville market specifically can be measured by the evaluation of historical data measuring the potential impact of new construction in recent years with the assumption that visitability policy had been enacted. Using data compiled by the Louisville-Jefferson County Metro Government for the Chamber of Commerce, four reports were obtained reporting the number of building permits issued between January 1, 2004 and November 29, 2017. These reports contained the following housing data.¹⁷⁹

Table 21: Permits Issued by the Louisville-Jefferson County Metro Government 2004-2017

Housing type	Permits	Total Units 2004-2017
5+ Units	709	13,928
3-4 Units	26	208
Duplex	70	140
Single family	16,872	16,872

Statistics from the Louisville-Jefferson Metro County government were extrapolated to a 20-year estimate of units that would be candidates for low-impact modification to design to address visitability criteria. As

new built multiplex developments in the Louisville metro area rarely have third floor-walk up entrances to a housing unit, conservative estimates of multi-unit properties have been divided in half to account for units that may be second floor walk-up entrances. Conversely, multi-story developments are likely to include elevators that would allow multi-floor units to be reached by wheelchair users. The adjustments with these assumptions are outlined in the table below.

Table 22: Housing types of new construction in Louisville-Jefferson County Metro Government 2004-2017

Housing type	Total Units 2004-2017	20 year extrapolation X 1.5	Adjusted Unit Count
<i>5+ Units</i>	13,928	20,892	10,446
<i>3-4 Units</i>	208	312	156
<i>Duplex</i>	140	210	210
<i>Single family</i>	16,872	23,308	23,308
Estimate of units eligible to meet low impact visitability criteria for 20-year period			34,120

With approximately 34,120 modifiable units being built over the past 20 years in the Louisville Metro area, each housing unit could have been made accessible for an average cost of approximately \$300-\$500 adjusted to the current value of the dollar. Therefore, the societal cost for

those units over 20 years would be approximately and conservatively \$17 million to make every new home in Louisville aligned to visitability criteria. The cost of implementation would be absorbed by the societal economy and there would be no cost to the City of Louisville or State government. Code compliance would be enforced by existing building inspectors.

Estimates for the Cost of Ignoring Visitability

Visitability is a cost-effective intervention that, over time, transforms neighborhoods, communities, cities and attitudes. Additionally, visitability also offers the potential to reduce health care costs by alleviating the burden of disease exacerbated by social isolation. On the other hand, the cost of adopting the cost of visitability at the bargain rate of less than \$1000 for one new home is most likely much lower than the societal cost of loneliness, which is understood to both cause and exacerbate chronic diseases. Several data sources were considered in this analysis following the review of peer reviewed literature, and four evaluations were conducted using data in peer reviewed literature that measured the impact of social determinants of health, social isolation and disability from multiple viewpoints.

Estimate #1

A study published by Frier and colleagues was one of the few data sources that actually seek to understand the causal relationship between social determinants of health and disability. This study was a qualitative

analysis that involved participants being measured following unstructured interviews, and the results of this study found a clear decline in social determinants of health on the part of the studied individuals with various neurological damage. Also, this decline in health was correlated with decreased progress in rehabilitation and increased social isolation. Although this study was important as it suggested a causal relationship between disability as it decreases health status due to a decrease in social status, this qualitative study did not assign economic values to this relationship.¹⁸⁰

According to data provided by Cornell, there are an estimated 71,800 individuals 15 years or older who are wheelchair users in Kentucky.¹⁸¹ Given the physician and psychological barriers that exist in both public and private spaces in addition to those ingrained in our culture, it is safe to assume that all wheelchair users are socially isolated. According to the Milken Institute, over 2.7 million cases of seven common chronic diseases were reported in Kentucky in 2003.¹⁸² According to the Kentucky state government, the population of Kentucky in 2003 was 4.1 million, which means that 66% of Kentuckians in 2003 had a diagnosis for one of these chronic disease.¹⁸³ As a result, Milken ranked Kentucky number 47 of the fifty states and the District of Columbia in health status, and forecasted the total cost of burden in KY of chronic disease at \$64 billion by 2023. See the tables below for more details regarding the prevalence and economic impact of disease burden in Kentucky.

Table 23: Reported Cases of Common Chronic Diseases 2003

Chronic Diseases	Number of Cases	Percentage of Population (%)
<i>Cancers</i>	173,313	4.2
<i>Diabetes</i>	219,242	5.3
<i>Heart Disease</i>	325,451	7.9
<i>Hypertension</i>	606,895	14.7
<i>Stroke</i>	37,364	0.9
<i>Mental Disorders</i>	377,594	9.2
<i>Pulmonary Conditions</i>	1,020,460	24.8

Table 24: Economic Impact in Kentucky 2003

Cost	Annual Costs in billions (\$)
<i>Treatment Expenditures</i>	4,700
<i>Lost Productivity</i>	16,900
<i>Total Costs</i>	21,600

Milken acknowledges the high cost burden of disease. Assuming public policy is in place to address chronic diseases in Kentucky, Milken places the following projections on the impact of disease burden in Kentucky. It is important to note that no detail regarding effective public policy was described, and it is also a safe assumption that Milken anticipates significant costs for creating effective policy that are factored into the projections outlined in the table below.¹⁸⁴

Table 25: Projected Annual Costs 2023

	Current Course in billions (\$)	Alternative Future in billions (\$)	Costs Avoided in billions (\$)	Cost Avoided (%)
Treatment Expenditures	13,900	9,900	4,000	28.8
Lost Productivity	50,500	36,700	13,800	27.3
Total	64,400	46,600	17,800	27.2

The vast majority of individuals that are wheelchair users have a chronic disease. These conditions shorten lives, reduce quality of life, and create considerable burden for caregivers. Using data from Cornell provided by special request along with data from the Milken Institute measuring the burden of disease while also accepting the findings from Frier and colleagues, disability, social isolation, chronic disease, and social determinants of health are interrelated.^{185, 186} Further, this relationship can be quantified. The estimate of cost burden in Kentucky per wheelchair user with a chronic disease is \$64 billion according to Milken.¹⁸⁷ Given that Milken reports that 2.7 million people were suffering from at least one chronic disease, this represents a cost of \$24,000 per individual. The cost resulting from social isolation of wheelchair users likely represents a significant fraction of this disease burden cost. Assuming social isolation represents as little as 10%, or \$2,400, this still represents a multiple of the cost of outfitting new home construction visitability features. Therefore, this analysis supports the cost

effectiveness of enacting compulsory visitability policy for economic reasons.

Estimate #2

Another perspective involves the use of the hazard ratio, which reflects the relative increased rate of death given select situations. For the purposes of this study, the hazard ratio is a measure of social isolation, or the increased likelihood of death in individuals who are socially isolated as compared with those who are not. Using data collected from 16,849 adults, the hazard ratio for socially isolated males defined by being unmarried, participating infrequently in religious activities, and lacking club or organization affiliations was 1.62. The hazard ration for females, as defined by being unmarried, infrequent social contact, and participating infrequently in religious activities was 1.75.¹⁸⁸

Taking this analysis a step further involves the use of the hazard ratio to calculate the probability of mortality. The formula for translating a hazard ratio to a probability of mortality is: $\text{Probability} = (\text{hazard ratio}) / (1 + \text{hazard ratio})$. By applying this formula from the findings of the study above, the probability of socially isolated individuals dying prior to individuals without social isolation can be calculated. See the table below for the probabilities of social isolated individuals as compared to other groups below.

Table 26: Social Network Index Score

Social Isolation Gradient	Gender	Conversion of HR to Probability	Probability
0/1 (High)	Men	$1.62 / (1 + 1.62)$	0.62
0/1 (High)	Women	$1.75 / (1 + 1.75)$	0.64
2 (Intermediate)	Men	$1.18 / (1 + 1.18)$	0.54
2 (Intermediate)	Women	$1.29 / (1 + 1.29)$	0.56
3 (Low)	Men	$1.04 / (1 + 1.04)$	0.51
3 (Low)	Women	$1.14 / (1 + 1.14)$	0.53

These findings show a 62% chance in males and 64% chance in females that the socially isolated individual will die before those that are not socially isolated. This suggests that social isolation may rob some fraction of Quality Adjusted Life Years from those isolated individuals.

Estimate #3

A meta-analysis conducted of peer-reviewed literature published between January 1980 and February 2014 found that social isolation results in higher likelihood of mortality, whether measured objectively or subjectively. Cumulative data from 70 independent prospective studies,

with 3,407,134 participants followed for an average of 7 years, revealed significant effect of social isolation, loneliness, and living alone on odds of mortality. Odds can be representing mathematically in the form of an odds ratio (OR), which is a measure between an association and outcome. After accounting for multiple covariates, this study identified the OR for social isolation and mortality as 1.29, loneliness as 1.26, and living alone as 1.32, which translated to an increased likelihood of death was 26% for reported loneliness, 29% for social isolation, and 32% for living alone. These data indicated essentially no difference between objective and subjective measures of social isolation when predicting mortality.¹⁸⁹

Probability is a mathematical representation for the degree to which an event is probable. This calculation can be converted from an odds ration using the following formula: $\text{probability} = (\text{odds}) / (1 + \text{odds})$. See the table below for a representation of probability of mortality using finding from this meta-analysis.

Table 27: Death Factor Odds and Probability

Risk Factor	(odds) / (1 + odds)	Probability
<i>Social Isolation</i>	1.26 / (1 + 1.26)	0.56
<i>Loneliness</i>	1.29 / (1 + 1.29)	0.56
<i>Living Alone</i>	1.32 / (1 + 1.32)	0.57

Although the odds ratios and probabilities of this meta-analysis are lower than those of some other studies, an increased likelihood of mortality in

the range of 30% for those who are socially isolated suggests that lives of those with social isolation, loneliness and even living alone are shortened by several months.

Estimate #4

The levels of mortality for prospective studies vary greatly across studies depending on the follow-up period and composition of the population by age, race, and ethnicity, and geographic locale, but the patterns of prospective association between social integration as defined by the number and frequency of social relationships and contracts and mortality are remarkably similar with some variations by race, socio-economic status and geographic locale.

Relative risk (RR) is a statistical technique used in population health and epidemiology to measure the probability of an outcome in an exposed group versus the probability of an alternative group without the exposure for the purpose of comparison. House and researchers in a review article looked at five prospective study results for Relative Risk measuring the likelihood of mortality for those with low social integration as opposed to high social integration. The probability of mortality for those with high social integration was not reported, so the increased probability of mortality for those with low social integration could not be calculated and reported. The results of the findings from these studies looking at specific populations and as they compare to one another per House and

others are noted in the table below.¹⁹⁰

Table 28: Relative Risks by Gender derived from Independent Studies

Study:	Relative Risk Males	Relative Risk Females
<i>Evans County Blacks</i>	1.08	1.59
<i>Evans County Whites</i>	1.83	1.07
<i>Tecumseh</i>	3.67	1.97
<i>Gothenburg</i>	4.00	-----
<i>Alameda County</i>	2.44	2.81
<i>Eastern Finland</i>	2.63	1.92

Significant RR difference between low and high social integration indicate survival in the high social integration cohort to be several months longer than those in the low social integration cohort.

Results

The data sources evaluated in the four estimates above piece together a clear picture of the relationship between social determinants of health, social isolation and disability with chronic disease, disease burden, and mortality. Using these data, an estimate of the impact of social isolation on lifespan can be mathematically derived. Once the magnitude of life-shortening is established, the cost to society of losing the productivity of socially isolated individuals can also be calculated. This value will be compared to the cost of providing visitability access to homes in Louisville with first-floor access. For this estimate, we assume all wheelchair users suffer from social isolation. This study focused on the

male population as an example, but these results could be transferable to the female and general population using the same methodology.

A conservative estimate of the hazard ratio for socially isolated males is 1.5, especially given that one study found this figure to be 1.62.¹⁹¹ When converted to probability using the following formula: $\text{probability} = (\text{odds}) / (1 + \text{odds})$, the probability is 60%. In other words, given a pool of expired individuals, the probability of death of the socially isolated male is 60% over a period of time while the probability of death of a male from the overall population over that same period of time is 40%.

In all populations, the survival rate changes with age. Healthy individuals increase their likelihood of death as they age, but the impact on populations with exposures known to impact health status and potentially shorten lives has an amplified impact on the survival rate as one ages. Survival rates can be calculated using the formula: $\text{Probability (of death within the following one year)} = 1 - e^{-rt}$; where r = the rate of death = (the number of people who died over time t) / the total number of people at the beginning). t = time. The equivalent death rate of socially isolated males is found by solving the same equation above for the rate r with the newly calculated probability: $\text{Probability (of death)} = 1 - e^{-rt}$. This equation is true for both the socially isolated male population and the overall male population as evaluated the table below. The death rate of the overall male population is used to determine the probability of death. The hazard ratio is used to determine the equivalent higher probability of death for the

socially isolated male. This probability is now used to calculate the equivalent death rate in a year for socially isolated males. The reported survival rates represented in the table below were derived from the United States 2010 Census.¹⁹²

Table 29: Death Rate Probabilities

Age	Death Rate (r) overall Male population – from the Reported Survival Rate Table	Probability of Death (overall Male population) calculated from the Reported Survival Rate Table	Probability of Death Socially Isolated Male Population) with a hazard ratio of 1.5, this number is 1.5 times the number to the immediate left	Equivalent Death Rate (r) of Socially Isolated Males calculated using the equation below	Months of life shortening As calculated below
75	0.044937	0.0439	0.0658	0.068065	4.1
80	0.073582	0.0709	0.1064	0.112497	4.2
85	0.154143	0.1429	0.2144	0.241308	4.3

Finally, if the probability of death over one year for the overall population is equal to the probability of death over a shorter time period for the socially isolated male population, then life shortening may be calculated for the specific age group in the male population above. The product of the rate (r) and the time (t) is equivalent for the overall and socially isolated

populations. The equation is Death Rate (r) of socially isolated males * time = Death Rate (r) of overall male population * time (1 yr.) So, life survival time of socially isolated males can be calculated using the following formula: $t = r \text{ (of the overall male population)} * t \text{ (1 yr.)} / r \text{ (socially isolated males)}$. See the table below for the impact of social isolation on life shortening.

Table 30: Variation in Equivalent Survival Times Socially Isolated Males

Age	Equivalent Survival Time of Socially Isolated Males	Life Shortening (Years)	Life Shortening (Months)
75	$t = 0.044937 / 0.068065 = 0.6602$ years	0.3398	4.1
80	$t = 0.073582 / 0.112497 = 0.6541$ years	0.3459	4.2
85	$t = 0.154143 / 0.241308 = 0.6388$ years	0.3612	4.3

Individuals who suffer from social isolation live fewer months and are more likely to die at any point in time as compared to those who are socially integrated. One Quality of Adjusted Life Year (QALY) is valued at \$50,000 and one month of survival is valued at approximately \$4,000. Therefore, even one month of quality life is equal to around \$4,000 and is valued at only a little less than 10 times the cost of providing new

construction with wheelchair access. Additionally, assuming the typical life-shortening factor at four months, the cost of social isolation for the male wheelchair users due to loss of productivity may be estimated as \$17,000.

According to estimates provided by Cornell, there are approximately 84,000 wheelchair users in Kentucky. The conservative estimate of wheelchair users is approximately 20,000 wheelchair users in Louisville.¹⁹³ Based on this estimate, one could assume 30,000 wheelchair users in Louisville over the past 20 years. If each wheelchair user experienced an average of four months life shortening of useful productivity, the cost to society can be calculated by multiplying 30,000 as the estimated number of wheelchair users by \$17,000, or the loss of productivity. The product is \$510,000,000 over this twenty-year time period with productivity valued at \$50,000 QALY.

The cost to society of inaccessible housing over a fifty-year generation is conservatively estimated at over one billion dollars. In comparison, the cost to outfit all 34,120 housing units at an estimated cost of \$500 in additional investment in Louisville to support visitability over the thirteen-year study period is \$17,000,000, and perhaps \$65,000,000 over a generation of fifty years. Therefore, the return on investment is as much as 20:1, but society only begins to recover this investment as the housing market begins to be transformed both functionally and psychologically by visitability.

This study shows that the enactment of visitability as a public policy should be the top economic priority as we consider the needs of wheelchair users in Louisville and Kentucky. This does not diminish the need for accessible public transportation, curb cuts, and level sidewalks, but these interventions require significant investment from state and local governments struggling to fund state pensions, healthcare, education, and many other areas of need. In comparison, visitability policy requires no investment of public funds. Instead, this policy would fall on builders and homeowners in the amount of less than \$1000. It is important to note that many consumers appreciate visitability features in their home and considered these minor changes to increase the value of their new home investment. In addition, realtors agree that accessible homes have a better resale value than homes that are not accessible. Therefore, accessibility can be considered an investment by the local economy with the value being recouped each time the home is sold.¹⁹⁴

Study Strengths

This is the first study to evaluate the relationship between wheelchair users and social isolation. This study describes the scope of the Louisville housing market and uses extrapolated data from four studies to measure the cost in terms of quality adjusted life years, noting both healthcare costs and the economic impact of disease. The purpose of this study was to determine the unrealized economic return to the system had

appropriate legislation been enacted in Louisville that improved the accessibility and visitability of local residential real estate, and it was the very first to mathematically determine a value for QALY for wheelchair users. Study findings emphasize the importance of initiating a societal change in order to improve inclusiveness of the disabled community, reduce stigma of disability in society, and normalize the participation of all citizens for both moral and economic reasons.

Study Limitations

This study measured the intersection of movement disabilities, specifically wheelchairs, disease burden and medical costs. Although these are common in daily life, the research identified gaps with regards to comprehensive studies published for any US state of the life shortening impact of wheelchair users. This investigation clearly provides the estimated costs and return on investment that can be attributed to public policy support for minimizing barriers and reducing the impact of social isolation.

Among the weaknesses of this study lie in the lack of published literature evaluating the impact of social determinants of health, social isolation, and other known factors that influence health status on the population of wheelchair users. Conversely, that lack of data on this topic also supports one of the most important theories that wheelchair users are

ignored as a population, not considered in public policy, and not studied. Also, this study assumed that 100% of wheelchair users are socially isolated, and no reference in the peer reviewed literature supports this claim. However, the personal experience of wheelchair users with the most resources to overcome physical and societal barriers would nevertheless make this claim. Specific weaknesses in the methodology include a lack of survival statistics of socially well integrated individuals. Survival statistics for the general population that include the relative population of socially isolated and socially integrated individuals were used. Also, the estimates provided are based on generalized assumptions made from the preponderance of data and not on any specific investigation.

CHAPTER 4: DISCUSSION

Disability along with stigma, social exclusion and discrimination has long been part of human history. Only recently have conversations and public policy initiatives taken place that have established baseline standards limiting the degree to which society will accept the exclusion of the disabled. The first conversation focused on public accessibility for the specific mobility impaired and led to the enactment of the Architectural Barriers Act of 1968 requiring access to federally supported buildings was signed into law by President Lyndon B. Johnson. The next disability focused legislation was the Rehabilitation Act of 1973. This law was an update to the existing vocational laws and it was the first to establish civil rights for those with disability, including in the work place, in education, and other settings. This law also expanded education and training in order to promote a better understanding of disability, and also created education and training programs to expand professional skills for disabled individuals. These laws led up to the sentinel Americans with Disabilities Act (ADA) signed into law by President George H. W. Bush on July 26, 1990. The ADA prohibited discrimination due to disability, equating the presence of disability with race, gender and other common sources of discrimination. Title II of the Americans Disabilities ensured that all Americans with disabilities have barrier free access in the city and state in which they reside.

“Title II of the ADA requires State and local governments to make their programs and services accessible to persons with disabilities. This requirement extends not only to physical access at government facilities, programs and events -- but also to policy changes that governmental entities must make to ensure that all people with disabilities can take part in and benefit from, the programs and services of State and local governments. In addition, governmental entities must ensure effective communication -- including the provision of necessary auxiliary aids and services -- so that individuals with disabilities can participate in civic life.”¹

Although these federal laws have all sought to establish civil rights for the disabled, the lack of enforcement of these laws has resulted in current disability policy existing as merely a suggestion as many of these guidelines are largely ignored. The Department of Justice is vested with the enforcement of the ADA mandates.

Despite the view that society and culture take, disability has affected or will affect all of us. Disability is estimated to affect one in five Americans. In some cases, disability may be temporary following a major surgical intervention or injury. As we age, many of us will not move around like we once did, and Americans living longer lives may rely more on more on assistive devices such as walkers, canes or wheelchairs. Even those of us without a disability may appreciate curb cuts in the street as we push babies in strollers, ride bicycles, or just seem to naturally

meander to a level path of least resistance. Even automatic doors meant for the disabled are helpful for abled bodies when pushing strollers, carrying children, or hauling packages after a productive shopping trip. Sooner or later, many of us will appreciate the mandates by the ADA if we have not appreciated them already regardless if we ever find ourselves with a disability. That being said, any person has an equally opportunity of joining the ranks of the disabled due to accident or illness, and those chances increase substantially for those who are fortunate to live a long life. In addition, findings from this study have demonstrated the economic benefits, above and beyond and compelling moral justifications, to build a more inclusive society. It turns out that the constant barriers that remain in the public sphere that is supposed to be barrier free are not only illegal and discriminatory, but it's making our populations sick, shortening lives, and reducing productivity.

One would think that public policy would be interested in improving disability legislation in the US. The ADA has important jurisdictional challenges that impact enforcement, as well as requiring the personal resources of the disabled to bring justifiable lawsuits without the prospect of recovering expenses. This is a particularly important problem for the disabled as they are disproportionately poor. Instead of strengthening laws that protect the civil rights of the disabled, Congress is considering the ADA Education and Reform Act, or H.R. 620. This legislation is scheduled to come for full vote in the House of Representatives during the

spring session of 2018. The outcomes of H.R.620 is expected to decimate the existing landmark ADA law. According to Zach Baldwin, the Director of Outreach for the American Association of People with Disabilities,

“the ADA Education and Reform Act would require a person with a disability to provide written notice to businesses if they encounter barriers to entry. Under the legislation, businesses would have 60 days to acknowledge that written notice and an additional 120 days to initiate improvements. However, businesses do not have to fix problems within that time period — only show “significant improvement.”¹⁹⁵

The significant improvement is vague as the law does not provide a definition. The presence of vague language is likely to exist as a barrier to any attempt to accommodate the disabled in this country.

Even with the limitations of the ADA, this piece of legislation that first provided rights for the disabled and an ideal public infrastructure accessible to everyone remains an important force. As this is the only policy the disabled can rely on as a baseline of expected behaviors, albeit unenforceable, repealing our values on paper would represent the only protection the disabled theoretically own.

An accessible town is a good business model. But the lack of ADA mandates including accessible transportation, curb cuts, and ramps on

buildings, narrow doorways, heavy doors and absence of accessible bathrooms, all violate not only federal law but also common sense. Bear in mind that every physical barrier to the disabled result in a loss for that individual and their community. If the disabled cannot shop, the store loses income. If the disabled cannot attend a public meeting, that individual loses understanding. If the disabled cannot navigate an educational activity, that individual loses knowledge. If there is no available transportation to a worksite, that individual cannot work. In the aggregate there is a cost to both the disabled and the community.

The research in this paper confirms that social isolation results in a higher burden of disease. Higher burden of disease has implications for higher medical costs. Given that Kentucky ranks as one of the sickest and highest disease burden of the 50 states, it would be the recommendation of any policy maker to look at opportunities that specifically address this need. Another important goal by Kentucky policy makers should be to support the aims of the ADA, but those aspirations appear to fall on deaf ears.

Policy makers from local and state governments fail to consider reasonable modifications in local laws, ordinances, and regulations that would avoid discrimination against individuals with disabilities. Despite the fact that “city governments are required to make reasonable modifications to policies, practices, or procedures to prevent discrimination on the basis of disability,” nothing Kentucky has done has succeeded in mitigating the

trend in a meaningful way that improves health outcomes and reducing medical expenditures.

Social exclusion has been part of human history since the beginning of time. Describing the need to segregate, ostracize, and exclude, social exclusion emerges following differences within populations, whether these differences are real or perceived. The most common example is racism. Racism is a cultural phenomenon that is learned, passed down from parents to children, and reinforced by cultural norms. Racism is not grounded in science, as findings from anthropology research indicate that genetic variations in human populations are significantly below the threshold to meet criteria for the existence of distinct subspecies, otherwise known as races.¹⁹⁶

Disability as a source of social exclusion represents a new culturally embedded bias related to members of our society who are perceived as different, inferior, or discarded. In fact, the impact is worse given that federal laws that provide protection for racial minorities have done very little to address the same behavior toward the treatment of the disabled. In the nearly twenty-eight years following the enactment of the ADA along with countless corresponding local and state ordinances, there have been very little changes to the number of barriers the disabled face on a daily basis. Instead, the legal exclusion of the disabled continues.

Research clearly demonstrates the cost of this social exclusion

when studying the human cost of racism. Social exclusion comes with a very high a measurable cost burden and an emotional drain on those who are faced with these barriers on a daily basis. The resulting social isolation shortens productive lives and robs society of the value of their productivity. Whether applied to racial minorities or the disabled, social exclusion is exactly the same and is universally evil.

Human history occurs in cycles and all too often our greatest sins are doomed to be repeated as they are repackaged. The slave trade began in the 1600s and continued for centuries and resulted in incalculable deaths of millions of blacks. The sequelae haunt us to this day. It took a world war and the murder of 6 million Jews before anti-Semitism was officially recognized. Apartheid existed for 50 years and 3.5 million people were forcibly removed from their homes and forced into Bantu, a “black homeland” where they in existed in despair and poverty before anything was done. Active racism and benign neglect of our disabled has existed for eternity which has not been adequately addressed over the years. Despite the fact that social isolation has been recognized as a major predictor of early death, this expensive habit seems especially difficult to break.

Science and education are the greatest weapons against social exclusion. This study is a piece of the science, as many other pieces are out there looking at different spheres of exclusion, the importance of relationships, and the impact of loneliness. Education represents a

proliferation of this knowledge as we share science with our friends, family, neighbors, policymakers, and anyone else who might listen. Chances are, the biggest racists are not even aware of the stigmas they hold and their discriminatory practices. Therein lies the danger of repackaging racism.

We have a better opportunity than ever to change our behavior as a society. We could enforce existing laws. We could make improvements to existing laws on the local, state and national level. Or most easily, we could remember disability when we form policy that impacts the physical and cultural barriers the disabled might face. But, given the lack of progress we have made in the last three decades, I am concerned this form of racism will be just as costly as the others documented in modern history.

CHAPTER 5: CONCLUSION

Social isolation is an increasingly important construct in population health. The strength of local communities is understood to be the fabric of contemporary life, and the impact of excluding our own is not only inhumane but also costly. Given there is no question that social isolation makes an individual sicker, it is also important to understand the impact of social isolation on the most vulnerable and fragile individuals in our communities. These are the ones most severely impacted. As the cost of healthcare rises for everyone, this increase in care cost for the chronically ill and the disabled is amplified, and this population grows by the day. Building our homes so that our disabled friends, family, neighbors, and colleagues can stop by for a visit, attend a holiday party, or drop off a meal when we are sick could be potentially priceless. As the community recognizes the important of their inestimable contribution, the lives of both our disabled friends and community members become restored. The health and well-being of everyone benefits just for including the disabled. The question is not whether we can afford to do it, it is why we did as a society, not actually do this 20-30 years ago, and can we afford to spend the next 20-30 years making the same shorted-sighted, exclusionary,

financial and ethical mistakes?

We must develop the political will to change the building codes in Kentucky. New homes must be required to be accessible, and this requirement must be enforced. The cost of making these changes is de Minimis compared to the economic gain over time. The consequences of inaction will result in a societal cost approaching one billion dollars and easily 10-20 or more times the cost of initial investment in new homes in Louisville over a generation. Conversely, the cost of inaction will waste the productivity of wheelchair users in Louisville and Kentucky, make the state less competitive and prosperous, and cause damage to individual lives that cannot be calculated.

In order to accomplish this, we need to establish visitability as a core value with industry and politicians. Having such a core value will support Louisville's growing reputation as a compassionate community. The standard zero step home access standards are also convenient to nondisabled home owners and renters as evidenced by the ease of moving in to a new home, the ease of having a large parcel delivered to the home, and the accessibility of your home to elderly relatives. Or as Eleanor Smith, an advocate for Visitability adds: watching as "Your college age child moving out with all his boxes and belongings." Ultimately, attracting individuals that embrace these values will add prosperity to our city.¹⁹⁷

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APPENDICES

Appendix A: Wheelchair Users Disability Statistics Primary Source

From: **Disability Statistics** disabilitystatistics@cornell.edu
Subject: RE: disability statistics question
Date: July 18, 2017 at 9:10 AM
To: Mary Beth Allen mbwallen@gmail.com

DS

Hi,

Here is what I have from my colleague, Bill Erickson, who performed an approximation of wheelchair users by state several years ago for someone else. Here's what he wrote:

I went back through some work that I had done previously and ran across this “back of the envelope” estimate that I had done for someone else a couple of years ago. It is rough and there are a number of caveats but the best I can do given the data available.

What I've done below is made use of two different data sources to develop an “back of the envelope” estimate of wheelchair users by state:

- The 2010 Survey of Income and Program Participation (SIPP) Disability report (<https://www.census.gov/content/dam/Census/library/publications/2012/demo/p70-131.pdf>)
- The 2012 American Community Survey (ACS) Public Use Microdata Sample (PUMS) data

From the Census Bureau's 2010 SIPP report Table A1:

- 8.3% of persons ages 15 and older in the US have a severe difficulty either using stairs or walking (closest parallel to the ACS “serious difficulty walking or climbing stairs”)
- 1.5% of persons ages 15 and older in the US use a wheelchair

Assuming that all wheelchair users also reported having a severe difficulty either using stairs or walking (which would seem a logical assumption): This means that approximately 18.07% (1.5%/8.3%) of persons ages 15 and older with severe difficulty either using stairs or walking, are wheelchair users.

I applied this SIPP based percent to the ACS estimated population ages 15 and older with an ambulatory disability living in each state. This approach means that any differences in the percent using wheelchairs is driven by differences in the number of persons reporting an ambulatory disability in the ACS. As you can see in the table the estimates vary between 1.1% to 2.4% of the non-institutionalized population ages 15 and older use wheelchairs. FYI I did consider breaking out persons 15-64 and 65+ but was surprised to discover that the proportion of persons reporting “severe difficulty either using stairs or walking” who use wheelchairs in the SIPP is virtually the same for both age groups.

Note that I believe using the ACS data ambulatory disability as the basis of the calculations should provide a pretty reasonable estimate based on the available data, however I have no way to confirm that assumption. **Please see the caveats regarding this approach below:

There are a number of important caveats that could affect the accuracy of this “back of the envelop approach”:

- The questions and methods that the SIPP uses to identify persons with “severe difficulty either using stairs or walking” and the ACS question regarding “severe difficulty either using stairs or walking”, are not identical. They are arrived at in different ways in the respective surveys. It is possible that this difference in approach is identifying rather different populations. However, it is encouraging that the overall prevalence rate and number are fairly similar - The ACS ambulatory prevalence estimate is 19,751,000 (7.9%), slightly lower than the SIPP estimate of 20,132,000 (8.3%). The fact that the ACS estimate is lower suggests that the wheelchair user estimates I developed below may be conservative.
- Persons in different states may be more or less likely to report an ambulatory disability in the ACS, and/or the level at which they do report it may be more or less severe.
- It does not take into account the number of children under the age of 15 who are wheelchair users, however that population is far less likely to have wheelchairs – (67,000 nationally) so that would have a very small impact on the overall number at the state level.
- Applying the SIPP based estimates at the state level assumes that the SIPP national level estimates/population regarding ambulatory disabilities is the same for each state and does not consider potential differences between states. There may very well be differences in wheelchair usage between states for other reasons (i.e. availability of wheelchairs, usability of wheelchairs in various terrains, etc.) as well as other characteristics that may be related to wheelchair need and use including age, gender, race, ethnicity, and income level just to mention a few.

The numbers below are limited to the non-institutionalized population ages 15 and older

State	Estimated Number of wheelchair users ages 15 and older	Estimated % population ages 15 and older using wheelchairs
AK	6,500	1.1%
AL	81,900	2.1%
AR	49,300	2.1%
AZ	72,400	1.4%
CA	362,200	1.2%
CO	44,700	1.1%
CT	33,100	1.1%
DC	7,100	1.3%
DE	10,900	1.5%

FL	242,700	1.5%
GA	114,000	1.5%
HI	14,600	1.3%
IA	30,200	1.2%
ID	16,000	1.3%
IL	131,700	1.3%
IN	75,100	1.5%
KS	31,800	1.4%
KY	71,800	2.1%
LA	66,000	1.8%
MA	65,400	1.2%
MD	55,300	1.2%
ME	16,100	1.5%
MI	124,200	1.6%
MN	46,300	1.1%
MO	81,100	1.7%
MS	51,100	2.2%
MT	11,700	1.4%
NC	121,600	1.6%
ND	6,100	1.1%
NE	16,000	1.1%
NH	13,600	1.3%
NJ	85,700	1.2%
NM	28,800	1.8%
NV	31,300	1.4%
NY	206,500	1.3%
OH	145,900	1.6%
OK	55,500	1.9%
OR	45,900	1.5%
PA	153,500	1.5%
RI	11,500	1.3%
SC	66,100	1.8%
SD	8,400	1.3%
TN	98,400	1.9%
TX	280,500	1.4%
UT	22,100	1.1%
VA	82,300	1.3%
VT	6,900	1.3%
WA	70,100	1.3%
WI	56,600	1.2%
WV	35,500	2.4%
WY	6,000	1.3%
Total	2,568,000	1.4%

Total	3,308,000	1.47%
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Please let me know if you have any additional questions, and good luck!

Take care,
Melissa Bjelland
Research Associate, Yang-Tan Institute

K. Lisa Yang and Hock E. Tan
Institute on Employment and Disability
ILR School, Cornell University
www.DisabilityStatistics.org
www.yti.cornell.edu

From: Mary Beth Allen [mailto:mbwallen@gmail.com]
Sent: Thursday, July 13, 2017 4:43 PM
To: Disability Statistics <disabilitystatistics@cornell.edu>
Subject: Re: disability statistics question

Melissa,

We took a second look at the data and we see that we could also use similar state by state data for all disability types if available.
Thanks,
Dr. A

On Jul 13, 2017, at 3:04 PM, Mary Beth Allen <mbwallen@gmail.com> wrote:

Melissa,
Thank you so much for getting back to me. I just had a meeting with the student and among the items we discussed was your response to my email. Thank you so much for providing such a comprehensive list with explanations as they might be relevant to us. We reviewed everything and I think the best option for us would be the 2010 data by state for wheelchair users. We are on a bit of a time crunch, so data that is not available soon is also not a great option for her.
Thanks so much!
Dr. Allen

On Jun 28, 2017, at 12:41 PM, Disability Statistics
<disabilitystatistics@cornell.edu> wrote:

Hi,

منى،

Am I correct in assuming that your student is in search of raw survey or administrative data to analyze? If so, the website DisabilityStatistics.org is currently being reviewed and updated to present content from a variety of new data sources on the Rehabilitation Dataset Directory (<http://disabilitystatistics.org/sources-rehab.cfm>). It may have more information in late summer and early fall for your student to review for source information. Additionally, plans are underway to streamline the content of the type of disability and health conditions presented on the interface (including ambulatory disability and special equipment use/assistive technology).

In the meantime, as it stands, this website can be used to uncover survey and administrative datasets that may be appropriate for her dissertation. She can either perform full-text searches (e.g., searches for "ambulatory," "wheelchair," or "special equipment") or can filter by criteria on disability measures or health conditions. This will yield a subset of datasets that can be further reviewed at a summary level to decide whether they may be worth further investigating. This link shows results for those datasets containing information about ambulatory disabilities and special equipment use:

http://disabilitystatistics.org/sources-results.cfm?Results_Criteria=28,47

The full profile for each dataset contains details regarding its sample size, specific disability measures and health conditions inquired about, topics covered, strengths and limitations, as well as information about how to access/download the datasets themselves. Links to technical papers and summary tables are also often included. Note that the profiles do not contain exhaustive lists of variables; they are meant to highlight each datasets features and if the dataset seems appropriate, it is probably worth reviewing the codebooks further.

Note that the Survey of Income and Program Participation (SIPP) is not appearing in the aforementioned search, but does contain ambulatory disability information. This began in 2008 with the inclusion of the set of 6 American Community Survey disability measures in certain topical modules (see <https://www.census.gov/people/disability/methodology/sipp.html>) and continues in the redesigned 2014 SIPP (wave 1 has just been released).

I am not certain whether the following will be of use to you, but I am including it just in case:

The Durable Medical Equipment (DME) file contains final action, fee-for-service claims submitted by Durable Medical Equipment suppliers:

<https://www.resdac.org/cms-data/files/dme-rif>

Note that there is this report on assistive technology that included analysis of the DME file and wheelchair use, however I believe it is limited to only working-age persons. Still might be of interest to you:

The Promise of Assistive Technology to Enhance Activity and Work Participation

<http://nationalacademies.org/hmd/reports/2017/promise-of-assistive-technology-to-enhance-activity-and-work-participation.aspx>

My colleague, Bill Erickson, has also worked out a "back-of-the-envelope" estimate of number of wheelchair users by state that is somewhat dated (using 2010 data) and that includes a number of caveats for someone who needed a general (non-precise) idea of wheelchair use by state. If you are interested in that, I can also send that your way.

As I will be going through a number of the datasets for the Rehabilitation Dataset Directory myself, I'd be happy to keep an eye out for specific information and keep your student in mind. It sounds as though your student will certainly need information about wheelchair use, but if she is open to considering a wider range of disability measures in her analysis (e.g., ambulatory disability and special equipment use, which may or may not necessitate the use of a wheelchair) that would be good to know. If you could also send a set of other key variables of interest she's interested in focusing on, that will give me more information to help with narrowing the search for data best suited for her dissertation.

If you have any further questions, or if my assumption about your student's need for raw data is incorrect, please feel free to send a follow-up message.

Take care,
Melissa Bjelland
Research Associate, Yang-Tan Institute
K. Lisa Yang and Hock E. Tan
Institute on Employment and Disability
ILR School, Cornell University
www.DisabilityStatistics.org
www.yti.cornell.edu

-----Original Message-----

From: Mary Beth Allen [<mailto:mbwallen@gmail.com>]
Sent: Tuesday, June 13, 2017 11:30 AM
To: Disability Statistics <disabilitystatistics@cornell.edu>
Subject: disability statistics question

I am working with a student currently enrolled in a doctoral candidacy program in public health. Her dissertation is looking at the cost burden of disease secondary to disability. She is looking specifically at wheelchair users. We have been accessing your database, of course we have been looking at the ambulatory disability data but we were wondering if you have any data more specific for wheelchair users. She is looking at both national data and specific data for Kentucky. Any assistance you can provide would be very helpful and greatly appreciated.

Mary Beth Allen, PhD, MBA
University of Louisville

Appendix B: Housing Data Primary Source

RE: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

OR

Open Records <openrecords2@louisvilleky.gov>

Reply

Wed 12/20/2017, 11:16 AM

You:

Open Records (openrecords2@louisvilleky.gov)

You're very welcome! Merry Christmas to you as well!

☐

Jacinta Scruggs

Open Records Specialist Intake
Louisville-Jefferson County Metro Government
Office of Management and Budget
611 W. Jefferson Street
Louisville, KY 40202
Direct Line: 502-574-3576
Fax: 502-588-3121

☐

From: connie light [mailto:connielight@hotmail.com]

Sent: Wednesday, December 20, 2017 9:58 AM

To: Open Records

Subject: Re: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

You are the best! Thank you so much. If I need an official report I'll let you know.

Merry Christmas to you Jacinta.

On Dec 20, 2017, at 8:25 AM, Open Records <openrecords2@louisvilleky.gov> wrote:

Good morning,

☐

☐

Sorry for the delay, it was on our end and not Codes and Regulations. On 12/13/2017, the Department of Codes and Regulations (Construction Review Division) sent the following response:

☐

"This data is from 01/01/2004 until current date; we had these reports already written as what is used to report to the Chamber of Commerce. If the request needs a special report written that is an request, but there is an hourly charge for report writing."

☐

- Five or more units: 709 Permits, 13,928 Units
- Three and four units: 267 Permits, 208 Units

- Two family: 70 Permits, 140 Units
- One family: 16,872 Permits, 16,872"

☐
Thank you,
☐
☐

Jacinta Scruggs

Open Records Specialist Intake
Louisville-Jefferson County Metro Government
Office of Management and Budget
611 W. Jefferson Street
Louisville, KY 40202
Direct Line: 502-574-3576
Fax: 502-588-3121
<image003.png>

☐
From: connie light [<mailto:connielight@hotmail.com>]
Sent: Wednesday, December 20, 2017 6:10 AM
To: Open Records
Subject: Re: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

Happy Holidays, Jacinta. Do you have any idea when I will receive my information?

☐
Thank you.
Connie Light
☐

From: Open Records <openrecords2@louisvilleky.gov>
Sent: Tuesday, December 12, 2017 2:20 PM
To: Connie Light; Open Records
Subject: RE: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

☐
You're fine. ☺

☐
Jacinta Scruggs
Open Records Specialist Intake
Louisville-Jefferson County Metro Government
Office of Management and Budget
611 W. Jefferson Street
Louisville, KY 40202
Direct Line: 502-574-3576
Fax: 502-588-3121
<image004.png>

☐
From: connie light [<mailto:connielight@hotmail.com>]
Sent: Tuesday, December 12, 2017 2:17 PM

To: Open Records

Subject: Re: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

☐

Thank you so very much. I'm very sorry that this communicated what I needed.

☐

Connie Light

☐

On Dec 12, 2017, at 2:14 PM, Open Records <openrecords2@louisvilleky.gov> wrote:

Good afternoon,

☐

I will forward your response to the agency to review.

☐

Thank you,

☐

☐

Jacinta Scruggs

Open Records Specialist Intake
Louisville-Jefferson County Metro Government
Office of Management and Budget
611 W. Jefferson Street
Louisville, KY 40202
Direct Line: 502-574-3576
Fax: 502-588-3121
<[image003.png](#)>

☐

From: connie light [<mailto:connielight@hotmail.com>]

Sent: Monday, December 11, 2017 10:25 PM

To: Open Records

Subject: Re: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

☐

I'm sorry but I don't think this will work for me because it's way more information than I need.

☐

Step 2 of the instructions asks for a specific address. I don't have a specific address. I need all of Jefferson County.

☐

I don't also don't want/need to see the actual permits. All I needed/requested was a simple count: how many building permits for single family homes were issued in Jefferson Co and how many building permits were issued for multiple family units.

☐

I requested 20 years of data, but, if you only have 10 or 15 yrs of data, I'll take it.

☐

Do you want to call me to discuss this? My cell is 502 634 8834.

☐

Thank you so much

☐

Connie Light

☐

On Dec 5, 2017, at 12:14 PM, Open Records <openrecords2@louisvilleky.gov> wrote:

Good morning,

☐

In response to your request, Louisville Metro's Department of Codes and Regulations sent the following link and response:

☐

"She can use the development reports tab: <http://portal.louisvilleky.gov/codesandregs/mainsearch>

☐

But we don't have 20 years of data. There are permits on early only as early as 2003."

☐

Per our retention schedule, building permits are supposed to be destroyed after 5 years.

☐

Thank you,

☐

☐

Jacinta Scruggs

Open Records Specialist Intake
Louisville-Jefferson County Metro Government
Office of Management and Budget
611 W. Jefferson Street
Louisville, KY 40202
Direct Line: 502-574-3576
Fax: 502-588-3121
<image004.png>

☐

From: Open Records

Sent: Tuesday, December 05, 2017 11:39 AM

To: connie light; Open Records

Subject: RE: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

☐

Thank you. You may expect a response on or before 12/8/2017.

☐

Jacinta Scruggs

Open Records Specialist Intake
Louisville-Jefferson County Metro Government
Office of Management and Budget
611 W. Jefferson Street
Louisville, KY 40202
Direct Line: 502-574-3576
Fax: 502-588-3121
<image003.png>

☐

From: connie light [<mailto:connielight@hotmail.com>]

Sent: Monday, December 04, 2017 1:00 PM

To: Open Records
Subject: Re: ORR #6910 Connie Light - Construction Review Permit 11/30/2017
I need all Jefferson County records please and thank you.
Connie Light

From: Open Records <openrecords2@louisvilleky.gov>
Sent: Thursday, November 30, 2017 4:51 PM
To: connielight@hotmail.com
Cc: Open Records
Subject: RE: ORR #6910 Connie Light Construction Review Permit 11/30/2017

Good afternoon,
What is the address you are requesting the records on?
Thank you,

Jacinta Scruggs
Open Records Specialist Intake
Louisville-Jefferson County Metro Government
Office of Management and Budget
611 W. Jefferson Street
Louisville, KY 40202
Direct Line: 502-574-3576
Fax: 502-588-3121
<

From: Open Records Requests [<mailto:no-reply@wufoo.com>]
Sent: Thursday, November 30, 2017 3:43 PM
To: Open Records
Subject: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

Requestor Name *	Connie Light
Are you a media organization? *	No
Email *	connielight@hotmail.com
Address	

To: Open Records
Subject: Re: ORR #6910 Connie Light - Construction Review Permit 11/30/2017
I need all Jefferson County records please and thank you.
Connie Light

From: Open Records <openrecords2@louisvilleky.gov>
Sent: Thursday, November 30, 2017 3:51 PM
To: connielight@hotmail.com
Cc: Open Records
Subject: RE: ORR #6910 Connie Light Construction Review Permit 11/30/2017

Good afternoon,
What is the address you are requesting the records on?
Thank you,

Jacinta Scruggs
Open Records Specialist Intake
Louisville-Jefferson County Metro Government
Office of Management and Budget
611 W. Jefferson Street
Louisville, KY 40202
Direct Line: 502-574-3576
Fax: 502-588-3121
<

From: Open Records Requests [<mailto:no-reply@wufoo.com>]
Sent: Thursday, November 30, 2017 3:43 PM
To: Open Records
Subject: ORR #6910 Connie Light - Construction Review Permit 11/30/2017

Requestor Name *	Connie Light
Are you a media organization? *	No
Email *	connielight@hotmail.com
Address	

CURRICULUM VITA

Connie Light, RN, BSN, MS
511 Belgravia Court
Louisville, KY 40208
connielight@healthcare-resolutions.com
(502) 314-8834

Masters of Science, 1983
Community Health Development
University of Louisville
Louisville, KY

Bachelors of Science in Nursing, 1978
Spalding University
Louisville, KY

EXPERIENCE SUMMARY

Connie Light founded and has lead a small consulting practice focused on the formulation of Evidence Based Guidelines for more than 10 years. Her consulting practice has developed an extensive catalog of evidence-based practice guidelines covering the entire spectrum of emerging healthcare techniques and technologies. In addition, she provides services as a medical consultant on standards of care and provided medical chart review for both billing audits and liability cases. Prior to establishing her own firm, she held a number of healthcare management roles and most notably established the Technology Assessment Department at one of the country's largest commercial health plans. Connie merges a strong combination of clinical nursing and health care business practice, with an emphasis on developing clinical practice and decision-making algorithms.

AREAS OF EXPERTISE

- Expert in literature search/distillation into defensible evidenced based criteria used for delivery and review of medical care

- Review medical documents involved in legal briefs (400 + cases) to determine defensibility and standards of care
- Established the design process, creation and implementation of evidence based medical practice paradigms and algorithms used in the care of 6.5-million-member health plan with business in all fifty states as well as Medicare and Medicaid recipients.
- Experienced in defining correct coding claims audits for a national subrogation processing firm.
- Experience in development of “correct coding” screening criteria to ensure proper payment and to collect on inappropriately paid claims. When criteria applied to a 3 months selection of claims for a 130,000 life population, over \$1.5 million in overpayments were identified.
- Experienced in the interpretation of trend data of managed care practices to support strategic planning
- Experience in hiring, training and management of medical researchers including nurses, pharmacists, web developers and librarians to support the information needs of field physicians
- Highly effective speaker and teacher - over 400 presentations to a diverse set of audiences
- Developed evidence-based practice paradigms for use by health plans, practicing physicians, nurses and pharmacists
- Developed materials and lead instruction on the topic of correct medical service coding. Learning objective was to minimize overpayments and ensure better control of inappropriate codes on submitted claims. Nurses and coding professionals were awarded CEU credits upon completion.
- Designed and developed evidenced based medical research algorithms for appropriateness of care determinations which resulted in a savings of more than 5 million dollars annually for a major insurer
- Research and present findings on prevailing medical opinion regarding issues involved in litigation cases
- Directed development of a web-based provider portal for online access for a health plan’s medical policies
- Supported the medical director of a major health plan with ad hoc research on medical issues and case review, including development of algorithms for use in development of Care Plans used by Case Management Vendors

- Experienced in establishing and supporting regular communication/education for all the medical policy determinations made by a major insurer to external physicians, vendors, case managers, patient care providers and advocates, nationwide
- Creation of documentation for legal practices that provides medical background, appropriateness of treatments delivered and overall opinions on medical documents on cases to be argued in court.

CONFERENCE SPEAKING VENUES

- Louisville, Jefferson County Alderman Roundtable Presentation of “Visitability” Standards, ordinances and legislation. Louisville, KY
- Professional Healthcare Institute of America (PHIAA) CEU Educational Roundtable for medical and coding executives, Louisville, KY
- CONSORTA – National Meeting of Hospital Purchasing Cooperative – Chicago, IL “Using Evidence Based Medicine to Control Pharmaceutical Cost Trends”
- American Association of Health Plan Quality and Information Management conference and Exposition, Phoenix, AZ. “Building a Glass House: Using the Internet to Provide Coverage Information”
- Medical University of South Carolina “Using Evidenced Based Medicine in Clinical Practice.”

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Anthology of HCRR Coverage Guidelines Papers, 2003- 2017