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On the Importance of Context: Examining the Applicability of Infertility Insurance Mandates in the United States Using a Mixed-Methods Study Design

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On the Importance of Context: Examining the Applicability of Infertility Insurance Mandates in
the United States Using a Mixed-Methods Study Design

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
College of Public Health
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ABSTRACT

Accessibility of infertility services is disproportionately experienced in the United States. Although there exist state-based health insurance mandates for infertility services, these mandates contain language that disqualify people from using them. In order to better understand why these mandates are not able to reduce the financial burden and bridge the income disparity for using infertility services, the purpose of this study is to add context to the applicability of these insurance mandates through qualitative and quantitative inquiry. Using the Glass and McAtee model of risk regulators as an operational paradigm, this research explores the role of environmental context, or “place”, as a risk regulator for accessing infertility services. The qualitative inquiry consists of informal interviews with people using those services and expert interviews with representatives from organizations providing types of financial assistance for infertility services. The quantitative inquiry consists of a survey instrument observing aspects of travel, health insurance, residence, health education, and self-efficacy in relation to seeking infertility services. The quantitative spatial analysis includes cluster analyses of CDC reporting fertility clinics in the United States, and spatial autocorrelation of census-tract level fertility estimates to give context to future spatial analyses of the use of infertility services.

Based on the survey results (n=134), only 20.41% of people living in a mandated state reported having all infertility services covered by health insurance. The results from 66 informal interviews and eight expert interviews suggests that both place and policy (infertility insurance mandates) act as risk regulators that affect levels of insurance coverage for, and decisions regarding, infertility services. Having residence in a mandated state does not mean one will have

access to their state's mandated coverage, but residence of the individual and of their employer's headquarters can regulate degrees of insurance coverage provided by a state's infertility insurance mandate. Spatial distribution of "All women with births" suggests that human reproduction is a highly spatially autocorrelated phenomenon based on age, education, ethnicity, nativity, and poverty status ($p < 0.0001$ for all variables), however the directional distributions show different directional patterns. Spatial distribution of fertility clinics shows significant spatial clustering of clinics in metropolitan areas, regardless of the presence of an infertility insurance mandate, and qualitative accounts of travel related to using infertility services suggests that placement of clinics near business centric areas is beneficial for patients.

The existing infertility insurance mandates place the state directly in the way of reproductive autonomy. Greater attention should be paid to the role of employers in facilitating insurance benefits for infertility services, considering employers establish insurance policies for their employees and can therefore mitigate the degree of infertility insurance benefits available to them. Due to the nature of the state-based insurance mandates, both place and policy will continue to be intra-active risk regulators that mitigate the access of infertility services and will be differently experienced at the individual level.

CHAPTER ONE: INTRODUCTION

Infertility services, such as assisted reproductive technologies (ARTs), provide an alternative to procreation via sexual intercourse for those who were otherwise unable to procreate through sexual intercourse (American Society for Reproductive Medicine (ASRM), 2015). It is the basis for which assisted reproduction is necessary that generates stigma: it is a deviation from what the majority, and related laws, deem to be *normal* (Slade et al., 2007; Whiteford & Gonzalez, 1995). Through this stigma, laws and social practices were constructed to ill-favor those who seek infertility services to fulfill their desire for a family, especially those who seek to develop a family outside of the heteronormative paradigm (Bell, 2016). As a result, there exists a disparity in accessing infertility services, and some of those barriers are due to policies that are based on interpretations of infertility, family planning, and medical need for assisted reproduction that do not reflect the entire spectrum of people who need access (Greil et al., 2011).

In 1977, the United States had the first state-based insurance policies that required certain types of employers to either *offer* or *cover* some degree of infertility services (Table 1.1) (National Conference of State Legislatures, 2019b). Now in 2020, 19 of 50 states have some type of insurance mandate for infertility services. Some of these new policies are inclusive to non-traditional family development and utilize definitions of infertility that are not exclusive to a single sexual orientation or marital status (Adashi, 2015; Centanni, 2019). However, there are still vast disparities in the utilization of these services. Important questions to ask are: How efficacious are these existing policies? Are state-based insurance policies the answer to solve the disparity issue?

Although the infertility insurance mandates should increase access to residents of mandated states, there are no data to suggest the mandates increase financial accessibility to infertility services. Observing the efficacy of public policy is encouraged when disparities exist in the accessibility of infertility services, and even more so when legislation infringes upon the reproductive autonomy of underrepresented groups. Due to their nationally increased use, not addressing this issue could lead to accessibility disparities for infertility services, resulting in a demographic shift of human health and reproduction rates.

Problem Statement

Current research shows rates of infertility service use, psychosocial issues from using infertility services, and birth outcomes from these services either quantitatively *or* qualitatively, without linking the contextual qualitative information that could help explain the quantitative patterns of infertility service use. Research shows there are many possible factors that influence accessibility to infertility services, such as sexual orientation (Conrad, 2007; The Ethics Committee of the American Society for Reproductive Medicine, 2013), ethnicity (Kelley et al., 2019; Lynch, 2019), presence of insurance (Hamilton & Mcmanus, 2012; Wu et al., 2017), and income (Hammarberg & Kirkman, 2013; J.R. Ho et al., 2017). Due to population-level shifts in postponing family development and the makeup of families themselves (single parents, same-sex parents), unequal access to infertility services could create unanticipated demographic shifts in the American population. What is more, the current infertility insurance mandates are written in such a way that they will not provide comprehensive coverage for these services. The limitations embedded in the language of the current infertility insurance mandates infringes on the reproductive autonomy for those who require infertility services but cannot afford to pay for them

out of pocket. Research show this disproportionately affects social and racial minorities (Insogna & Ginsburg, 2018).

Purpose of the Study

The purpose of this study is to add context to the use of infertility services in the United States by exploring the role of environmental context (place) as a risk regulator in accessing those services. A risk regulator is variable that has inconsistent contextual influence on health behavior or health outcomes and is not considered deterministic, but rather influential – maintaining a regulatory effect on health outcomes that affect different people in different ways (Glass & McAtee, 2006). From here on, anything related to “environment” or “environmental context” will be referred to as “place”. For the purpose of this study, place refers to any influence outside of an individual’s own behavior, but that may affect an individual’s behavior. This research assumes that place is socially constructed through politics and culture (Rodman, 1992). An overarching place-based context studied in this research are the state-based infertility insurance mandates because they are meant to increase accessibility to infertility services by residents whose state has one of those mandates. However, there are no data to substantially support the proposition that residence – the *place* someone lives – in a state with an infertility insurance mandate will increase one’s access to infertility services.

Data collection used to observe place includes both qualitative and quantitative methods in order to fill the contextual gaps in the current literature related to the access of infertility services. The qualitative inquiry observes place as a factor in the reciprocal interplay between person, behavior, and environment (Bandura, 2004). The context of place in qualitative inquiry consists of aspects of travel and residence, use and presence of health insurance, and the role of organizations

providing infertility-specific insurance or other financial assistance for infertility services. The quantitative inquiry includes a survey instrument inquiring about reasons for seeking infertility services, aspects of travel, residence, presence of health insurance, and self-efficacy in the face of accessing infertility services. The quantitative spatial analyses observe place in terms of spatial patterns of fertility based on sociodemographic variables of women who had a birth in the last 12 months, and location of fertility clinics reporting data to the Centers for Disease Control and Prevention (CDC).

Research Questions

There are a total of seven research questions included in this research, and each question refers to aspects of place and human reproduction. Research questions were constructed in a way that permits these data to complement each other, allowing some questions to be answered with both qualitative and quantitative sources. The alignment matrix in Appendix A lists the research questions, data collection instrument, and item on that instrument used to answer the research question. More detailed rationale for each research question is located in Chapter Three.

- R1: Why do people access infertility services in the United States?
- R2: What influence does geographic location have on access to infertility services?
- R3: What influence does living in a state with mandated insurance have on access to infertility services?
- R4: What are the roles of specialized infertility specific insurance or other financial aid organizations in increasing access to infertility services in the United States?
- R5: What is the spatial relationship between fertility of women between the years of 2013-2017 based on age, education, ethnicity, nativity, and income?

- R6: What is the spatial relationship between fertility of women between the years of 2013-2017 and states with or without infertility insurance mandates?
- R7: What is the spatial relationship between fertility of women age 15-50 and the spatial distribution of Society of Reproductive Technology (SART) reporting clinics between the years of 2013-2017?

Significance of the Study

Many of the current state-based infertility insurance mandates, and state-based definitions of human infertility, represent institutionalized discrimination against non-traditional family development (Abel, 2004; Mastroianni, 2016; Pendo, 2005). There are still 31 more state-based infertility mandates that could be developed. With new information about the utilization of current mandates by individuals and employers, and the geospatial spread of fertility clinics across the United States in relation to local fertility trends, legislatures can have the data to create mandates that truly do facilitate equitable access to infertility services.

Conceptual Framework

This research operates under the social-ecological model (SEM) of human health and observes place (environmental context) as it is defined in social cognitive theory (SCT), as a dynamic factor within reciprocal interaction between person, environment, and behavior (Bandura, 2004). This research also uses social constructionism, which observes the social environment as an objective reality from which knowledge and meaning are created, and assumes that reality is socially constructed and differently experienced at the individual level (Berger & Luckmann, 1967). The ways infertility services are accessed, researched, and practiced, are complex and do

not function the same way as some other public health concerns (Craig, 2020). Such complexity may be due to the high priority human society places on human reproduction, and how uncontested the heteronormative paradigm of human reproduction has been over time (Boutell, 2018).

Due to this complexity, observing the social ecological model of health will be helpful in determining factors affecting the accessibility of infertility services that are not necessarily deterministic, but are rather influential and differently experienced across the spectrum of people who want to use them. Not only can micro-level intrapersonal factors differently influence the disease state of infertility, such as the degree of infertility manifestation based on one's own biology (it does not affect everyone to the same degree) (Humphries et al., 2016; Silva & Machado, 2008), there are varying degrees of influence from the interpersonal and community levels, where fertility is constructed as an adulthood milestone (Cousineau et al., 2007), and excessive reinforcement of reaching that milestone from social circles can have bidirectional influence on health behaviors taken to access infertility services (or not). There are also macro level pressures such as workplace policies and state-level policies that affect the degree of accessibility the healthcare system provides to its citizens (Boutell, 2018).

The concept of embeddedness within the social ecological model should be emphasized, especially considering that a disparity perspective must consider the nonlinear interaction between levels of influence. Embeddedness refers to the affect that each level of influence exerts on the level within and around it (Simons-Morton et al., 2012). Embeddedness could also be argued to be present in Bandura's reciprocal determinism in social cognitive theory, which allows these theories to further complement each other.

Summary of Methodology

This research utilizes a mixed-method, pragmatist research design, where both quantitative and qualitative data are used to understand a phenomenon more fully (Biesta, 2015; Feilzer, 2010). In review of the literature surrounding the experience of using infertility services, there is much of discussion about social environment and its effect on the psychological impact of using infertility services (Adashi & Dean, 2016; Hershberger & Kavanaugh, 2008). However environmental influence has not been directly observed as a variable of direct inquiry related to the use of infertility insurance mandates. Place is usually tangentially referred to as *an influence*, but no research has critically reviewed or analyzed environmental context (place) regarding access to infertility services in the United States. It may be because place encompasses many potential domains of everyday life (Clark, 1990; Saker & Evans, 2016). What is needed, then, is an approach that is designed to observe type of place from different perspectives – from different points along the cycle of reciprocal causation.

The mixed-method research design is sectioned into two parts: Part 1: Interviews and Online Survey, and Part 2: Spatial Analyses. Part 1 includes the qualitative inquiry and a quantitative survey. There are 66 informal interviews with male and female U.S. residents who are between the age of 18 to 45. Expert interviews are also included in this research, consisting of eight interviews with representatives of organizations that offer some type of insurance, financial, or informational service specific to infertility services. Social Cognitive Theory (SCT) guided the construction of the informal interview questions. Interviews were audio recorded and the PI transcribed the interviews verbatim. Interview transcripts were analyzed using applied thematic analysis through the mixed method analysis software MaxQDA. The quantitative survey was developed to observe risk regulators that affect people's ability to access infertility services, such

as the state of residence, type of employment, presence of insurance, aspects of travel, fertility education, and perceived self-efficacy measured using the validated Infertility Self-efficacy Scale (Cousineau et al., 2006).

Part 2 consists of quantitative spatial analysis of fertility data from the 2013-2017 American Community Survey 5-year estimates on women who had a birth in the last 12 months. Spatial analyses are based on census tract-level fertility estimates stratified by demographics of age, ethnicity, poverty status, education, and nativity. This section also consists of spatial analysis of geocoded fertility clinics that report their data to the SART via the CDC, observing their location and spatial clustering in relation to fertility and population density. This type of a location intelligence approach allows for the observation of spatial dynamics related to the placement of fertility clinics that assumes: medicine is a business, and businesses need clients to survive, so these types of medical businesses will be located in areas of high population density.

A strength of this research will be the dynamic integration of qualitative and quantitative data in order to add context to the use of infertility services when state-based infertility insurance mandates are present or absent.

Terms and Definitions

ART – assisted reproductive technology; refers to the high-tech options for human reproduction outside of sexual intercourse; in vitro fertilization (IVF), intracytoplasmic sperm injection (ICSI), etc (Centers for Disease Control and Prevention [CDC], 2017c).

Aspatial – not related to or associated with a space or area; social dimensions of potential influence (Bissonnette et al., 2012)

Bayesian statistics (inference) – a statistical method that applies Bayes’ theorem to enhance the probability of a hypothesis when more information becomes available (Theodoridis, 2015)

Biopedagogy: *biopedagogies*; meaning associated with the body, where those meanings are constructed in multiple areas of influence and power by a majority – thereby making social practices referring to the human body *normalized* or acceptable and by result condemning deviations from that norm to be abnormal (Wright, 2009)

Biopower – the political and social enactment of structures based on the paradigm of the majority to influence the reality of living life “that endeavors to administer, optimize, and multiply it, subjecting it to precise controls and comprehensive regulations” (Foucault, 1984a, pg 136; Wright, 2009)

Environment – (environmental) in the context of this research, relates to a mode of regulatory influence in the use of infertility services; also referred to as *place*

Euclidean distance – the straight-line distance between two points, assuming no obstructions exist (Liberti & Lator, 2017); “as the crow flies” (“As the Crow Flies,” 2020)

Geographic variable – a variable used to define geographic context (ie. state of residence, census tract boundary, geolocated fertility clinic)

GIS – A Geographic Information System (GIS) is a framework to gather, manage, and analyze spatial and aspatial data (Environmental Systems Research Institute [ESRI], 2019)

Habitus – [sociology] social habits, norms, assumptions of the individual that affect how they perceive their reality but that are also based on one’s social environment (socialization) (Bourdieu, 1977)

Heteronormative – *heteronormativity*; idea that heterosexual attraction is the preferred and normal form of human sexuality, linked to a dichotomous interpretation of sexuality and gender – unchanging (Barker, 2014).

Heteroskedasticity – occurs when the assumption that all variables relate to X in the same way; the errors vary based on the effect on the value of one or more of the independent variables (Barreto & Howland, 2005)

Hotspot, coldspot – spatially defined areas of significantly high (hotspot) or significantly low (coldspot) areas or points of interest in relation to each other, given a set of weighted features (Lessler et al., 2017)

Infertility services - healthcare services provided to people attempting to conceive through methods other than sexual intercourse; includes ARTs (Kaiser Permanente, 2019)

Insurance mandate – also termed a *mandated benefit*; “benefits that are required to cover the treatment of specific health conditions, certain types of healthcare providers, and some categories of dependents, such as children placed for adoption. A number of health care benefits are mandated by either state law, federal law – or in some cases – both” (National Conference of State Legislatures, 2019a, pg 1)

Mixed-methods – type of research methodology that utilizes both qualitative and quantitative methods in combination to understand a certain topic (Creswell & Plano-Clark, 2011)

Multicollinearity – a statistical phenomenon that occurs when a predictor variable in a multivariate model can be predicted by other values in the model with high accuracy; variables are too similar (Farrar & Glauber, 2006)

Place – a contextual concept that represents aspects of spatial and aspatial subjects; in this research, it can be referred to as environment or environmental context; socially constructed through politics and culture (Rodman, 1992)

Pronatalist – *pronatalist society*; advocacy and support of high birth rate; socially encouraging sexual reproduction as a means of social responsibility (Heitlinger, 1991)

Risk regulator – a variable that has inconstant contextual influence on some health behavior, and is not deterministic but rather influential – maintaining a regulatory effect on health outcomes (Glass & McAtee, 2006)

Self-efficacy – the perceived and actual ability of an individual to complete some task (Bandura, 2003)

Shapefile – A collection of geographic information within a compressed file to be used in ArcPro 2.4; allows for visualization of spatial variables and quantification of spatial statistics (ESRI, 2020c)

Spatial autocorrelation – values of a variable have a spatial relationship or are related to each other in some way in space (Getis, 2001)

Limitations

Quantifying health-related estimations based on geographic boundaries has a degree of error associated with it due to the plasticity of influence that a place can have on different people and at different times. However, some statistical tests can account for the potential error in over or underestimating spatial relationships, such as the Poissonian and Negative Binomial regressions which are linear regression statistics that affect overdispersion and unequal mean and variance differently that a log transformation of the data – which is important when the integrity of the count variables must be maintained (Haight, 1967; Jacob, Alwiss, et al., 2013).

A limitation to the majority of reproductive health data is that they are linked to spatial variables that is the most recent available data-representing the previous year or later. This is due to the need to de-identify the data, which is a requirement due to the protections to health information defined in HIPPA policy (U.S. Department of Health and Human Services, 2015). As a result, the analyses may not reflect patterns that exist in the current year, however those patterns may still be present and relevant.

Chapter One Tables

Table 1.1 Types of coverage among state-based infertility insurance mandates

State	Date Enacted	Mandate to Cover	Mandate to Offer	Includes IVF Coverage	Excludes IVF Coverage	IVF Coverage Only	Includes Fertility Pres. For Iatrogenic Infertility
Arkansas	1987	x ⁽¹⁾				x	
California	1989		x		x ⁽²⁾		x
Colorado	2020 [†]	x		x			x
Connecticut	1989	x		x			x
Delaware	2018	x		x			x
Hawaii	1987	x				x ⁽³⁾	
Illinois	1991	x		x ⁽⁴⁾			x
Louisiana	2001				x		
Maryland	1985	x ⁽⁵⁾				x	x
Massachusetts	1987	x		x			
Montana	1987	x ⁽⁶⁾					
New Hampshire	2020	x		x			x
New Jersey	2001	x		x			x
New York	1990	x		x			x
Ohio	1991	x ⁽⁷⁾					
Rhode Island	1989	x		x			x
Texas	1987		x			x	
Utah	2018	x ⁽⁸⁾					
West Virginia	1977	x ⁽⁹⁾					

*adapted from ASRM (2020) State Infertility Insurance Laws.

<https://www.reproductivefacts.org/resources/state-infertility-insurance-laws/> and (RESOLVE, 2020)

[†] effective 2022

(1) Includes a lifetime maximum benefit of not less than \$15,000.

(2) Excludes IVF but covers gamete intrafallopian transfer (GIFT).

(3) Provides a one-time only benefit covering all outpatient expenses arising from IVF.

(4) Limits first-time attempts to four oocyte retrievals. If a child is born, two complete oocyte retrievals for a second birth are covered. Businesses with 25 or fewer employees are exempt from having to provide the coverage specified by the law.

(5) Businesses with 50 or fewer employees do not have to provide coverage specified by law.

(6) Applies to HMOs only; other insurers specifically are exempt from having to provide the coverage.

(8) Applies to HMOs only.

(9) Allows for adoption indemnity benefit to be used for infertility treatment.

CHAPTER TWO: LITERATURE REVIEW

Research Review

This review of the literature begins with explanations of what infertility services are, types of infertility services used to circumvent human infertility, current rates of infertility in the United States, and a brief history of the infertility insurance mandates. Next, there are summaries of quantitative and qualitative approaches used to observe the use of infertility services in the United States, and research designs that observe aspects of *place* related to the use of infertility services. At the end of this review is a section dedicated to the conceptual framework under which this research operates, which includes the Glass and McAtee model of risk regulators, an analysis of the SEM, SCT, and Social Constructionism as they relate to the use of infertility services described in the current literature.

Defining Infertility Services

Currently there is no definition for infertility services, however the phrase appears in state legislation. The term is associated with data categories from national surveys such as the National Survey of Family Growth which describe infertility services to be healthcare services provided to people attempting to conceive through methods other than sexual intercourse. In academic and medical literature, however, the term assisted reproductive technologies, or ARTs,

typically describe research referring to infertility services. These two phrases are used interchangeably, but they do not define the same things.

While ARTs are the high-tech options considered invasive, infertility services include ARTs but also non-invasive techniques such as physician visits and hormone therapies. As an example, information from the insurance company Kaiser Permanente describe infertility services they cover as: an initial office visit that includes pelvic exam, any routine blood tests, cultures, and Pap smears, as well as health education on taking basal body temperature, reviewing test results, checking temperature charts, and making referrals (Kaiser Permanente, 2019). They also warn that several other infertility services that are typically necessary may not be covered by most insurance plans, which include semen analysis, hysterosalpingogram (HSG), hysteroscopy, endometrial biopsy, and hormone therapy to induce ovulation (Kaiser Permanente, 2019). Due to the lexical uncertainty in the literature, herewith infertility services will refer to healthcare services provided to people attempting to conceive through methods other than sexual intercourse.

At times ARTs may be discussed specifically due to the fact that data relating to the use of those services are collected by national health agencies such as the CDC, and it is important to include the frequency of use of those services to observe changes over time. There are numerous factors that affect the use of infertility services, and those factors act as facilitators for some, and barriers to others. There is a considerable amount of literature that draws attention to specific factors that serve as barriers to accessing infertility services, which include but are not limited to: the presence of insurance (Kissil & Davey, 2012), race and ethnicity, where there exists a higher frequency of Caucasian patients (Dieke et al., 2017), the use of ARTs for people with diseases such as cancer (Panagiotopoulou et al., 2018) and HIV (Cook & Dickens, 2014; Hagey et al.,

2015; Leech et al., 2018), religious restriction (Collins & Chan, 2017; Jones, 2014), and physician bias against ethnicity and sexual orientation (White et al., 2006).

Multiple health agencies collect prevalence data on the types of infertility services, but to date the most detailed data on infertility services are those for ARTs. However not all agencies report those data in the same way (Collura & Stevenson, 2016). While some clinics report all use of ARTs, some only report successful pregnancies from using an ART. Based on a 2016 report published by the ASRM, the number of ART clinics in the United States continues to rise but has slowed some since the year 2000 (Toner et al., 2016). Clinics in the United States can report their data to SART, or via the National ART Surveillance System (NASS) housed by the CDC. There are currently 463 clinics reporting to the CDC, 82% of which are SART members and 92% of which have verified lab accreditation (CDC, 2018). Among some of the trends observed from the surveillance data are: 1) maternal age is the most influential factor in successful pregnancies through ARTs, 2) single embryo transfers are increasing, and more so for younger patients, 3) a reduction in the number of twins, and, 4) a reduction in the number of ovarian hyperstimulation syndrome (OHHS) as a result of taking fertility hormone treatments (Toner et al., 2016).

Rates and Types of Infertility Service Use

Based on the preliminary 2018 SART annual report, there were 271,398 initiated cycles in the United States. A cycle begins once a woman begins medications in preparation for starting an ART procedure (SART, 2020). Patient characteristics for using ARTs suggest that patients under the age of 35 use ARTs most frequently and have the highest birth rate (47.6%), compared to those who are 35-37 (30.7%), 38-40 (19.7%), 41-42 (9.7%), and >42 (2.9%) years old.

Infertility Rates. Multiple agencies collect data on infertility diagnoses both in the United States and internationally, however these agencies do not collect or present data in the same way. This diminishes an accurate view of the status of human infertility. For example, the National Survey of Family Growth (NSFG) observes infertility rates based on self-reports from women of reproductive age (15-49), whereas SART observes infertility diagnoses based on clinical data. SART observes success rates from different ARTs within the reporting clinics and observes success rates based on the type of infertility diagnosis.

Current rates of infertility produced by the NSFG estimate that, in the United States between the years 2015-2017, the percentage of all married women 15-49 years of age who had impaired fecundity was 13.1% ($\sigma=0.59$), and those diagnosed as infertile was 8.8% ($\sigma=1.09$). However when looking at parity, there are differences, where the rate of infertility for married, childless women 15-49 years of age was 19.0% (3.16), and at 6.5% (1.13) for married women of the same age who had at least one child (NSFG, 2020). The percentage of women 15-49 years of age who have ever received any infertility services was 12.7% (0.93). Women aged 40-49 were the highest users of any type of infertility service, at 20.5% (4.25).

According to SART, rates of infertility types within reporting SART clinics listed from highest frequency to lowest, are as follows: diminished ovarian reserve (30%), male factor (28%), ovulatory dysfunction (14%), “other” factor (24%), unexplained (11%), endometriosis (7%), and uterine factor (6%) (SART, 2020). Unfortunately, it is difficult to determine an actual prevalence of human infertility due to the different ways these agencies collect data. Further complicating research on the prevalence and incidence of infertility is the multiple types and levels of human infertility.

Types of human infertility. Defining, and thus diagnosing, infertility remains a challenging task, and affects the research, policies, and practices associated with ART (CDC, 2014). Infertility was only recently acknowledged as a disease (Berg, 2017), Presently infertility is considered a disability due to its categorization under the Convention on the Rights of Persons with Disabilities Act due to the impairment of male or female reproductive function [see Macaluso et al., (2010); World Health Organization [WHO], (2011)]. Human infertility is a complex disease with many etiologies, ranging from genetic mutations, such as deletions of certain genes on the azoospermic factor regions (AZFs) of the Y-chromosome in men (Esteves & Agarwal, 2011; Lee et al., 2011; Lee et al., 2003), physiological issues with ovulation or fallopian tube function in women (Meng et al., 2015), a result of menopause in women (Friese et al., 2006; Lemoine & Ravitsky, 2015), STDs (Tsevat et al., 2017) chemotherapy treatments for cancer (Loren et al., 2013), and occupational hazards, such as injury or being exposed to certain chemicals (Benoff et al., 2000).

The WHO (2018) lists six types of infertility: clinical, demographic, epidemiological, disability, primary, and secondary. Clinical definitions of infertility include unsuccessful clinical pregnancy after having unprotected sexual intercourse for at least 12 months. Demographic definitions include individuals incapable of becoming pregnant who are of reproductive age (15-49 years), or who are not able to carry a live birth. The difference between primary and secondary infertility is that primary infertility refers to when a woman is unable to become pregnant and is nulliparous (never had children), while in secondary infertility is defined as a woman who was previously pregnant and is unable to become pregnant now (WHO, 2018).

Beyond the definitions of human infertility, there are also levels of infertility, such as fertile, infertile, subfertile, and impaired fecundity. Both subfertility and impaired fecundity refer

to a period of time when becoming pregnant is either difficult or not wanted (Wilcox & Mosher, 1994). Due to the many definitions, types, and degrees of human infertility, assessing an accurate prevalence or incidence is difficult (CDC, 2014), especially due to the findings that stress can cause impaired fecundity that is misdiagnosed as infertility. This potentially overestimates rates of infertility, resulting in a spontaneous pregnancy once the couple stops medical intervention to become pregnant (Kupka et al., 2003).

How infertility is defined can have social effects as well, such as the provision of infertility services for same sex couples – where diagnosed infertility is not necessarily the reason the couple wishes to use assisted reproduction. The way(s) in which infertility is defined will have effects on the methods used to track the frequencies of use of the infertility services, and more importantly the influence of the many co-factors contributing to why medical intervention is necessary to achieve pregnancy. A person or couple do not have to have an infertility diagnosis to need to use infertility services. For instance, same sex couples may seek infertility services in order for at least one in the couple to have a genetic connection to their offspring, or to use surrogacy. Regardless of sexual orientation, there might be a genetic disorder that could be circumvented through the use of infertility services such as the three-parent IVF procedure to remove mitochondrial disease from an embryo (Amato et al., 2014).

Types of ARTs. ARTs are included under the definition of infertility services. There are several types of ARTs, ranging from invasive, high-tech options such as in vitro fertilization (IVF) to low tech options such as ovarian stimulation, to third-party options such as adoption or surrogacy. Often, a successful pregnancy resulting from ARTs requires multiple high- and low-tech options, increases the risk of multiples (twins, triplets), and presents an increased maternal and child mortality risk (Chambers et al., 2007). Also, at times a couple or individual may

require the use of a high-tech option along with a third-party option, such as using a gestational carrier due to complications that inhibit the ability to carry a child that manifest from using hormone therapy, which can cause ovarian cysts.

High-tech options. *Artificial insemination (AI)/Intrauterine insemination (IUI).* Artificial insemination, also referred to as intrauterine insemination, uses a tube inserted into the vagina to release sperm into the uterus, and is often used in conjunction with ovarian stimulants due to the increased chances of success (National Institute of Child Health and Human Development [NICHD], Child Development and Behavior Branch [CDBB], 2017). Before the semen is injected into the uterus, it goes through a washing process that removes the seminal fluid (ASRM, 2015). Multiple failed attempts at IUI often result in patients pursuing IVF or intracytoplasmic sperm injection (ICSI) (Victorian Assisted Reproductive Treatment Authority [VARTA], 2016).

IUI and IVF tend to be combined when observing statistics. Based on the 2017 annual report on ART Success Rates from SART, IVF success rates reached 51.6% for achieving live birth per cycle for persons age 35 and younger (Centers for Disease Control and Prevention [CDC], 2017a).

In-vitro fertilization (IVF). In-vitro fertilization (IVF), or in-vitro fertilization with embryo transfer (IVF-ET), is one of the most common types of ART, and it was the method used with the birth of the first baby born from assisted reproduction. (Kamel, 2013). There are three types of IVF, and they differ in that amount of ovarian stimulation. These types are natural, where the mother does not receive fertility medication to induce ovulation; conventional, the most commonly performed method where the ovaries are downregulated up to 10 days and then stimulated to form multiple follicles – the ultimate goal being to increase success by increasing

the quantity of embryos released; and mild, a more recent development that does not downgrade the ovaries, but instead uses the natural cycle and low amount of fertility medication to produce higher quality eggs – going for quality over quantity (CREATE Fertility, 2015).

There are four stages of IVF: superovulation, also referred to as ovarian stimulation, ovarian induction, where hormone treatments taken for 8-14 days stimulate growth of follicles and eggs, following an injection of human chorionic gonadotropin (hCG) to initiate ovulation; egg retrieval, where the mature eggs are removed for fertilization ex-utero by use of an ultrasound probe and a needle that goes through the wall of the vagina to retrieve the eggs; fertilization, where the removed, mature eggs are fertilized ex-utero in a petri dish with semen and placed in an incubator; and embryo transfer, where a long tube inserted into the vagina released the embryos into the uterus with the intention of an embryo attaching to the uterine wall within 6-10 days (NICHD Child Development and Behavior Branch (CDBB), 2017). The advent of oocyte and embryo cryopreservation allows patients to preserve removed oocytes and embryos for later use, so not all gametes have to be used at once (Gook, 2011).

The latest development in IVF is the three-parent IVF procedure, first used in the United Kingdom in 2016 and most recently used by an American doctor in Mexico in 2017 (Scutti, 2017). Also termed mitochondrial donation, the three-parent IVF procedure was developed to overcome mitochondrial disease for women, a disease that is difficult and expensive to treat (Senger et al., 2016). The disease is due to a mutation in the mitochondrial DNA (mtDNA), which is inherited maternally (Liu & Chu, 2015). The use of preimplantation genetic diagnosis has not proved successful in detecting mitochondrial disease pre-procedure (Liu & Chu, 2015). Currently there are two procedures used to create a three-parent embryo: pronuclear transfer, where both of the normal pronuclei from the infected mtDNA are transferred to the donor

zygote; and spindle transfer, involving the transfer of the mutated mtDNA nuclear genome to the mtDNA of the donor oocyte (Liu & Chu, 2015).

In-vitro maturation (IVM). IVM does not use any ovulation hormones and is a specialized procedure practice in a few areas of Europe (CREATE Fertility, 2015). The process of IVM involves removal of immature eggs during a woman's natural cycle, and maturing them ex-utero and performing ICSI for fertilization (Child et al., 2002). SART does not publish results on IVM, but some research suggests that it has comparable success rates to IVF (Ellenbogen et al., 2014).

Gamete intrafallopian transfer (GIFT) and zygote intrafallopian transfer (ZIFT). GIFT is a procedure not widely used, but it was created as a way to avoid using the petri dish for fertilization, and is one of the few procedures approved by the Vatican due to it being so close to normal conception compared to other ARTs (Gilson, 2008; Victorian Assisted Reproductive Treatment Authority (VARTA), 2016) Similar to IVF, hormone treatments occur before the procedure begins (Gilson, 2008). The sperm and unfertilized egg are moved into the fallopian tube for fertilization to start, so the procedure requires that the woman have healthy fallopian tubes and that the sperm be of good quality (Aurora, 2017). Research suggests that GIFT has similar success rates to IVF, and some statistics report that women age <38 tend to have a 37% chance of a successful pregnancy, and women age >39 have about 24% chance of a successful pregnancy (Ding, 2016).

ZIFT is a similar procedure to GIFT, but it is the fertilized zygote that is moved into the fallopian tube (Aurora, 2017). It combines processes in IVF and GIFT (Zhu, 2011). ZIFT can often overcome failed GIFT procedures, or issues with male factor infertility (Aurora, 2017). Fertilization occurs either in-utero or ex-utero, requiring ICSI (Zhu, 2011). Rather than wait until the oocytes divide as in IVF, the oocytes are placed into the fallopian tube once cell division

starts, using a laparoscopy (Zhu, 2011). The success rates for ZIFT are also comparable to IVF, but they are highly variable based on the type of infertility to be overcome and the ages of the patients (Ding, 2017).

Intra-cytoplasmic sperm injection (ICSI). ICSI is a procedure that becomes necessary when the sperm is not able to fertilize the mature eggs during the fertilization phase of IVF (De Vos, 2000). A needle injects the mature eggs with sperm in order to overcome lack of motility. This procedure occurs in about 60% of all IVF done in the United States (NICHD Child Development and Behavior Branch (CDBB), 2017). Rates for ICSI tend to focus on fertilization success, where the Advanced Fertility Center of Chicago reports that fertilization with ICSI is successful in about 75-85% of eggs (Advanced Fertility Center of Chicago, 2017).

Low-tech options. Low-tech ARTs are those infertility services that are not considered invasive medical technologies such as those discussed above. Research by Messerlian, et al (2015) include low-tech ART in their epidemiological analysis of preterm birth risk among ART types. They define “low-tech” as any non-IVF method, such as ovarian stimulation. Based on that definition, it is most likely that people utilize both high- and low-tech ART procedures. However, this definition is not standard. Although “low-tech” ARTs have no supporting evidence for efficacy, or definition for what exactly constitutes as low-tech, empirical research brings up the importance to consider the existence and active searching for low-tech options. Infertility patients navigate the high cost of existing, invasive ARTs (Messerlian et al., 2015), and the leniency some religious institutions have for low-tech ARTs as opposed to high-tech, invasive procedures make review of these options important (Klitzman, 2018).

Third-party options. Third party reproduction includes the use of gametes or embryos donated from an individual other than the intended parents of the potential offspring and is often

considered an altruistic act on behalf of the donor (ASRM, 2012; Pennings, 2015). Types of third-party reproduction include sperm, egg, embryo and oocyte donation, surrogacy, and gestational carriers (ASRM, 2012). Mitochondrial donation, for the three-parent IVF procedure, is also considered under third party conception (Liu & Chu, 2015).

Gamete donation. SART tracks the number of births from use of donor eggs and separates those rates by whether they were fresh (non-frozen) or frozen. Based on their 2016 annual report, the rate of live, normal weight, singleton births from transferring fresh embryos was 32%, and with frozen embryos 26.7% (CDC, 2016). The rates for transfers resulting in pregnancies were 65.9% for fresh embryos, and 52.3% for frozen embryos.

The anonymity of donors varies by country and type of gamete and continues to be an ethical consideration due to rights to privacy and risks of consanguinity (Gong et al., 2009). Other ethical considerations raised by third party reproduction are parentage designation laws that are not standard, especially in the United States (Tsfati & Ben-Ari, 2018), compensation for gametes (Lee et al., 2017), and risks of taking advantage of low-income donors in medical tourism exchange (Inhorn, 2011; Neri et al., 2016).

Surrogacy. A surrogate is a woman who donates her egg to another couple and carries that pregnancy to term. The main difference between surrogates and gestational carriers are that surrogates use their own eggs and maintain a genetic link to the child, but gestational carriers use the egg from another woman and carry that child, without having a genetic link to the child (ASRM, 2018). Some research observes the difficulty in determining parenthood with surrogacy cases, due to some legislative definitions of “parent” and “mother” under the Uniform Parentage Act referring to the existence of genetic links between the two women. Often times, surrogate

mothers will be referred to as “natural” mothers, and the woman who is using the surrogate is the *intended* mother or parent (Surrogate online, 2018).

Gestational carriers. Gestational carriers are different from surrogates in that they do not have any genetic relation to the baby they carry, however gestational carriers can be relatives of the intended parents – sometimes referred to as gestational surrogates (Daar et al., 2017). The Ethics Committee of the ASRM defines intrafamilial gamete donation and gestational surrogacy as being within ethical parameters, but the risks of consanguinity (incest) are still cautioned due to the risk of not knowing who one’s paternal father is (ASRM Ethics Committee, 2018). Research by Perkins et al, (2016) on trends in gestational carriers between 1999-2013 show that rates of gestational carriers in ART is increasing, where in 1999 gestational carrier cycles were at 727, in 2013 the number increased to 3,432.

Adoption. Child adoption is not necessarily a third-party reproduction method, but it is a solution some individuals and couples pursue to achieve their parenthood aspiration(s) (Hoffman-Reim, 1990). Adoption existed before the development of ARTs, and although it can satisfy the desire to be a parent, it does not satisfy the desire to be a parent to a child whom you carried, birthed, and is genetically related to you (Petersen et al., 2015). Data from the NSFG show that the rate of people adopting a child decreased from 1.1% of respondents (0.6 million) in 2002, to 0.7% (0.4 million) in 2015; and that people who took steps to adopt fluctuated between 3.4% (1.9 million) 2002, to 4.4% (2.5 million) in 2010, to 3.7% (2 million) in 2015 (National Survey of Family Growth, 2017). The greatest debate between choosing ART or adoption has to do with comparative costs and perceived power over outcomes of the situation. Some couples perceive to have more control over what they do to their own bodies than relying on an agency to

determine whether or not they are suitable as parents, and hoping that the natural mother does not change her mind (Gumus & Lee, 2012).

In terms of cost, a single IVF cycle in the United States costs an average of \$12,400, with an additional \$2,000-\$6,000 for the IVF medications (Jain et al., 2019). There are some insurance mandates that offer varying degrees of coverage for infertility services, but the problem is that the language in the policies to not increase accessibility for everyone. The policies inform people of the services that are covered (or, more often services that are not covered) based on their residency. However, they do not equitably empower people to access those services.

The effect of the existing insurance mandates in reducing costs associated with using ARTs is also tenuous. Research by Boulet et al. (2019) found that women fully insured with per member per month (PMPM) in states with infertility reimbursement mandates experienced 3.1x more expenses than women fully insured with PMPM in states without infertility reimbursement mandates. On the other hand, some research also found that women in states without an insurance mandate had greater pregnancy rates than women using ARTs in states with infertility insurance mandates (Martin et al., 2011). These types of discrepancies may be the result of researchers choosing to focus on certain types of ARTs, certain age ranges, and specific fertility clinics due to research demands or funding.

History of State-based Infertility Insurance Mandates

The development of the infertility insurance mandates is directly linked to the development and increased ART use in multiple countries. Experimentation using ARTs first occurred with animals such as mice and rabbits, and many of the methods used today for cryopreservation are

based on the historical development of assisted reproduction using animals (Gook, 2011; Passos, 2004). The Scottish surgeon John Hunter is often cited as the first to perform human artificial insemination, around the 1790s and supposedly using a syringe (Clarke, 2006; Harvard Medical School Center for Mental Health and Media, 2017). However, some researchers speculate the technology could have occurred successfully before this time, but was never publicized due to the private nature of the topic of human infertility (Clarke, 2006). Even the success by Dr. Hunter was not made public until after his death in 1799 by Sir Everard Home (Clarke, 2006; Poynter, 1968). The first published success of human artificial insemination came from France in 1838 by Dr. Girault, which included 12 cases (Clarke, 2006; Girault, 1868; Poynter, 1968).

The first in-vitro fertilization (IVF) on an ovum was conducted by John Rock and Miriam Menkin in 1944 in Boston, MA. In 1978 the United Kingdom saw the first successful IVF pregnancy and birth (Kamel, 2013). The first baby born from IVF in the United States, Elizabeth Jordan Carr, occurred in 1981 in Virginia (Kamel, 2013). Multiple successful pregnancies and births using ARTs occurred in several other countries starting in the early 1980s, including Australia (1980), France (1982), Sweden (1982), Germany (1982), Austria (1982), and Nigeria (1998) (Kamel, 2013). Towards the end of 1980 and continuing today, more methods of ART started to develop, including successful births using frozen embryos and donated eggs in 1984, GIFT and ZIFT in 1986, ICSI in 1992, and use of frozen eggs in 1997 (Harvard Medical School Center for Mental Health and Media, 2017; Kamel, 2013).

Some of the first government oversight specific to infertility services in the United States occurred in 1977 from recommendations from the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, the same organization that appointed the requirement of Institutional Review Boards for federally funded research (Brinsden, 1999). The

Committee called for Congress to establish an Ethics Advisory Committee for the Secretary of Health, Education, and Welfare to assist in the oversight of in-vitro fertilization research (Brinsden, 1999). In 1979, the Ethics Advisory Committee gave the official option that IVF was ethically acceptable (Brinsden, 1999). This brief history of ART shows that, through continued use and legitimization of assisted reproduction, came laws protecting both the persons using the technology and holding those practicing the technology ethically accountable for their methods.

The first infertility insurance mandates were established during the creation of the 1989 *Human Embryo Laboratories – Standards Favored to Ensure Quality* (Brinsden, 1999). Beginning in 1977, the first state to pass the initial infertility insurance mandate was West Virginia, followed by Maryland in 1985 and Arkansas, Hawaii, Massachusetts, and Texas in 1987. The most recent mandates come from Delaware and Utah in 2018, and New Hampshire and Colorado in 2020, however some states such as California, New York, and Utah passed amendments to their mandates since their initial passing. In 2019, North Dakota attempted to pass an infertility insurance mandate (SB 2233) that would increase the coverage for infertility services to \$20,000 and could include egg extraction and diagnostic services such as lab tests (Hyatt, 2019). However this bill failed in the North Dakota Senate as it was met with opposition, and some speculate it was due to assumptions that mandated insurance coverage for a service that few people in the state utilize would result in increases in insurance premiums for all residents (Hyatt, 2019).

Current Research on Infertility Insurance Mandates

A common salient topic in research regarding infertility services is that financial accessibility will increase in the 19 states (Figure 2.1) that now have mandated insurance for infertility services, (Martin et al., 2011). However, current research that explores the extent of

increased access to infertility services have conflicting results, where some previously highlight increases in use (Jain & Gupta, 2007), and some suggest negligent positive benefits at alleviating the financial burden of infertility services (Adashi & Dean, 2016). The majority of these research designs utilizes a frequentist perspective that quantitatively observes utilization of infertility services in states with vs states without mandated insurance for infertility services. Without qualitative accounts of how people who live in states with mandated insurance navigate the financial burden of these services, the *benefit* of living in a state with mandated infertility services insurance could be masking other factors that people have to overcome in order to obtain that coverage. What is more, much of the research does not observe all types of people who utilize these services. While women of reproductive age are typically the staple population to observe, current research leaves out marginalized groups such as same sex couples. The following are a collection of research designs that observe the effect of state mandated insurance for infertility services.

Quantitative approaches. Research by Martin et al. (2011) observed the effect of embryo transfers of fresh non-donor IVF cycles in 2006, using retrospective analysis of data from the SART and CDC. They acknowledged the differences within each state's insurance mandate, where some were more comprehensive than others, and to account for those differences that included at least one cycle of vitro fertilization (IVF), specifically. Of the 426 reporting clinics, they found that 74 (17%) were in states with mandated insurance for at least one IVF cycle, and of the 91,753 non-donor IVF cycles performed in the United States, 64,188 (70%) were in states that had mandated insurance for at least one IVF cycle (Martin et al., 2011). They observed multiple processes and outcomes from the IVF cycles, such as the frequency of the cycles, rates of fertility, multiple births, cancelation rates, embryos transferred, and live births. They found that women

whose cycles were performed in states without mandated insurance for infertility services had higher pregnancy rates, live birth rates, cancellation rates, and multiple birth rates (Martin et al., 2011).

In their discussion, they reduced their results to the significant increases in multiples for women between the ages of 35-37 (being the age range where multiples are highest) in states without mandated insurance to mean that insurance mandates might reduce the number of cycles performed (because only one cycle might be covered) and thereby reduce the number of multiple births resulting from IVF and embryo transfers. They interpreted their results to mean that states with mandated insurance coverage “is strongly and consistently associated with responsible embryo transfer practices in the United States...”, which also means that insurance mandates might not actually increase the accessibility of these services (Martin et al., 2011, pg 968). Although their results suggest increased access to infertility services are not affected by insurance mandates, they suggest that the insurance mandates might reduce the risk of multiples from IVF, which is associated with increased mortality risks to the mother and infant as well as places more economic pressure on the State to provide long-term care for large families (Carson et al., 2013; Martin et al., 2011). In their analysis, they are not able to ascertain to what degree an infertility insurance mandate alleviated the economic burden of the individual.

Schmidt (2007) observed the effect of the enactment of state mandates on birth outcomes over time and across states to observe state mandates on access to infertility services, using the Vital Statistics Detail Natality Data from the National Center of Health Statistics. The researcher utilized a differences-in-differences-in-differences (DDD) model to observe the effect that insurance mandates have on birth rates coming from ARTs and takes into account when the statute was enacted, and the female population aged 35+ who delayed childbearing. In her analyses, age

was considered to be an important factor due to variations in outcomes. This type of statistical model is suited to observe potential causal relationships between variables and assumes “confounders varying across the groups are time invariant, and time-varying confounders are group invariant”, meaning the confounding variables do not change after transformations are applied (Wing et al., 2018, pg 455). In order to account for the variability of coverage in the existing state mandates, the researcher grouped the mandates into those that *cover* infertility services, meaning the statutes require insurance companies to provide coverage for infertility as a benefit in all policies; and those that *offer* coverage, meaning that insurance companies can make purchasable policies available that might cover some costs associated with infertility services (Schmidt, 2007). The researcher also observed differences between Caucasian and African American women in those groups.

Results from Schmidt (2007) revealed weak statistical significance for women living in states with mandated insurance, where the presence of a mandate increased overall birth rates (this outcome was for all women, not grouped by ethnicity or age). However, when observing women over age 35, the significance was greater, meaning that women over 35 who live in a state with mandated insurance had an increased birth rate than women over 35 living in a state *without* mandated insurance for infertility services. A more interesting result is that, when ethnicity is integrated into the equation, the same effects occur for white women aged 35+, (DD=0.0071 [0.0131]), but not for black women (DD=-0.0655, [0.0485]) no matter the age or if they lived in a state with or without mandated insurance coverage for infertility services. When observing the type of mandate (cover vs offer), it was hypothesized that there would be a positive correlation between mandates that *cover* and overall birth rates from IVF, however there were no statistically significant results that showed that mandates that *cover* certain infertility services are more

facilitative than mandates that require certain infertility services to be offered. She also observed the outcomes for white and black women and found the same association, where accessibility was perceivably increased for white women but not for black women, no matter the age, type of mandate, or if IVF was included or not (Schmidt, 2007).

In sum, the results from Schmidt (2007) revealed that insurance mandates do increase accessibility of infertility services, but only for those women who are white, older, and highly educated. Some limitations to this research were that there were only two types of demographic characteristics observed, white and black races. Although there is mention that education is also associated, it was not included in the research design and may have been haphazardly added in order to show similarity to other research. The other limitation was that the study design is retrospective, where the research was published in 2007 but used data from between 1980-1999 – so its application to practice is limited. There are some strengths, however, in that the types of mandates were grouped into categories of *cover vs offer*, which are important distinctions to make in order to observe a more robust association between their presence and absence. This research identified that state mandates do not solve the disparity problem for accessing infertility services for minority groups, specifically African American women.

Another frequentist approach comes from Boulet et al. (2019), where they applied linear regression in a retrospective cohort study to observe expenditure differences in states with or without insurance mandates. This study is different than the previous ones in that the foci of the research was to observe expenditures using actual health insurance claims from the 2011 Truven Health Market Scan Commercial Claims and Encounters Database, observing aggregate and per-member-per-month (PMPM) costs in states with and without insurance mandates. They included women 19-45 years of age and limited the observed time to 12 months. From their total of

6,006,017 women, 48.1% were enrolled in fully insured plans. They separated those claims into groups based on three types of infertility service: one or more IVF claim (9,199; 0.15%), one or more IUI claim (10,112; 0.17%), and one or more ovulation inducing medication (OI) (23,736; 0.40%). No matter which claims group was reviewed, the expenditure was significantly higher in states *with* mandated insurance for infertility services, where average expenditure for infertility services was at \$12,337 compared to \$11,422 in states without insurance mandates for infertility services (Boulet et al., 2019).

Although their research used actual health insurance claims and was able to distinguish between self-insured vs fully insured employer-funded plans, it was limited by the way they describe the significance of their results. The results were limited to significance of expenditure by those who already accessed services; and in that there are no other demographics observed – it is not possible to determine if insurance alleviates the disparity in access to infertility services. They acknowledge in their discussion that a limitation was that they could not account for state differences regarding the type of insurance mandates, such as in the Schmidt (2007) research. Their geographic variables were limited to 4 regions: Northeast, North Central, South, and West – none of which provide meaningful spatial associations due to the existing states with mandates not centralizing in any one of those regions.

Qualitative approaches. Interestingly, there are no qualitative studies that directly observe the use of health insurance for infertility services. Instances of qualitative and survey-based research that identify cost and presence/absence of insurance as factors in whether someone will seek infertility services (Greil et al., 2020) or are reported as barriers to access services (Goossen et al., 2018) have been done, and there are law and policy reviews that observe the language in the current infertility insurance mandates to see what is included and excluded.

In a review by Dupree (2016), the absence of inclusive infertility insurance benefits for males is highlighted through observing the language of existing infertility insurance mandates. The review found that six of the then 16 states with infertility insurance mandates included coverage specific to male factor infertility, but those provisions are mainly for diagnostic testing. Dupree posits that the exclusion of male infertility benefits in those mandates places an undue burden on female partners and can delay knowing the etiology of an infertility issue by only focusing on female diagnosis and treatment.

In a law review by Centanni (2019), the language of Rhode Island’s infertility insurance mandate is called into question, highlighting the heteronormative language that limits the ability for same-sex couples to access the benefits of the mandate. For same-sex couples, there is no diagnosed infertility in the disease sense, but the couple is considered “structurally infertile” due to not being able to conceive through sexual intercourse. In the first iteration of Rhode Island’s mandate in 1989, the language described infertility in a way many state’s still do: a married man and woman who cannot conceive after 1 year of unprotected sexual intercourse. In 2007, the mandate was amended to remove the “married” stipulation, and although the Governor vetoed the bill at that time, the marriage stipulation was removed in 2017 (Centanni, 2019). However, there remains the interpretable stipulation of “unprotected sex for at least 1 year”, which is not the reason for infertility in all cases. Centanni (2019) reports that Rhode Island is not the only state to have this type of restrictive language, in fact Hawaii still has the marriage requirement in their statute.

Although reviews and law reviews are not accounts of qualitative research, they bring to light important factors to consider when attempting to observe the efficacy of a policy. The language of the policy itself can provide explanatory context to why some disparities in accessing infertility services exist to the degree that they do.

Addressing Place in Infertility Services Research

Place is not linear; it is dynamic and not restricted to geographic location (MacEachren, 2017). In geography scholarship, it is however assumed that things close to each other tend to be more related to each other than things far apart (Tobler, 1970). Many theories related to place and health focus on the physical and built environment, but such dichotomization can ignore aspects of place related to social context and change. This research attempts to apply current concepts of place to the utilization of infertility services in the wake of changing public opinion and technological advancement that circumvents barriers to natural cycles of human reproduction. Attention must be paid to the contexts of place and the regulatory effect that sociodemographics have on the degree of contextual influence on healthcare accessibility.

Much of the literature focused on the geographic aspects of place for infertility services resort to comparing the distances to services. Research on the effect of living in an urban versus rural area regarding access to infertility services tends to perceive accessibility through distance to those services (Kunicki et al., 2018), costs associated with traveling to those services (Maxwell et al., 2018), and the frequency of the workforce providing the service compared to the population needing the health service in a specific area (like a county or city) (Nangia et al., 2010). Very little research has observed disparity in access to infertility services through observing rural versus urban residence. The CDC reports that in 2010, 1/5 of the U.S. population had residence in an area considered rural (Daniels et al., 2017). The NSFG estimates between 2011-2015, rural women of reproductive age had their first sexual encounter at an earlier age, had higher frequencies of marriage and former marriage, exhibited a higher frequency of having at least one birth, and used the most effective contraceptive methods (contraceptive sterilization or intrauterine device), when compared to women of reproductive age living in urban areas (Daniels et al., 2017). These data

suggest there are aspects of reproductive health that differ between rural and urban populations of reproductive age, however the intricacies of those differences in terms of race/ethnicity, education, annual income, and sexual orientation are difficult to observe quantitatively.

Research by Harris et al. (2017) observed the location of 510 CDC-reporting fertility clinics that existed between 2009-2013 in the United States. They found that 442 of the clinics existed in places with median populations of 1.45 million people (considered metropolitan), and in 68 of those areas there was a single fertility clinic. They compared the clinic frequencies to the number of women of reproductive age during that same time frame and found that 38.1 million women of reproductive age lived in an area with more than one fertility clinic, 6.8 million lived in an area with a single fertility clinic, and 18.2 million lived in an area with no fertility clinic. Their overall result was that over 25 million women of reproductive age live in areas with limited to no geographic access to fertility clinics, highlighting a disparity in geographic choice when seeking infertility services. They summarize that expenses associated with long-distance travel for specialized medical care can reduce the ability for some (Harris et al., 2017).

A potential strength from their research was that they used core-based statistical areas (CBSAs), or geographic areas specified by social and economic influences within surrounding counties, to define the geographic areas used in their analysis (Harris et al., 2017). This method was an improvement on the previous methods of measuring the effect of distance to services on disparity, which relied on measuring Euclidean distances from provider locations using spatial buffers. A limitation to their research was that they did not include a variable to observe the effect of state mandated insurance for infertility services, which could have influenced the frequencies of people using those services. Another limitation was qualitative accounts of how place influences accessibility, regarding a lack of knowledge about how far people are willing to travel for services,

or if there are more people accessing those services who live in geographic proximity to those services, compared to people who access those services and do not live in their geographic proximity (Harris et al., 2017).

It is important to reiterate that place is not linear. However, geographic place can be considered a risk regulator to the use of infertility services due to the state-specific nature of the current mandates and lack of any federal mandate for these services. Measuring distances to services to predict patterns of use or levels of accessibility can be informative, but qualitative accounts of travel associated with these services, as well as how residence affects access to these services, could add important context to how people are qualified or disqualified from accessing insurance coverage.

It is also important to consider natural boundaries and population distribution when observing the locations of specialized medical practices. If there is a low population, there is less incentive for business development because there are fewer projected potential patrons for the services or product being offered (Adler & Florida, 2020). It may be beneficial to observe the locations of fertility clinics through the lens of a business analysis, where rather than observing few clinics in rural locations as a lack of perceived importance by the state, to interpret the accrual of fertility clinics in larger metropolitan areas as logical due to the location of more people in those areas. The observation that some metropolitan areas lack fertility clinics, then, becomes more informative because those instances are not masked by a larger disparity of clinics in rural areas where it would not make sense to build a fertility clinic.

Conceptual Framework: Place as a Risk Regulator for Infertility Service Use

Glass & McAtee (2006) provided a conceptual framework (Figure 2.2) in which to observe factors that influence health behavior change. The Glass and McAtee model is similar to the SEM, however it addresses a different type of influence – the risk regulator – that positions itself not as a determining factor that leads to a behavior, but that might influence a behavior in different ways due to the differences that exist in people’s everyday reality. According to the Glass and McAtee model of the social determinants of health, the risk regulators in this research are drivers of disparity in access to infertility services that affect people in different ways, and they will change over time. Place (where people live, where people travel to access services, where clinics are based) is considered a risk regulator due to its affiliation with the environmental context of everyday reality. The concept of place (often referred to as environment) is present in many health behavior theories, but few research studies have directly observed the influence of place on health behavior.

A main construct in theories of place posit that concepts of place are constructed, and that constructions of place are dynamically influenced by culture, policy, individual cognition, and social forces (Wolf et al., 2018). Concepts of place are “imbued with meaning, shaped by social and political-economic forces” and therefore have and will continue to have an influence on human health (Neely & Nading, 2017, pg 55). Due to these realities, an observation of the SEM as it relates to the access of infertility services is required in order to better understand the multilevel influence of human society and cognition in the construction of the infertility insurance mandates and their use.

Social Ecological Model of Infertility Service Use

Previous research on infertility services demonstrates that infertility services – the ways they are accessed, researched, and practiced – are very complex, and that reproductive dysfunction does not affect the public in the same way as some other public health concerns. This may be due to the high priority human society places on human reproduction (Robertson, 1991) and how uncontested the heteronormative paradigm of human reproduction has been over time (Boutell, 2018). Due to this complexity, it is beneficial to observe health disparity in accessing infertility services through the SEM of health, specifically to observe factors affecting the lived experience that are not necessarily deterministic but rather influential in terms of how accessible infertility services are across the spectrum of people who want to use the technology – such as where people live (place). The following section reviews infertility service accessibility through the SEM. Place is not inherent at every level, but it is beneficial to observe possible influences at every level of the SEM to derive meaning for place.

Intrapersonal: Physiology and cognition. At the intrapersonal, or individual, level, there are beliefs and assumptions for what is considered “normal” in terms of human reproduction. Human society established the acts of fathering children and giving birth as normative acts that define masculinity and femininity, respectively (Paechter, 2006). These beliefs are observed, learned starting at childhood and reinforced/reformed throughout the life of the individual based on influences in their social environment– often referred to as primary socialization (Berger & Luckmann, 1967). However, biology can inhibit the act of childbirth due to issues with infertility, thus the need for infertility services. Biological factors such as age and diagnosed infertility inhibit sexual reproduction, leading to a necessity to use infertility services in order to have one’s own biological offspring (Albertini et al., 2017).

According to Judith Butler’s explanation of performative acts of gender, we can postulate that the act of “motherhood” is a repeated performance over time that solidified the idea that an individual who is biologically female gives birth, “an identity instituted through a *stylized repetition of acts*” (Butler, 1997, pg 519). As supporters of women’s rights continue to demand equality for women in the workplace, society’s acceptance of women as career-driven individuals and the tenacity of women to pursue careers outside of the home became a sociocultural movement, especially in Western society (Fortin, 2015). However, women who choose to act against the normative act of childbearing before career development are perceived as what Foucauldian theorists could call *deviant* – because they act in opposition to *normative* acts (Foucault, 1984a). This reveals a structurally founded biopedagogy leading to a socially constructed barrier to accessing infertility services.

Much of the current research on infertility service use focuses on psychological factors that could inhibit the ability to conceive, such as stress and depression (Cousineau et al., 2007; Purewal et al., 2017; Slade et al., 2007). Although it is important to address the psychological impact of needing to use infertility services in order to procreate, as well as the impact of failed attempts using infertility services, a focus on psychological outcomes is often reduced to the need for individualistic therapies to overcome psychological trauma (Lemoine & Ravitsky, 2015). Regardless of the physiological inhibition those psychological factors have, they can reduce the perceived ability (reduced self-efficacy) in achieving parenthood through the use of infertility services (Altiparmak & Aksoy Derya, 2018). One important cognitive aspect of perceived ability to access infertility services that is missing from the literature is qualitative accounts of how accessibility is perceived by people living in states with or without mandated insurance for infertility services. It is assumed that state mandated insurance coverage increases accessibility of

infertility services, but it is not clear if they truly do increase access – and if they do, to what extent they increase accessibility. Furthermore, are the presence of these mandates acknowledged by those who need to use those services?

Interpersonal: Socialization through family, friends, time in life pressures. At the interpersonal level, the individual experiences reinforcement or reframing of their beliefs based on influences from their social reality (Glanz et al., 2015). These include a person’s social networks – such as friends, co-workers, and extended family (Simons-Morton et al., 2012b). Missing out on social gatherings associated with parenthood and motherhood creates a type of social isolation. Interpersonal influences affect the individual identities of people who choose a method of conception outside of how it has been done before, and the resulting isolation felt in going that route (Cardenuto et al., 2020; Hochberg & Konner, 2020).

There are several influential forces on the individual and couple who begin the processes of using infertility services – forces that are both consciously and unconsciously accepted and rejected. A desire to reproduce is not a categorized phenomenon; it is a unique psychological process born out of a personal history no theorist can comprehend unless they have observed it from its very beginning. Just as renowned feminist scholar Judith Lorber (1993) emphasizes that bodily functions such as lactation and menstruation are not rigid characteristics of *female* or *woman*, reproductive desire should not be reduced to primal instinct or social responsibility. The decisions made in the process of acting on those reproductive desires are intra-actively engaged in the mind of the patient, and then further reinforced through interacting with others in society and acting on those desires that are constructed to be normal (Langher et al., 2019).

Organizational: Employers, medical and legal organizations. Socio-ecological influences at the organizational level include medical and legal organizations, and employers. The

role of employers in making infertility services available has not been emphasized in the literature as much as the focus of infertility insurance mandates on clinic activity. While it is important to observe the effect these mandates have on clinic activity – essentially observing the effect of the mandates on birth outcomes by state – the role of the employer in making these services part of the company’s health insurance plan should not be understated. Should the employer not offer infertility services under their health insurance policy, the infertility mandate will not be available to the patient even if they live in a state that has an infertility insurance mandate. The applicability of infertility insurance mandates are also influenced by the number of employees. For example, the Federal Employee Retirement Income Security Act (ERISA) established that self-insuring businesses (which offer private insurance) do not have to follow state insurance mandates (RESOLVE: The National Infertility Association, 2019). In Illinois, employers that have fewer than 25 employees do not have to offer the infertility mandate, and employers in Maryland and New Jersey that have fewer than 50 employees do not have to apply the infertility mandate in their states. Another exception for Texas, Maryland, New Jersey, California, Connecticut, and Delaware is that, regardless of the number of employees, religious employers do not have to apply the infertility insurance mandate (RESOLVE: The National Infertility Association, 2020b).

Different religious and political affiliations and their associated ideological preconceptions of human reproduction also have an impact on the preconceptions and opinions of individuals, communities, employers, and governments enforcing laws regarding infertility services (Inhorn, 2006; Jones, 2014). In addition, gender, race/ethnicity, and age also play large roles in facilitating access to infertility services (Sigillo et al., 2012). Provision of infertility health services are often based on the ideological majority of the country in question, and accessibility to those reproductive health services reflect those dominant ideologies (Žuk & Žuk, 2017). These social, religious, and

political views all represent biopedagogies of human fertility, and emerging biopedagogies of human *infertility* (Sigillo et al., 2012).

Community: Reinforcement of interpersonal social norms, online communities. At the community level, there are pressures to reach adulthood milestones at a certain time in life (Faircloth & Gürtin, 2017), coupled with increasing trends in postponing parenthood (Simoni et al., 2017). Much of the research on psychological and psychosocial stressors for people dealing with an infertility problem highlight the role of social pressures of meeting adulthood milestones. These are identified as being facilitators of anxiety and depression while living in a pronatalist society – being one that supports and emphasizes the importance of human reproduction through policy and practice (Benyamini et al., 2017). Ironically, the cultural shift in postponing family development started in the 1970s with the creation of birth control, giving women more autonomy on when to decide to get pregnant. Now, however, the act of waiting to become pregnant creates problems of infertility, thereby requiring new methods that preserve fertility options rather than inhibit them (Bozzaro, 2018).

Some companies, such as Facebook and Microsoft, created programs for women to freeze their eggs (cryopreservation) to facilitate more of an option for postponed family development – the ability to circumvent the time restraints due to juggling higher education, work mobility, and child rearing – without having to sacrifice genetic parenthood (Bozzaro, 2018). However, those programs received scrutiny for still emphasizing a pronatalist mindset – reinforcing what ethicist Bozzaro (2018) refers to as the “perpetual postponement of important life decisions” (pg. 600), especially when considering the social and cultural factors that lead to a woman to freeze her eggs – the lesser of which is the ability to overcome time-constraints. Although the gamete and embryo freezing options provide a window of opportunity for future family development, the social

pressures to start a family remain and negatively affect those who cannot access cryopreservation, which is an increasing trend for infertility services due to advances in vitrification – the cryopreservation of biological material into a glass-like state (Mandawala et al., 2016). These programs suggest that employers have a role in increasing financial accessibility to infertility services.

The development of the Internet opened the possibility for people to educate themselves by looking for the information on ARTs and infertility services online (Culver et al., 1997; Diaz et al., 2002; Fox & Duggan, 2013; Grunberg et al., 2018; Hesse et al., 2005; Omurtag et al., 2012; Omurtag & Turek, 2013). There are many qualitative accounts with people diagnosed with infertility or using infertility services who use online communities as sources for emotional and informational support (Feasey, 2019). Research by Beeder & Samplaski (2019) observed male infertility online discussion boards to explore the types of themes present in the posts and discussion threads. They found the most common posts to be related to diagnosis and testing, information forms of support, but also found instances of expressing emotions such as fear, anger and frustration, and encouragement for others (Beeder & Samplaski, 2019).

According to research by Omurtag & Turek (2013), internet searches for gaining information on reproductive health are increasing, and most people rely on internet sources alone for such information. They identify a shift in doctor-patient information sharing, where social media is used in higher frequency by SART member fertility clinics, creating a more complex cyber-relationship between patients and providers of infertility services. Facebook and Twitter are just two examples the authors used in the model, but the social media outlets also include forums, blogs, and online news sources (Omurtag & Turek, 2013; Street et al., 2011). The existence of these blogs and support resources shows a general desire for people wanting to know more about

the possibility of infertility services, but also brings to light the problem that information being accessed on those social sites may be providing medical misinformation, or information specific to one individual's experience that might not be transferable to others.

These online spaces allow people to vent emotions and discuss challenges and successes with people who are going through a similar process. Sometimes, there are expressions from people using those online spaces about not feeling they can discuss these issues with friends or family for fear of rejection or judgement for seeking medical intervention (Billett & Sawyer, 2019).

Policy: Lack of legislation. The most prominent aspect of policy development regarding access to infertility services is the development of statutes that specify the extent of infertility services to be covered by insurance companies, ranging from no coverage to diagnostic tests for fertility to a cap on numbers of IVF cycles. The Affordable Care Act (ACA) did not have much of an effect on existing legislation due to the freedom states have in defining what types of infertility services can be covered. However, the ACA does assume that if infertility treatments are not mandated by a state, it is most likely covered under the “ambulatory patient services and maternity and new-born care” essential health benefits (EHBs) as identified by the Institute of Medicine report (Stapleton & Skinner, 2015, pg 652).

Research by Dieke et al., (2017) using the 2014 National ART Surveillance System (NASS) data found that regardless of race/ethnicity, infertility service utilization was greater in states with infertility insurance mandates. Although their research showed some higher use in states with infertility service mandates, their research used a database that consisted of people who had access to a fertility clinic and their services. Showing some geographic distribution of people already accessing services is marginally useful in terms of epidemiological assessment, but it is

also important to address the underlying regulators that influence the degree of access these statutes actually offer.

Although there are 19 states that include statutes with infertility services, none of those statutes require comprehensive coverage, and not all definitions of *infertility services* are the same (National Conference of State Legislatures, 2019b). As can be seen from the adapted table from the National Conference of State Legislatures (Table 2.1), the provisions, limitations, and exclusions for the types of services, and the type of person accessing those services, differs from state to state. States that currently have a statute referring to some form of coverage for infertility services are Arkansas, California, Colorado, Connecticut, Delaware, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Hampshire, New Jersey, New York, Ohio, Rhode Island, Texas, Utah, and West Virginia (RESOLVE, 2020).

The National Conference of State Legislatures (NCSL), a political advocacy organization that assists state legislatures with improving quality and effectiveness of state legislatures, promote policy innovation, and help maintain that state legislatures have a voice at the federal level. They published a report on state level measures to decrease health disparities. In that report they acknowledged the trickle-down effect that policy has on individual access to health services. They posit that medical care is essential to one's health, but that factors outside of the health care system are also linked to health and health disparities. The report acknowledged the reciprocal causation between social, economic and environmental circumstances that affect individual health behavior (National Conference of State Legislatures, 2019b).

Under their key recommendation "Assess barriers in access to care", the NCSL calls for increased research in examining the drivers of disparities in access to health care services, such as the ability to navigate the health care system and the presence or absence of insurance, gaining an

in depth look at what social determinants inhibit or facilitate access to health services (National Conference of State Legislatures, 2019a, pg 8). Research by Klitzman (2017) observed the impact of insurance mandates and economics for patients deciding on types of procedures for treating infertility. He found that decisions made by patients, and jointly by patients and physicians, were affected by insurance and economics to the extent that patients delayed the procedures, chose less costly procedures with reduced efficacy, moved to a different area that had better insurance coverage, actively sought cheaper and free methods, and used medications from others. The effects of finances and insurance are cited in the literature to lead to disparities in access, where people living below a certain socio-economic status (SES) or in a state where infertility insurance is non-existent or limited for infertility services experience greater disparity in access than people with higher annual income, private insurance, and in a state where insurance is mandated (Jain & Hornstein, 2005; Stapleton & Skinner, 2015).

Reviewing the levels of influence from the SEM on disparity in access to infertility services, reveals discourse about place or “environment” – where people live, work, and socialize – and its effect on perceived and actual access to infertility services. However, through observation and reflection on research regarding access to infertility services, the influence of place has not been critically observed. It is usually tangentially referred to as *an influence* but there have been no contributions in the literature which has critically analyzed its effect regarding access to infertility services in the United States.

To identify new knowledge based on empirical evidence, theory and methods of research need to be selected based on the imperative of the research, which should address the current gaps on the topic in question. The use of theory facilitates reflection on public health practice, which can maintain the existence of professional ethics and social justice within public health research

and practice (Goodson, 2010). It also reduces the chance of ideological hegemony that can control how health and illness are observed and thus acted upon, risking marginalization of groups of people and stagnation of research innovation (Goodson, 2010). This is a present concern for research on infertility services.

Social Cognitive Theory: Person, Place, and Seeking Infertility Services

SCT, originally termed Social Learning Theory, was developed in the 1960s by psychologist Albert Bandura (LaMorte, 2016). At the core of SCT is the idea of triadic reciprocal interaction (determinism), where personal factors, health behavior, and environment are effects and are affected by each other (Korin, 2016). Bandura (2001) highlights the agential nature of the individual in SCT, emphasizing that individuals do not simply exist in their environment, rather they engage with, change, and are changed by their environment in a model of “emergent interactive agency” (pg. 4).

SCT does not dismiss thought processes as ephemeral occurrences with no basis in the physical world, because, in Banduras’ explanation, thoughts can determine actions we choose to take, or not to take (Bandura, 2001). Bandura explains the interaction between the individual and his/her learned experiences, the social environment, and behavioral responses of the individual as triadic reciprocal causation (Bandura, 2001). A key concept in SCT is that individuals learn from both their own experiences, but also from observations from their social environment (Office of Behavioral and Social Sciences Research, 2018). The idea of reciprocal determinism characterizes the individual as an initiator of change and a responder to change (Korin, 2016; Office of Behavioral and Social Sciences Research, 2018). Principles of SCT include attention to social context, retention of external stimuli, reproduction of the improved behavior, and motivation to

pursue the change (Bandura, 1977). Here we can observe how important self-efficacy is to the agency of the individual in SCT by observing the interplay between environmental influence (the social environment) and psychological theories that interpret behavior: “social cognitive theory rejects a dualism between personal agency and a disembodied social structure”, in other words, we need to observe the social *and* psychological aspects of behavior (Bandura, 2001, pg 24).

SCT considers the very prominent psychological aspects of human infertility and the use of infertility services. It positions those cognitive processes in the context for which behaviors developed – stemming from observation of, retention of, reproduction of, and motivation to act on influences from the social environment. The construct of self-efficacy is key to this research because of the amount of the obstacles that inevitably ensue when attempting to access infertility services. In fact, the reason for using infertility services can be because an obstacle was encountered (issue with fertility). Therefore, inclusion of the triadic reciprocal causation between the thoughts of the individual, their social influences, and the motivation to act on behaviors based on the bidirectional exchange between those factors might be effective in explaining why some people desire genetic parenthood to the extent that they sacrifice marriage, lifestyle, income, and time to obtain it. This research will utilize the Infertility Self-Efficacy Scale (Cousineau et al., 2006) to measure self-efficacy among people seeking and accessing infertility services.

Social Constructionism and Infertility Service Use

The origin of social constructionism comes from sociology and communication disciplines and is considered a post-modern theory in qualitative research (Andrews, 2012). Two prominent theorists who used social constructionism were Rom Harre and Michael Billig, who both wrote seminal works that challenged individualistic psychology, which reduces identity to personal

thought process without much attention to social environmental influence (Galbin, 2014). Also having roots in the philosophy of knowledge, social constructionism is associated with rethinking the practice of grounded theory by assuming that knowledge is constructed rather than created (Andrews, 2012). Social constructionism has to do with “the shared social aspects of all that is psychological”, emphasizing the agency of the individual in constructing their reality, but the near impossibility of authentic behavior (authentic meaning uninfluenced by the social environment) (Galbin, 2014, pg 82). The attention to individual interpretations of reality are embedded in social construction, as Berger & Luckmann (1967) would define as the social construction of reality.

In a review of psychosocial effects of human infertility by Greil et al. (2010), they call for a move away from viewing the psychological effects of infertility in a medicalized view. They suggest moving from a focus on the prevalence of depression in those who suffer from infertility to one that focuses on a lived experience approach, and views infertility as a socially constructed reality. Attention to the construction of knowledge and individual reality can be very informative in research for infertility services because social constructionism is sensitive to changes that initiate new “practices and behaviors” (Galbin, 2014, pg 91). The emergence of new knowledge relating to the legitimacy of reasons for using infertility services led to the reconstruction of some of the existing infertility insurance mandates. This led to more inclusive language for non-traditional family development (Centanni, 2019) – a reaction to emerging practices and behaviors.

Although infertility services have been used in practice for over 70 years, the influence of reproductive technological advancements on society have been drastic, from changing the way we view the nuclear family, to the degree of humanity the state gives to a maybe-baby cluster of cells. The *ability* to circumvent a physiologically-based barrier to procreation creates the tenacity to act in opposition to socially founded biopedagogies, leading to a Foucauldian idea of deviance, where

the individual is perceived negatively by the majority in society as a result of engaging in new practices and behaviors (Gillespie, 2000). Becker & Nachtigall (1994) conducted a qualitative study with 275 persons undergoing infertility treatment to assess how risk is constructed while seeking medical assistance for infertility. Although they do not specifically utilize social constructionism, they do find that culture affects the way people construct disease. Since infertility is a medicalized disease (although at that time it was not considered a disease, explicitly) it can be circumvented. The ability to be treated for infertility is a possibility that overpowers financial and at times physiological risk to the patient, due to the importance that human society places on parenthood and motherhood and the reinforcement of those biopedagogies by one's social networks (Becker & Nachtigall, 1994).

Existing research that discusses the use of infertility services through a social constructionist perspective highlights the effect that social environments have on the construction of, and reinforcement of: infertility as a disease (Becker & Nachtigall, 1994; A. Greil et al., 2011), infertility as a “problem” (Miall, 1996, pg 310), childlessness (Petersen et al., 2015), being infertile (Scritchfield, 1995), motherhood (Mukherjee, 2016), and target populations for infertility policy reform (Montpetit et al., 2005).

The qualitative and quantitative approaches so far used to observe the efficacy of the state-based infertility insurance mandates led to more questions than answers. Qualitative approaches address the psychological trauma associated with living in a pronatalist society that established heterosexual parenthood as an adulthood milestone, continuously reinforced by popular media. Although these observations are important for understanding the lived experience of using infertility services in the United States, they do not offer solutions as to reduce the psychological strain placed on people accessing these services. They also do not address any aspects of the

state-based infertility insurance mandates. Quantitative studies accounted for the use of certain types of infertility services, comparing outcomes in states with and without an infertility insurance mandate, but their designs do not allow us to observe the utility of the mandates themselves and assume that if someone lives in a mandated state they will have coverage.

Social constructionism has not been widely used in the analysis of infertility services, but aspects of cultural and social influence have been referenced as contributing contextual factors that have some degree of influence (Becker & Nachtigall, 1994; Greil et al., 2010). SCT is useful in observing the role of self-efficacy in seeking infertility services and there is a validated psychometric tool used to measure self-efficacy in relation to seeking infertility services (Cousineau et al., 2006). However, SCT used in infertility services has not been applied to the use of infertility services in relation to aspects of place.

This research functions within the social-ecological perspective of human health, which maintains two central concepts: multiple levels of influence affect human behavior; and reciprocal causation, which is the idea that an individual's behavior is shaped by their social environment, which is also shaped by individual behavior (National Cancer Institute, 2005). Due to the objective of a dissertation being the provision of new evidence and new knowledge, this research addresses some of the *missing* contextual forces affecting the applicability of infertility service insurance mandates in the United States.

Chapter Two Tables

Table 2.1 State-based insurance mandates for infertility services in the United States

State	Summary of Statutes
Arkansas	<p>Ark. Stat. Ann. § 23-79-510, specifies that the Arkansas Comprehensive Health Insurance Pool shall not include coverage for any expense or charge for in vitro fertilization, artificial insemination or any other artificial means used to cause pregnancy.</p> <p>Ark. Stat. Ann. § 23-85-137 and § 23-86-118 (1987, 2011) require accident and health insurance companies to cover in vitro fertilization. Services and procedures must be performed at a facility licensed or certified by the Department of Health and conform to the guidelines and minimum standards of the American College of Obstetricians and Gynecologists and the American Society for Reproductive Medicine. (2011 SB 213)</p>
California	<p>Cal. Health & Safety Code § 1374.55 and Cal. Insurance Code § 10119.6 (1990, 2011) require specified group health care service plan contracts and health insurance policies to offer coverage for the treatment of infertility, except in vitro fertilization. The law requires every plan to communicate the availability of coverage to group contract holders. The law defines infertility, treatment for infertility and in vitro fertilization. The law clarifies that religious employers are not required to offer coverage for forms of treatment that are inconsistent with the organization's religious and ethical principles. The law was amended by 2013 Cal. Stats., Chap. 644 (AB 460) to specify that treatment of infertility shall be offered and, if purchased, provided without discrimination on the basis of age, ancestry, color, disability, domestic partner status, gender, gender expression, gender identity, genetic information, marital status, national origin, race, religion, sex, or sexual orientation.</p>
Colorado	No information from NCSL (most recent mandate)
Connecticut	<p>Conn. Gen. Stat. § 38a-509 and § 38a-536 (1989, 2005) require that health insurance organizations provide coverage for medically necessary expenses in the diagnosis and treatment of infertility, including in vitro fertilization procedures. Infertility, in this case, refers to an otherwise healthy individual who is unable to conceive or produce conception or to sustain a successful pregnancy during a one-year period. Amended in 2005 to provide an exemption for coverage that is contrary to the religious beliefs of an employer or individual.</p>
Delaware	<p>18 Del. C. §3556 (2018) requires all group and blanket health insurance policies, contracts, or certificates that are delivered, issued for delivery, renewed, extended, or modified in the state of Delaware by any health insurer, health service corporation, or health maintenance organization and that provide for medical or hospital expenses shall include coverage for fertility care services, including in vitro fertilization services for individuals who suffer from a disease or condition that results in the</p>

Table 2.1 (continued)

	inability to procreate or to carry a pregnancy to live birth and standard fertility preservation services for individuals who must undergo medically necessary treatment that may cause iatrogenic infertility.
Hawaii	Hawaii Rev. Stat. § 431:10A-116.5 and § 432.1-604 (1989, 2003) require all accident and health insurance policies that provide pregnancy-related benefits to also include a one-time only benefit for outpatient expenses arising from in vitro fertilization procedures. In order to qualify for in vitro fertilization procedures, the couple must have a history of infertility for at least five years or prove that the infertility is a result of a specified medical condition.
Illinois	Ill. Rev. Stat. ch. 215, § 5/356m (1991, 1996) requires certain insurance policies that provide pregnancy-related benefits to provide coverage for the diagnosis and treatment of infertility. Coverage includes in vitro fertilization, uterine embryo lavage, embryo transfer, artificial insemination, gamete sperm artificial intrafallopian tube transfer, zygote intrafallopian tube transfer and low tubal ovum transfer. Coverage is limited to four completed oocyte retrievals, except if a live birth follows a completed oocyte retrieval, then two more completed oocyte retrievals are covered. (1996 Ill. Laws, P.A. 89-669)
Louisiana	La. Rev. Stat. Ann. § 22:1036 (2001, 2008, 2009) prohibits the exclusion of coverage for the diagnosis and treatment of a medical condition otherwise covered by the policy, contract, or plan, solely because the condition results in infertility. The law does not require insurers to cover fertility drugs, in vitro fertilization or other assisted reproductive techniques, reversal of a tubal ligation, a vasectomy, or any other method of sterilization. (2001 La. Acts, P.A. 1045)
Maryland	Md. Insurance Code Ann. § 15-810 (2000) amends the original 1985 law and prohibits certain health insurers that provide pregnancy-related benefits from excluding benefits for all outpatient expenses arising from in vitro fertilization procedures performed. The law clarifies the conditions under which services must be provided, including a history of infertility of at least a 2-year period and infertility associated with one of several listed medical conditions. An insurer may limit coverage to three in vitro fertilization attempts per live birth, not to exceed a maximum lifetime benefit of \$100,000. The law clarifies that an insurer or employer may exclude the coverage if it conflicts with the religious beliefs and practices of a religious organization, on request of the religious organization. Regulations that became effective in 1994 exempt businesses with 50 or fewer employees from having to provide the IVF coverage. (2000 Md. Laws, Chap. 283; H.B. 350) Md. Health General Code Ann. § 19-701 (2000) includes family planning or infertility services in the definition of health care services.
Massachusetts	Mass. Gen. Laws Ann. ch. 175, § 47H, ch. 176A, § 8K, ch. 176B, § 4J, ch. 176G, § 4 and 211 Code of Massachusetts Regulations 37.00 (1987, 2010) require general insurance policies, non-profit hospital service

Table 2.1 (continued)

	<p>corporations, medical service corporations and health maintenance organizations that provide pregnancy-related benefits to also provide coverage for the diagnosis and treatment of infertility, including in vitro fertilization. This law was amended in 2010 to change the definition of "infertility" to be a condition of an individual who is unable to conceive or produce conception during a period of one year if the female is under the age of 35, or during a period of six months if the female is over the age of 35. If a person conceives but cannot carry that pregnancy to live birth, the period of time she attempted to conceive prior to achieving that pregnancy shall be included in the calculation of the one year or six month period. (SB 2585)</p>
Montana	<p>Mont. Code Ann. § 33-22-1521 (1987) revises certain requirements of Montana's Comprehensive Health Association, the state's high-risk pool, and clarifies that covered expenses do not include charges for artificial insemination or treatment for infertility. (SB 310)</p> <p>Mont. Code Ann. § 33-31-102 et seq. (1987) requires health maintenance organizations to provide basic health services on a prepaid basis, which include infertility services. Other insurers are exempt from having to provide the coverage.</p>
New Hampshire	<p>New Hampshire Revised Statutes Annotated (RSA), Title XXXVII, Chapter 417-G Access to Fertility Care. requires all insurance companies subject to state law, which sell group policies, plans, or contracts providing benefits for medical or hospital expenses, to provide coverage for the diagnosis and medically necessary treatment of the disease of infertility. Coverage is required as well for standard fertility preservation services for patients undergoing treatments that may impair their ability to reproduce</p>
New Jersey	<p>N.J. Stat. Ann. § 17:48-6x, § 17:48A-7w, § 17:48E-35.22 and § 17B:27-46.1x (2001, 2013) require health insurers to provide coverage for medically necessary expenses incurred in diagnosis and treatment of infertility, including medications, surgery, in vitro fertilization, embryo transfer, artificial insemination, gamete intrafallopian transfer, zygote intrafallopian transfer, intracytoplasmic sperm injection and four completed egg retrievals per lifetime of the covered person. The law includes some restrictions as well as a religious exemption for employers that provide health coverage to fewer than 50 employees. (SB 1076)</p>
New York	<p>N.Y. Insurance Law § 3216 (13), § 3221 (6) and § 4303 (1990, 2002, 2011) prohibit individual and group health insurance policies from excluding coverage for hospital care, surgical care and medical care for diagnosis and treatment of correctable medical conditions otherwise covered by the policy solely because the medical condition results in infertility. The laws were amended in 2002 to require certain insurers to cover infertility treatment for women between the ages of 21 and 44 years. The laws exclude coverage for in vitro fertilization, gamete intrafallopian tube transfers and zygote intrafallopian tube transfers. The laws were amended again in 2011 by N.Y. laws, Chap. 598 to require every policy</p>

Table 2.1 (continued)

	<p>that provides coverage for prescription fertility drugs and requires or permits prescription drugs to be purchased through a network participating mail order or other non-retail pharmacy to provide the same coverage for prescription fertility drugs that are purchased from a network participating non-mail order retail pharmacy provided that the network participating non-mail order retail pharmacy agrees in advance to the same reimbursement amount and the same terms and conditions that the insurer has established for a network participating mail order or other non-retail pharmacy. The policy is prohibited from imposing additional fees, co-payments, co-insurance, deductibles or other conditions on any insured person who elects to purchase prescription fertility drugs through a non-mail order retail pharmacy. (2011 AB 8900)</p> <p>N.Y. Public Health Law § 2807-y (2002) creates a grant program to improve access to infertility services, treatments and procedures from the tobacco control and insurance initiatives pool.</p>
Ohio	<p>Ohio Rev. Code Ann. § 1751.01 (A)(1)(h) (1991) requires health maintenance organizations (HMOs) to provide basic health care services, which are defined to include infertility services, when medically necessary.</p>
Rhode Island	<p>R.I. Gen. Laws § 27-18-30, § 27-19-23, § 27-20-20 and § 27-41-33 (1989, 2007) require any contract, plan or policy of health insurance (individual and group), nonprofit hospital service, nonprofit medical service and health maintenance organization to provide coverage for medically necessary expenses for the diagnosis and treatment of infertility. The law clarifies that the co-payments for infertility services not exceed 20 percent. Infertility is defined as the condition of an otherwise healthy married individual who is unable to conceive or produce conception during a period of one year. Rhode Island includes IVF coverage. Amended in 2007 to increase the age of coverage for infertility from forty (40) to forty-two (42) and redefines infertility to mean a woman who is unable to sustain pregnancy during a period of one year. (2007 R.I. Pub. Laws, Chap. 411, SB 453)</p>
Texas	<p>Tex. Insurance Code Ann. § 1366.001 et seq. (1987, 2003) requires that all health insurers offer and make available coverage for services and benefits for expenses incurred or prepaid for outpatient expenses that may arise from in vitro fertilization procedures. In order to qualify for in vitro fertilization services, the couple must have a history of infertility for at least five years or have specified medical conditions resulting in infertility. The law includes exemptions for religious employers.</p>
Utah	<p>2014 Utah Laws, Chap. 353 (HB 347) amended § 31A-22-610.1, which requires insurers that provide coverage for maternity benefits to also provide an adoption indemnity benefit of \$4,000 for a child placed for adoption with the insured within 90 days of the child's birth. The law was amended to allow an enrollee to obtain infertility treatments rather than seek reimbursement for an adoption. If the policy offers optional maternity benefits, then it must also offer coverage for these indemnity benefits under certain circumstances.</p>

Table 2.1 (continued)

West Virginia [W. Va. Code § 33-25A-2 \(1995\)](#) amends the 1997 law and requires health insurers to cover basic health care services, which include infertility services. Applies to health maintenance organizations (HMOs) only.

*Table adapted from National Conference of State Legislatures. (2019). State Laws for Insurance Coverage for Infertility Treatment. Retrieved September 2020, from <http://www.ncsl.org/research/health/insurance-coverage-for-infertility-laws.aspx>

Chapter Two Figures

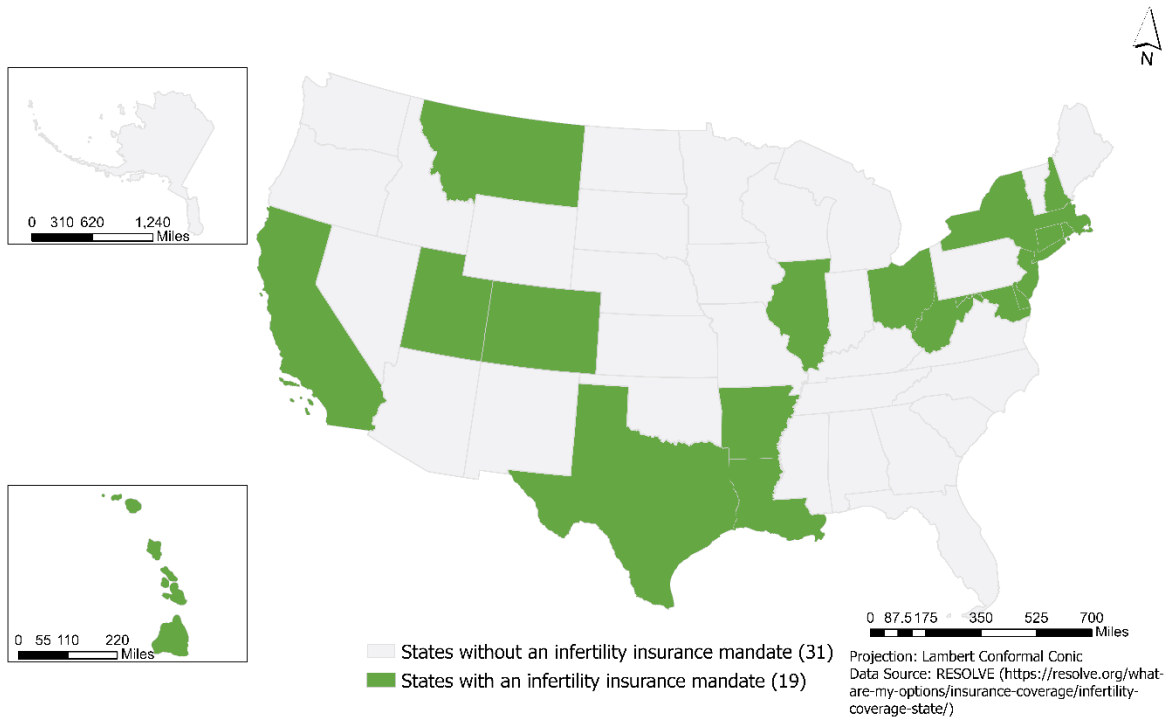


Figure 2.1. States with and without an infertility insurance mandate

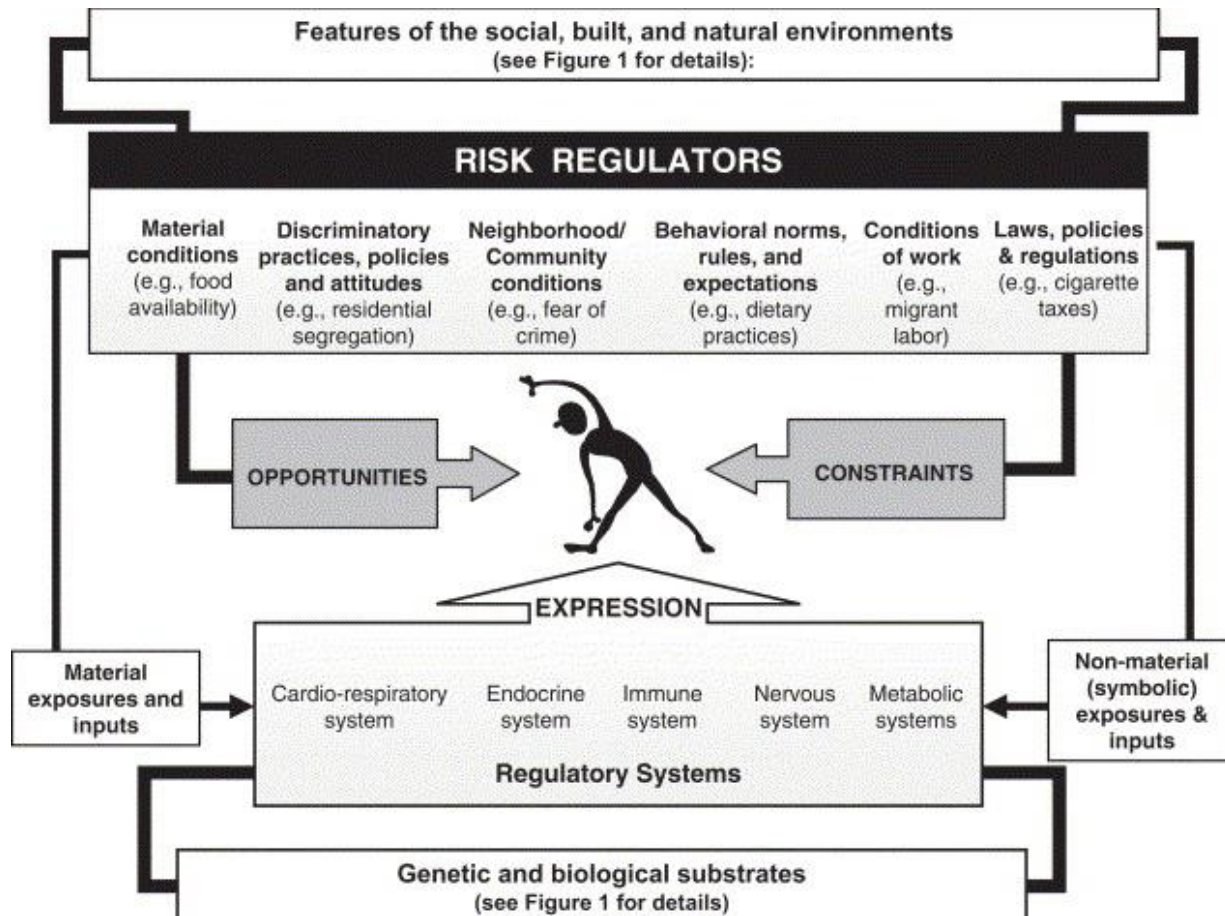


Figure 2.2. Glass and McAtee model of risk regulators

CHAPTER THREE:

RESEARCH DESIGN AND METHODOLOGY

Mixed Method Research Design

The current literature is missing a mixed method design specific to observing the effect of state mandated insurance on accessibility to infertility services. The literature review described some quantitative projects that attempt to observe the effect of insurance on increasing accessibility to infertility services. However current quantitative research ignores one of the main assumptions of place-based research: place-based context relating to where people live and where they access infertility services affect people in different ways.

This research utilizes a mixed-method, pragmatist research design, using both quantitative and qualitative data to understand this phenomenon more fully. Pragmatism is a philosophical idea that suggests that “something is true only if it works”, meaning truth of a theory’s utility comes from the theory confirming its constructs through its application (Goodson, 2010, pg. 172). The pragmatist approach via mixed-method research design was a result of moving away from methodological dichotomization of qualitative and quantitative methods, suggesting that research is not a method of superiority reification, but rather research should observe qualitative and quantitative paradigms as inclusive, contributing to a “continuum of scientific research” (Onwuegbuzie & Leech, 2005, pg. 173).

This research uses qualitative and quantitative data in a multiphase design described by Creswell & Plano-Clark (2011) which involves iterative analysis of the qualitative and quantitative

data, and making analysis decisions based on how best to combine the results to answer the research question. The design of this mixed method research was carefully planned as to collect qualitative and quantitative data that would add context to the use of infertility insurance mandates in the United States.

Limitations of mixed methods research can largely be due to using strategies that are not complimentary to each other, causing issues of validity and generalizability. A still present debate against mixed methods research is the applicability of multiple paradigms (Creswell & Plano-Clark, 2011). The design of this research attempts to avoid these limitations by choosing theories and operational paradigms that complement each other based on their constructs.

Research Questions

There are a total of seven research questions included in this research, and each question refers to aspects of geographic place and human reproduction. Due to the need for these types of data to complement each other, some questions will be able to be answered with both qualitative and quantitative sources. The alignment matrix in Appendix A lists the research questions, data collection instrument, and item on that instrument use to answer the research question. The following are the rationale for each research question.

R1: Why do people access infertility services in the United States?

This question is important to add context of why people use infertility services. Some people have issues with fertility, some people wish to circumvent recessive genetic traits, some went through cancer treatment and require assisted reproduction, and some others are in same-sex relationships. The identification of similar or different experiences can add context to facilitative and prohibitive factors that are common or unique to certain groups. Data used to answer this

question are both qualitative and quantitative. Qualitative data came from the informal interviews with people in one of the three stages of infertility services: looking for information (Prospective), currently using services (Active), and used in the past (Past). Data also was reported from the survey instrument, specifically the demographic questions and the infertility self-efficacy scale (ISE). The ISE can give context into the self-efficacy of continuing to access or try to access infertility services, and how those experiences might be different based on reasons for using these services.

R2: What influence does geographic location have on access to infertility services?

Missing from the current literature are qualitative accounts of how residence or travel affect the ability to access infertility services. There are also missing quantitative observations of how frequently people move residences or travel domestically or internationally to access infertility services. Both qualitative and quantitative data was used to answer this research question. Qualitative data came from the informal interviews, where participants were asked about where they accessed services, and if they have ever traveled out of state or country to access services. Qualitative data came from the survey, specifically questions in the Residence, Insurance Coverage, Travel, and ISE scale sections. The ISE scale may give some insight into levels of self-efficacy for accessing infertility services being different for people in different geographic locations, and with different travel requirements. A

R3: What influence does living in a state with mandated insurance have on access to infertility services?

Attempts to answer this question in the current literature are based on quantitative methods (Boulet et al., 2019; Schmidt, 2007). The issue this poses is that there are no qualitative contexts regarding the extent of insurance coverage people had on the services they accessed. The research

question posed here adds missing context surrounding the actual utility of the infertility insurance mandates by inquiring into the experiences of people living in states with and without those mandates. This question was answered using both qualitative and quantitative data. Qualitative methods using informal interviews asked questions about insurance coverage, payment for services, influence of the existing mandates for their situation, and dealings with employers in gaining coverage. Quantitative data came from the survey, specifically in the Insurance block, which inquired about the person's insurance coverage, use of mandates, and extend of use of mandates (covered nothing, covered some, covered everything).

R4: What are the roles of specialized infertility specific insurance or other financial aid organizations in increasing access to infertility services in the United State?

Missing in the discourse surrounding insurance for infertility services are the organizations that are essentially filling in accessibility gaps by providing grants, loans, payment programs, reduced rate programs, or specialized infertility insurance directly to employers to offer to their employees. These organizations can add important missing context into the use of infertility services by observing how these organizations functioned as facilitators in the access to infertility services in the United States. Data to answer this question came from the expert interviews. However, data from this question may also be used to add context to the answers provided in the informal interviews, due to some of the informal interview participants using services from some of the participating "expert" organizations.

R5: What is the spatial relationship between fertility of women between the years of 2013-2017 based on age, education, ethnicity, nativity, and income?

There are two primary reasons why this research does not observe the spatial distribution of diagnosed infertility or use of infertility-specific medical procedures such as in vitro fertilization (IVF): 1) The absence of geospatial fertility research, and 2) Cost and access restriction on datasets.

Of primary importance here is the lack of geospatial fertility research by which to compare spatial analyses of *infertility*. Johnson et al (2018) discussed the different trajectories of fertility and infertility research, observing that fertility research historically focused more on demographic trends, applying theory and economics, observing trends over time, while infertility research has focused more on medicine, looking into the genetics of infertility, psychological distress management, levels of diagnosis for males and females, and some social and clinical research observing disparities in access to infertility services. They propose observation of the “dynamically interrelated” relationship between fertility and infertility through observing these data in tandem, inclusively (Johnson et al., 2018, pg 25). By observing fertility at the census tract level, future spatial analyses of infertility can be interpreted with more meaning due to having a distributional norm to measure it against to answer questions such as: Do spatial trends of infertility follow the same trends as fertility? Do spatial trends of diagnosed infertility follow similar spatial trends of fertility, and are there demographic differences? Analysis of fertility at the census tract level will provide that foundational perspective, and a method of analysis from which to build.

R6: What is the spatial relationship between fertility of women between the years of 2013-2017 in states with or without infertility insurance mandates?

The rationale for observing fertility by states with and without insurance mandates is based on two reasons: 1) projected fertility decline in the United States, which could be due to changing socio-cultural preferences for when and how to start a family; and 2) lack of research that observes fertility in states with and without an infertility insurance mandate.

Fertility Decline. Population projections from the Census Bureau indicate that between the years of 2016-2060, the United States population will grow slower and that the growth will not be due to fertility rates, but rather due to internal migration (Vespa et al., 2020). This is attributed to the increased aging population in the United States, predicting that persons age 65 and older will increase by 93.8% from 44 million in 2016 to 95 million in 2060 (Vespa et al., 2020). Research by Tannus & Dahan (2019) observe that while diagnosed infertility may not be increasing, the act of delaying childbearing has increased due to a variety of reasons, including career development prior to family development. The authors suggest a reason why state-based infertility insurance mandates should be common practice, being the fact that delaying childbirth leads to increased chances of natural infertility due to increased age (Tannus & Dahan, 2019). A continuous observation of spatial fertility trends by state could inform policy makers of a need for increased access to these services to stabilize a falling fertility rate due to social factors- rather than purely physiological factors.

Research gap. There is some research that statistically shows uses of infertility services in mandated vs non-mandated states. Boulet et al. (2019) observed the difference of payment for infertility services between claims filed in states with and without an infertility insurance mandate, and Schmidt (2007) found infertility insurance mandates do increase accessibility of infertility services, but only for those women who are white, older, and highly educated. There are no analyses of fertility rates in states with and without an infertility insurance mandate. It would be informative to observe the fertility of women with those same demographics of women accessing infertility services with the most frequency, to see if the sociodemographic disparities regarding births from infertility services are also disparities that exist in the fertility of women in states with and without an infertility insurance mandate.

R7: What is the spatial relationship between fertility of women age 15-50 and the spatial distribution of SART reporting clinics between the years of 2013-2017?

The purpose of this question is not to estimate or predict the number of live births from assisted reproduction, but rather to spatially observe the density of births and total population in relation to fertility clinics. Based on the Preliminary 2018 CDC Fertility Clinic Success Rates Report, there were 73,831 live births from 456 reporting clinics (Centers for Disease Control and Prevention [CDC], 2020), compared to the CDC projection of total births in the United States of 3,791,712 (National Center for Health Statistics, 2020). This means that births from ARTs in 2018 accounted for approximately 2% of all births in the United States. This research question includes birth density, where $\frac{\text{"All women with births"}}{\text{census tract mi}^2}$, and population density, where $\frac{\text{Total Population}}{\text{census tract mi}^2}$. It was assumed that 1) clinics will be located in census tracts with high birth density and high population density; and 2) there will be a spatial disparity in the distribution of the clinics, but that could be informed by the qualitative interviews.

Part 1: Online Survey and Interviews

This research utilizes SCT to guide the development of interview and survey questions and analysis of both the qualitative interview and quantitative survey data. SCT considers the very prominent psychological aspects of human infertility and behaviors of use of infertility services and positions those cognitive processes in the context for which behaviors developed. This stems from observation of, retention of, reproduction of, and motivation to act on influences from the social environment. The construct of self-efficacy is key to this research because of the number of potential obstacles that exist when attempting to access infertility services.

Part 1a: Quantitative Survey Instrument: Context of Infertility Service Use. Part of the quantitative research component is the development of a survey instrument that can be distributed online. The survey is titled “Access to Infertility Services in the United States”. When reviewing the different surveys available that include questions related to the use of infertility services, such as SART and the NSFG, not only were the datasets very expensive and difficult to access (due to needing the geographic variables), they did not include questions that would provide insight into aspects of place assumed to be influential, such as employment status (part time, full time) and whether people travel for services, including distance and time.

Clinic-based surveys, such as from SART, are also not able to obtain responses from people who have not yet been able to access infertility services because clinic-based data come from the reporting clinics – people included are already accessing those services. The rationale for the survey instrument is that there are information gaps which can be addressed with the right questions, and there is an exclusion of people who are looking for information regarding infertility services but who may not have yet accessed them. Questions about place, not just the state in which people live, could be informative to learn when linked to answers about the state people live in, employment, knowledge of mandates, fertility education, type of insurance, travel for services, and how these aspects affect the perceived self-efficacy in accessing infertility services.

Survey development. There are three main stages of infertility service use reported in this research: looking for information (Prospective), using the infertility services (Active) ,and no longer using (Past). The rationale for seeking these three stages is due to the nature of the current literature only observing people who are currently using infertility services. The perspectives of people who are in the beginning stages of looking for options and people who have accessed infertility services already and had either successful or unsuccessful pregnancies are perspectives

that could reveal important contextual information about how insurance applicability affects people's decisions at different stages of infertility service use. The entire survey is located in Appendix B. The online survey was developed using Qualtrics (Qualtrics, 2005).

The first part of the survey includes 18 demographic questions regarding the stage of use. Table 3.1 lists the demographic variables chosen for the survey and their source from the literature. Skip logic was employed in this survey to direct people in different stages to the questions applicable to them. For example, if a person indicated they had "not yet used infertility services but are looking into it", the next question asked, "What is the reason you are seeking infertility services?". In the same way, if a person indicated they "used infertility services in the past", the next question they were asked was "What was the reason you *sought* infertility services?", to ensure the proper tense of the questions asked. The survey was broken into seven sections: demographics, health education, health insurance coverage, residence, online communities, travel for services, and the ISE scale.

Health education. This section has two questions of primary education regarding ever receiving health education related to infertility at various stages, and personal opinions for the education level when children should learn about the risk of infertility. Education on fertility decline in school is referenced in some literature as lacking (Kudesia et al., 2017), so inquiring about when people learned (or if they learned) about fertility decline could reveal an educational gap that needs to be addressed.

Health insurance coverage. This section has nine questions regarding types of insurance the person has, and if the insurance covers infertility services. Regarding types of health insurance, it is important to link this question with sociodemographic data and type of employment to understand if the types of insurance influences the accessibility of infertility services. Also

important to be determined is if that effect is different in states with or without mandated infertility insurance. This section also inquired into the person's knowledge of an infertility mandate in their state, and if one is present, if they could apply it to their situation. Knowledge of infertility service mandates in the respondent's state of residence is important because knowledge of insurance availability could increase perceived self-efficacy in accessing those services. Employment is also a component in this section. This is important to address because of how influential employers are in making these services visible and available for their employees (Nathenson, 2020; Worthington et al., 2020). It is assumed that employment will be a determining factor for infertility service access and self-efficacy.

Residence. There are three questions about the person's residence. One of the goals of this research is to determine the effect of where people live on their access to infertility services. Since the present infertility insurance mandates are state-specific, it is assumed that residence will affect the accessibility of infertility services. Questions about residence include the person's state of residence, state they accessed infertility services, and if their state of residence is the same state as the one where they used infertility services.

Online communities. It is referenced in literature that people living with infertility prefer to discuss their experience using infertility services with people online rather than in person (Craig, 2020; Gazit & Amichai-Hamburger, 2020; Sormunen et al., 2020). There are three survey questions related to the use of online communities to express experience using infertility services. The questions inquire about using online support communities for help in decision making for what types of services to use, preference for discussing infertility with people online more than in person, and use of online support prior to having discussions with physicians about infertility services.

Travel for services. There are seven questions related to travel for infertility services. Observing types of domestic or international travel are important because some literature suggests people will travel out of their state of residence or even to a different country to access more affordable infertility services (Simopoulou et al., 2019). Data to observe from the answers will be the travel tendencies from non-mandated states to mandated states, which is a behavior research on infertility health insurance has not reported.

Infertility Self-Efficacy Scale (ISE). The Infertility Self-Efficacy Scale (ISE) was developed by Cousineau et al. (2006), and since then appears in many qualitative and quantitative research designs related to infertility (Table 3.2). Most of the research is focused on psychosocial issues in dealing with infertility within a pronatalist society (Altiparmak & Aksoy Derya, 2018; Cox et al., 2006), however it will be useful to measure self-efficacy in continuing to seek infertility services. The ISE is a validated Likert scale that consists of 16 statements that refer to the experience of living with infertility that literature shows affects individual levels of self-efficacy to continue using infertility services (Cousineau et al., 2006). The responses range from 1-9, where 1 is “Not at all Confident” and 9 is “Extremely Confident”. Respondents are asked to rate their degree of confidence in embodying the statements posed to them in the survey, with the prompt: “I feel confident that I can...”.

Internal consistency of this scale reached 0.94, where the items ranged from 0.59 to 0.89, and the authors make note that “none of the items improved the scale’s Cronbach’s *a* estimate if deleted” (Cousineau et al., 2006, pg 1691). Test-retest reliability from the two analysts was correlated at 0.91 ($P=<.01$), meaning the scale measured the same construct – self-efficacy. This survey instrument does not require permission for use. This scale is used in other research, mainly psychosocial (Altiparmak & Aksoy Derya, 2018; Cousineau et al., 2006), and it is important to

use it in this research due to its ability to link the ISE results to demographics and responses to health education. It is assumed those factors will influence a person's self-efficacy in accessing infertility services.

Eligibility. Eligibility criteria included: persons age 18-65, must be a United States citizen or permanent resident, and must be in one of the three stages of using infertility services: (Prospective) looking for information on using infertility services, (Active) using any type of infertility services, and (Past) no longer using infertility services. Excluded from this research are people who do not use and do not intend to use infertility services to become pregnant or start a family.

Recruitment. Due to the need for diverse stages of infertility service use, the researcher accessed recruitment sources that would include persons in any one of those stages. Recruitment included online support forums for infertility services, advocacy organizations, and word of mouth. Participants provided their interest in an interview at the end of the voluntary online survey "Access to Infertility Services in the United States", where they could indicate their interest and provide an e-mail at which to be contacted.

Recruitment style for this research is defined as passive recruitment (Estabrooks et al., 2017), meaning the researcher does not approach patients directly in person, will not recruit from inside a clinic area, and will not utilize patient records in any way. Recruitment materials included a survey link and QR code located on a survey flier (Figure 3.1). This research received Institutional Review Board (IRB) approval with an "Exempt" status on 8/26/2019 (Pro00041799) (Appendix E), and again on 12/10/2019 (STUDY000110) (Appendix F) after a revision to the research protocol, discussed further in the informal interview section.

The survey link was located on an IRB approved research flyer that was distributed on online forums specific to infertility and assisted reproduction. The recruitment sources are described in more detail in the Informal Interview section because of an IRB change to facilitate greater reach. Recruitment for the survey and informal survey are the same because interest in participating in an interview was the last question in the survey.

Survey data analysis. The survey analysis helped answer research questions 1, 2, 3, and 4 (Appendix A). Frequency statistics, including means and standard deviations, were generated using SAS statistical software (SAS Institute Inc, 2019). There were a total of 161 surveys initiated during the recruitment period between September 2019 – January 2020. Of those surveys, 134 were included in any analyses. Of the 27 survey responses excluded from the research, 22 were surveys that were less than 100% complete based on the variable “Finished”, which was a variable automatically generated by Qualtrics, and 5 were excluded due to being test surveys conducted to evaluate the survey and increase reliability that the questions asked are appropriate for the target audience and aim.

Analysis of the ISE Scale includes mean and standard deviation for each of the 16 items in the scale. A power analysis for ANOVA fixed effects model using the GPower software revealed that, with a sample size of 134, where $f=0.40$ (large effect size), the survey is powered to detect differences with a 7.6% chance of both Type I (α) and Type II (β) errors, Power ($1-\beta$ err prob) =0.932 (Figure 3.2). In literature, sample sizes using the ISE Scale range from between 45 to 250 (Altıparmak & Aksoy Derya, 2018; Kovářová et al., 2010; Turner et al., 2013). The sample size in this research is situated in the middle of that distribution.

Using SAS 9.4 statistical software (SAS Institute Inc, 2019), analyses of the survey data included analysis of variance (ANOVA) to compare the total mean scores for the ISE scale to

observe differences in ISE mean scores based on stage of use, demographics including age, sexual orientation, education, ethnicity, religion, and state of residence as well as questions from the online communities, health insurance, and health education sections of the survey. Analysis of variance was computed using the GLM procedure and post hoc Tukey-Kramer studentized range test for multiple comparisons. Selection of the PROC GLM procedure over PROC ANOVA was due to unequal cell values in the data. The Tukey-Kramer studentized range test is suited for pairwise comparison, and calculates the minimum significant difference (MSD) for each pair of means in the sample population (McDonald, 2014b). The Tukey test is also capable of detecting significant mean differences when the ANOVA was not significant, so it may reveal mean differences between variables. Some literature suggested using a Games-Howell test when the mean variance are unequal (Day & Quinn, 1989; McDonald, 2014a), which in this case they are, however SAS does not have a function for the Games-Howell post hoc test, and the Tukey-Kramer test is similar to the Games-Howell so it was used instead.

Reliability and content validity. Reliability and content validity of the survey were based on pre-testing the survey with a group of moderators from the r/infertility Reddit group before posting the survey on the r/infertility subreddit, which is where the majority of the survey and interview data came from. The moderators were able to provide critique that assisted with clarity of questions regarding infertility diagnoses, gender identity, insurance types, and questions asking about parity. The recommendations were made to the survey before posting the survey online for data collection. It should be noted that two moderators thanked the researcher for including questions regarding health education, travel, and knowledge of infertility insurance mandates, because those topics are rarely asked to people accessing infertility services.

Part 1b: Qualitative Inquiry: Informal and Expert Interviews. *Informal interviews.*

Informal interviews consisted of one-on-one interviews with individuals who encountered an issue with procreation and who intend to pursue, are currently using, or used in the past, some form of infertility service to procreate.

Eligibility. Eligibility criteria included: persons age 18-65, must be a United States citizen or permanent resident, and must be in one of the three stages of using infertility services: (Prospective) looking for information on using infertility services, (Active) using any type of infertility services, and (Past) no longer using infertility services. Excluded from this research were people who do not use and do not intend to use infertility services to become pregnant or start a family.

Recruitment. Recruitment for the survey and informal interviews are the same due to the interview request being the final question of the survey.

The informal interview recruitment began in August 2019. This research first utilized networking and two different infertility advocacy groups as sources for informal interview participants. The advocacy groups included RESOLVE: The National Infertility Association, and the Family Equality Council. Networking consisted of a co-worker offering to post recruitment materials on personal Facebook and Twitter pages.

Networking. One networking source offered to post recruitment materials on the person's personal Twitter feed, as well as Facebook pages for the College of Nursing at USF, Black Nurses Rock, and Sigma Theta Tau – The International Honor Society of Nursing. These postings occurred in January 2020.

RESOLVE: The National Infertility Association. RESOLVE is possibly the most active and well-known infertility advocacy organization in the United States. It was founded in 1974 and

is a 501(c)3 national patient advocacy organization (RESOLVE: The National Infertility Association, 2019a). Members of the organization actively advocate in Washington D.C., such as the most recent in-person Advocacy Day in Washington D.C. May 15, 2019 (RESOLVE: The National Infertility Association, 2019b). RESOLVE members and advocates, along with the same from the ASRM, were involved in the First Virtual Federal Advocacy Day on May 20, 2020, due to the Covid-19 cautions for large gatherings (ASRM: The American Society for Reproductive Medicine, 2020). After contacting the Chief Engagement Officer at RESOLVE and completing a research proposal application approved by their department, recruitment materials were placed on the online support forum Inspire, specifically on the “What’s Happening at RESOLVE?” page.

The Family Equality Council. The Family Equality Council (FEC) is an advocacy organization founded in 1979 at the National March on Washington for Lesbian and Gay Rights. They embody the mission of advancing legal and lived equality for same-sex couples who want to start a family, and one of their methods is to initiate policy change (Family Equality Council, 2019). Because of the lack of attention to same-sex couples in infertility services research, inclusion of the FEC will encourage more perspectives of LGBTQ couples and individuals to be integrated into the discourse on how to reduce the disparities in accessing infertility services. After contacting the Chief Program Officer at the FEC via email, the researcher was able to set up a time to discuss the research. After the discussion, the organization agreed to help distribute recruitment materials through their email listserv.

Due to a low number of responses from these two sources, there was a need to diversify recruitment reach. Between September-October 2019, a total of 23 organizations providing infertility services, ranging from clinical services to patient advocacy, were invited to participate in the research by disseminating recruitment materials. From those, 4 (17.4%) responded, and only

one, The Oncofertility Consortium at Northwestern University, agreed to collaborate. The recruitment materials were placed on their Facebook page by one of their staff.

Recruitment revision. By the beginning of December 2019, the current recruitment efforts yielded two informal interviews and four surveys. In an effort to increase participation, the methods were amended (STUDY000110) to include a \$30 Amazon Gift Card for completing an interview (Coopersmith et al., 2016; Morgan et al., 2017), as well as the addition of two other sources for recruitment: Reddit and Craigslist.

Craigslist. Although not used often in research, Craigslist has served as a platform for research recruitment for clinical trials (Antoun et al., 2016), reaching rural populations (Warren et al., 2015), and reaching stigmatized groups for different genres (Worthen, 2014). Strategies for using Craigslist are often centered around posting in main sections for major cities, and then in smaller sections of major cities if rural populations are a target (Worthen, 2014). For this research, the perspective of rural populations would be informative in terms of observing the role of residence in accessing infertility services, which is one of the main reasons Craigslist was chosen as a recruitment site.

Geographic selection for the Craigslist posting started with selecting five random states to test the use. States randomly selected were Montana, Oregon, New Mexico, Nevada, and Georgia. Initial post attempts started in January 2020, with five postings. The primary topic area for each post was in the “Community” section, and the secondary topic area, if applicable, was the “Volunteers” section. However, none of the posts lasted online for longer than 48 hours before being flagged and removed by online moderators. Flagging of research posts on Craigslist is a common occurrence, and can at times be mediated by adding a note that the research is approved and based from a university or hospital (Worthen, 2014). However, attempts to use that method in

this research were fruitless. Attempts to post research recruitment on any Craigslist page ended in January 2020.

reddit Inc. Reddit is an online social platform where people can post information, suggestions, videos, photographs, and have discussions on any type of topic, and those topics are sectioned into subreddits – indicated by “r/” prefix. Reddit is referenced in the literature as a reliable and potentially rich source for qualitative and survey recruitment when the correct subreddit forums are selected (Amaya et al., 2019; Shatz, 2017).

A search on the Reddit homepage for “infertility” revealed 125 subreddits that were specific to human infertility. The larger subreddits were more general to infertility issues, and other smaller subreddits were specific to aspects of the infertility experience, such as being male, having cancer, experiencing loss of pregnancy, adoption, and some specific to procedures like in vitro fertilization (IVF) and intrauterine insemination (IUI). Recruitment for this research was based in the subreddit r/infertility, which is the largest infertility specific subreddit with approximately 18,000 members from multiple countries. English is the primary language spoken on this subreddit.

Each subreddit has a single moderator or group of moderators who monitor the discussions and postings on the forum. The moderators are the gatekeepers for removing unapproved postings on the subreddit, so in order to post something on the subreddit page it must follow certain guidelines. The moderators for the r/infertility subreddit had an organized list of criteria for posting on the forum, as well as a note for researchers to contact the moderators directly before posting research recruitment materials. The r/infertility subreddit moderators were contacted in January 2020, and after discussing the project and sharing the IRB approval letter, permission was given to post the recruitment material on the r/infertility public forum.

Recruitment on the r/infertility subreddit began on 2/3/2020. Within four hours of posting, the interview request number increased to 30. Within eight hours of posting, the interview request number reached 77. After 12 hours from the initial post, there were a total of 105 requests to do an interview, at which point the post was taken down due to reaching nearly 4x the initial recruitment goal of 30. All requests were from people who qualified as eligible for the research. Each request was individually followed up by an email to the address provided by the participant.

Between September 2019 and February 2020, 66 people (62.9%) who responded to do an interview completed an interview. Of the total 105 persons who requested to be contacted for an interview, 38 (36.2%) did not respond to the follow-up email, 3 (2.7%) who scheduled an interview did not answer the phone on the interview date, and 1 (0.95%) declined to do an interview.

Informal interview procedures. After indicating interest in doing an informal interview via the survey, participants were contacted via email to set up a time for an interview. Interviews were conducted over the phone between September 2019 – February 2020. Consent to participate in the research was confirmed verbally by participants as allowed by the IRB. All interviewees had the option to not have the conversation audio-recorded, however all participants allowed the conversation to be recorded. Interviews were recorded using an Olympus WS-821 voice recorder.

Social Cognitive Theory and the Glass and McAtee model of risk regulators informed the construction of the interview guide for the informal interviews (Appendix C). The interview guide included demographic questions, and questions in the following domains: reason for accessing/wanting to access infertility services, travel associated with accessing infertility services, health insurance, and out-of-pocket expenses related to infertility services.

These questions reflect the assumption that a person's state of residence and presence/absence and type of health insurance will affect decisions made regarding the timing,

location(s), and magnitude of financing people will undergo when accessing infertility services. The intent was to be able to identify facilitators and barriers to infertility service use, to see if those facilitators and barriers were present at different stages of infertility service use and observe how they were associated with the constructs of SCT.

Expert interviews. This research also utilizes expert interviews with members of a specialized insurance companies and non-profit organizations that specifically offer insurance, financing, or other types of funding specifically for infertility services. This research uses the sociological interpretation of “expert knowledge,” meaning those chosen for interviews maintain levels of knowledge that have not been reconstructed empirically- rather they have knowledge they are aware of and embody – also referred to as discursive consciousness (Giddens, 1984; Meuser & Nagel, 2009). Expert interviews are used in an increasing number of qualitative social science research projects, as well as in political research (Bogner et al., 2016). This research utilized the exploratory and explanatory expert interview types, as defined by Bogner, Littig, and Menz (2016). These are positions that views the expert as a topic orienting actor used to generate knowledge through subjective experience – as such it falls on the researcher to consider the *expert* advice in the context of the research. One could argue that people who use infertility services are also experts, however the utilization of the expert in this research is specific to understanding the function of for-profit and non-profit philanthropy for infertility-specific medical procedures to individuals and infertility-specific insurance to employers. Appendix G contains the expert interview guide.

Eligibility. In order to be eligible to be an expert interview participant, the contact had to offer some type of financial assistance for paying for infertility services. There are multiple types of companies that offer services like this, such as Progyny that offers employer options for health

insurance specific to infertility services, and non-profit organizations such as the Baby Quest Foundation, which offers grants to a limited number of applicants per year to help pay for services.

Selected organizations were contacted by email, and the contact was described online as the “media contact”. If no media contact was listed, an e-mail was sent to the generic email for the organization. Exclusion criteria for expert interviews were that they did not represent a company that offers insurance, specialized financing, or grants or scholarships for infertility services in the United States. Financing organizations that were specific to an individual clinic system or individual clinic were not included in this research.

Recruitment. The recruitment style for this research is defined as passive recruitment (Estabrooks et al., 2017), meaning the researcher did not approach participants directly in person, did not recruit from inside a clinic area, and did not utilize patient records in any way. Recruitment materials included an IRB Informed A consent letter was sent through email. Interested interviewees were directed to reply via email. Although informal interviewees received a \$30 Amazon gift card, the expert interviewees were not compensated for their participation based on their role as employees for an organization from which information is being requested. Expert interview participants did not complete the survey because it was not applicable to them.

To identify potential organizations, this research first utilized a Google search for “infertility+financial+support”. The search revealed multiple advocacy websites that listed sources of funding for infertility services, ranging from loans to grants to types of private insurance. Also utilized were lists of organizations disclosed on websites from RESOLVE, NeedyMeds.org, Alliance for Fertility Preservation, CadeFoundation, Growing Family Benefits, FutureFamily, CapexMD, Maven, and WinFertility. Many of the organizations were replicated on other websites.

A total of 30 organizations were contacted up to two times between January 2020 and February 2020. Of those 30 organizations, 11 responded (36.7%), and 19 (56.7%) did not respond to any emails. Of the 11 organizations that responded, 8 (26.7%) completed an interview, 2 (6.7%) declined to do an interview, and 1 (3.3%) was lost to follow-up. Reasons for declining an interview were that the organization representative did not feel their organization was within the inclusion criteria because they offer refunds or discounts to patients who use physicians within their network; and/or the representative was also the founder of the organization and did not feel he or she had the time to dedicate to the interview due their work responsibilities.

Expert interview procedures. Interviews were conducted over the phone between January and February 2020. The consent to participate in the research was confirmed verbally by participants and the verbal consent process. All interviewees had the option to not have the conversation audio-recorded, however all participants allowed the conversation to be recorded. Interviews were recorded using an Olympus WS-821 voice recorder. Interview questions were informed by the previously described informal interviews, as well as inquiry into the nature of the organization's development, the types of services they offer, and to whom those services are available.

Within Bandura's triadic model of causation, the expert interview organizations function within the 'environmental' domain due to their ability to facilitate increased financial access to infertility services, and the concept that the applicability of their services will affect decisions on types and extent of infertility services on which an individual or couple decide. As such, the questions asked during the expert interviews inquired into the services offered, who they were offered to, and how they (as a representative of the organization) perceived the facilitative function

of state-mandated health insurance for infertility services. The researcher thought these organizations would be in favor of state-mandated health insurance for infertility services.

Interview data analysis. This research utilized a constant comparison method of qualitative data analysis to code for themes related to constructions with SCT. Transcript coding was done by two doctoral candidates from the USF College of Public Health trained in qualitative data analysis. The software utilized was MaxQDA 2020.

Codebook development. This research utilizes a theory-driven coding methodology, using Social Cognitive Theory (SCT) constructs and themes within the survey instrument as parent codes (Appendix D). Simons-Morton et al. (2012) and the Office of Behavioral and Social Sciences Research, (2018) provide definitions for the SCT constructs used in this research. In the construction of theory-driven codes, there are three necessary steps (DeCuir-Gunby et al., 2011). These are: 1) obtain the theory for which the codes will be based on, using the definitions of the theory constructs as definitions for the codes; 2) review and revise the code definitions within the context of the data (transcripts), which entailed rewording the constructs to be specific to observing the behavior of accessing infertility services; and 3) establish reliability, which in this research involved review of the codebook by the qualitative coders to ensure validity of the coding scheme and clarity of the code definitions.

The codebook was revised four times due to some constructs needing clearer definitions, and the addition of emergent codes. The final codebook listed the code name, code abbreviation, a section for what the code is, and a section for what the code is not. The coders were instructed to use the memos in MaxQDA to account for any potential uncertainty in the codes used, which reduced bias during the constant comparison of coding among the transcripts (Given, 2012). The memos were reviewed along with the coding discussions. After the fourth revision, the coders

agreed to remove “Self-Control” because it was difficult to discern it from “Behavioral Capability,” and to remove “Reinforcements” as it was difficult to discern a negative reinforcement from a barrier and a positive reinforcement from a facilitator. The final SCT constructs that remained as codes were: *Environment* (Office of Behavioral and Social Sciences Research, 2018; Simons-Morton et al., 2012a), *Self-Efficacy* (Office of Behavioral and Social Sciences Research, 2018; Simons-Morton et al., 2012a), *Behavioral Capability* (Simons-Morton et al., 2012a), *Expectations and associated Outcomes* (Simons-Morton et al., 2012a), and *Observational Learning* (Office of Behavioral and Social Sciences Research, 2018; Simons-Morton et al., 2012a). There were also codes for barriers and facilitators, and although these are often coded along with environment (addressing environmental facilitators and barriers), this research observes them as separate codes in order to observe their co-occurrence with environmental variables (Glanz et al., 2015). Definitions of these constructs are located in the codebook (Appendix D).

There are seven SCT construct codes, and a total of five literature-informed codes specific to insurance for infertility services. One emergent code developed – Infertility Story – as a result of wanting to capture the interviewee’s process of obtaining an infertility diagnosis because at times the story was not captured with any of the pre-defined codes.

The purpose of the six literature-informed codes was to observe their occurrence in conjunction with the SCT constructs. Survey-informed codes include: Insurance, Finances, Travel, Employer, Legal, and Health Education. Rationale for these topics are disclosed in the methods section for the survey development. To observe the interplay between aspects of insurance or finances in one’s decision-making process, it is important to be able to observe his or her co-occurrence within the discourse.

Qualitative data visualization. MaxQDA 2020 graphics tools were utilized to observe the relationships between qualitative codes includes Code Maps of the relationship between SCT-based and survey-based codes, and a development of Code Relations tables that showed the frequency of times a code occurs along with another code. The function of the Code Map is to see a visual representation of how close qualitative codes appear in proximity to others. The logic is that, the closer the codes are in the map, the more similar they are in terms of their application to the content of the data. The larger the code name, the more frequently it appears in the corpus of interviews. If a codes are not connected by lines, it means they do not appear in the same segment of coded text as other codes (MAXQDA, 2020a). The Code Relations tables show the actual frequencies of co-occurrence of the selected codes (MAXQDA, 2020b).

Use of expert interviews. This research does not assume the sample of organizations included reflect the entire population of organizations offering types of financial or advocacy assistance specific for infertility services in the United States. However, the opinions reflected by the organizations included in this research are perspectives that exist among that population of organizations, and thus do have merit.

The codebook for the expert interviews was based on interview-guide based thematic codes. The structure of the conversation was to obtain knowledge of the organization, and the questions posed were related to the following five themes: types of services offered (Services offered), who the services were available to (Eligibility), how the services are advertised (Advertisement), the source of the funding (Source of Funding), and the perspective of the organization representative on the role of state-mandated health insurance for infertility services (Perspective). The domains served as the thematic codes: Services offered, Eligibility, Advertisement, Source of Funding, and Perspective (Appendix G).

This research utilizes expert interviews in exploratory and explanatory functions, as defined by Bogner, Littig, and Menz (2016), utilizing the expert as a topic orienting actor to generate knowledge through subjective experience, and confirming knowledge through triangulation of data sources (Muskat et al., 2012). The overall objective of this research is to add context to the use of infertility services. The organizations that exist to facilitate greater access to infertility services – whether financially, through advocacy, or through dissemination of information – are important actors in the discourse surrounding the medical legitimacy of human infertility to be covered by health insurance because they are in a sense on the frontlines of both the politics and the practice of infertility services. The founders and members of these organizations know how people access infertility services, they know reasons why people are denied coverage, and some, like Progyny, have the perspective of the employer when it comes to infertility services because they provide insurance options directly to employers.

The expert interviews included in this research provide important contextual information regarding the inconsistency of how existing state-based infertility health insurance mandates are applied to individual experiences, how employers can act as facilitators in increasing financial accessibility to infertility services (regardless of a state mandate), and the perspectives of the business of medicine. The non-profit organizations and advocacy groups exist due to a nationwide problem of unequal access to infertility-related medical care.

Trustworthiness. The absence of bias is not possible in qualitative research, but it can be reduced by engaging in and reporting on certain measures enacted at all stages of the research process (Miles et al., 2014). Measures used to reduce bias in this research included reliability and credibility.

Reliability. Reliability refers to the research process stability over time, where research questions and methods are disclosed a priori and adhered to throughout the research process (Miles et al., 2014). An aspect relating to reliability of the qualitative data and analysis in this research comes from the consistent use of SCT in the creation of research questions, interview guides, codebooks, and data observations, specifically observing self-efficacy both in the informal interviews and the online survey. A theory-based link was established between the qualitative and quantitative data through the observation of SCT constructs and literature-derived themes related to place as a risk regulator (health education, health insurance, residence, employer, travel for services) during the conceptualization of this research and throughout the data collection and analysis phases.

Another aspect of reliability comes from the use of two graduate level trained qualitative analysts to code the interviews. Before the two coders began the coding for reliability testing, the researcher used a random number generator to select seven transcripts, 10% of the 66 transcripts (n=7). In this research, the coders used segmentation to standardize the amount of text included for each code, where each segment was a unit of text used to answer the question posed to the interviewee (O'Connor & Joffe, 2020). The researcher segmented the seven transcripts based on the question asked to the interviewee. Inter-coder reliability was based on Cohen's kappa statistic, where $Pr(a)$ represents the actual observed agreement, and $Pr(e)$ represents chance agreement. The coding file was exported from MaxQDA as an excel file. Kappa calculations were conducted in MS Excel using the coding file exported from MaxQDA. The Kappa statistic is a squared correlation coefficient, called the coefficient of determination, which can be interpreted as a statistic to represent agreement between two coders – albeit with an acknowledged degree of error

(Cohen, 1960; McHugh, 2012). A value between .80-.90 is agreed to be a strong level of agreement, with greater than .90 being near perfect agreement.

Coders for this research reached an overall kappa of 0.91 (range: 0.88-1.0) for all codes after one round of coding, meaning there was approximately a 4% chance the agreements are erroneous. Standard, unweighted error is reported at SE=0.0031 (CI: 95%, lower: 0.9596, upper: 0.9716). Standard error was calculated using VassarStats (<http://vassarstats.net/kappa.html>), which calculates error based on unweighted, linear weighting, and quadratic weighting. Interestingly, none of the error estimate types were different. Establishing interrater reliability increases the trustworthiness of the data (O'Connor & Joffe, 2020), and a kappa score of 0.91 represented strong agreement in the SCT constructs and literature derived codes.

Credibility. The concept of credibility is closely related to establishing the trustworthiness of the conclusions made by the researcher (Korstjens & Moser, 2018; Mills et al., 2010). Establishing trustworthiness of qualitative research can be established through credibility and reliability of both the source of the data, and the analytical methods used. In this research, credibility of the results and suppositions came from a rich source of interview and survey data, being the subreddit r/infertility that is specific to the topic of this research. Members of the subreddit r/infertility provided unsolicited confirmation that the topic of health insurance for infertility services is an important topic for those experiencing infertility – a sentiment also expressed in expert interviews. The inclusion of expert interviews allowed for confirmation on topics expressed during the informal interviews, which increased credibility in the qualitative results of this research.

Part 2: Spatial Analyses.

Part 2a: Spatial Analysis of Fertility in the United States. *Data collection.* Boundary lines for states and census tracts comes from the 2017 TIGER/Line geodatabase for National Substate Geography (US Census Bureau, 2017). The American Community Survey 2013-2017 5yr dataset is the source of data for both fertility (S1301) and total population (B01003). The American Community Survey in this research includes 50 states plus Washington D.C., and their associated census tracts. The data are specifically related to fertility of women age 15-50, with various demographic characteristics related to age, ethnicity, poverty status, marriage status, and nativity. Between the years of 2013-2017, there were a total of 3,994,223 +/- 20,838 women who had a birth in the United States, which is a rate of 52 +/- 1 births per 1,000 women (Table 3.3). Number estimates from the American Community Survey are based on sample data and thus are subject to some degree of sampling variability, which is accounted for in the 90% margin of error. The 90% margin of error allows this data to be interpreted to mean that there is a 90% probability that the defined intervals plus and minus the margin of error contains the true value.

There are two primary reasons why this research does not observe the spatial distribution of diagnosed infertility or use of infertility-specific medical procedures such as in vitro fertilization (IVF). These are 1) Cost and access restriction on datasets, and 2) the absence of geospatial fertility research.

Cost and access restriction. Datasets specific to the use of ARTs that are linked with geospatial reference data to the state and county levels are expensive, costing upwards of \$3,000 depending on dataset, and difficult to access taking up to five months for project approval, depending on the dataset (CDC, 2017; National Center for Health Statistics, 2020). There are legitimate privacy reasons for the restricted access to this data, such as those required under Public

Health Act Section 308(d) in the protection of private medical information (CDC, 2017), but it does pose a limitation on its analysis. Although this research includes geocoded fertility clinics that have frequency statistics for certain infertility services and procedures conducted, the analysis of the geocoded clinic data did not observe the frequency data for infertility services, as those analyses were outside the objectives of this dissertation. There is an intention for future geospatial analyses on the geocoded clinic data.

Geospatial analysis of fertility. The current literature on infertility services does not analyze fertility data along with it, outside of observing rates of national fertility over time. Some researchers are researching the relevance of observing both fertility and infertility with the same type of analytical approach. This includes Johnson et al (2018) who bring up the different research trajectories of fertility and infertility research. They observe that fertility research historically focused more on demographic trends, applying theory and economics, observing trends over time, and infertility research has focused more on medicine, researching the genetics of infertility, psychological distress management, and levels of diagnosis for males and females, and some social and clinical research observed disparities in access to infertility services (Johnson et al., 2018). One of the authors' main propositions is that understanding the "dynamically interrelated" relationship between fertility and infertility through research that observes them both could give meaningful insight into the perceived and lived experiences of both conditions (Johnson et al., 2018, pg 25). In this research, geospatial observation through a mixed method research design will to give insight into the utility of observing place with both fertility and infertility related data.

The geospatial observations of fertility and infertility below the county level, using geostatistical software and statistics suited to account for geographic place, are largely absent from the literature. Although some research tangentially refers to a decrease in fertility in the United

States (Simoni et al., 2017; Vander Borgh & Wyns, 2018), there are no analyses that observe recent fertility trends relating to the demographics of people who use infertility services (white, highly educated, household income over \$90,000). Observing the geospatial patterns of fertility in the United States can give insight into future geospatial analyses of infertility, creating the ability to compare linear and geostatistical trends.

Data preparation. This research utilized the software ArcPro 2.4 (ESRI, 2018) for data preparation, creation of shapefiles, spatial analyses, and visualizations including maps. Statistical analyses were also conducted using SAS/software, Version 9.6 of the SAS System for Windows Copyright © 2019 SAS Institute Inc (SAS Institute Inc, 2019). Figure 3.3 shows a diagram of the geoprocessing preparation for the census data.

Spatial joins. Data from the American Community Survey came in an MS Excel format that contained geographic variables that can be used to join the excel table to polygon shapefiles of the same variables that define geographic extent. After downloading the American Community Survey Fertility (S1301) data at the census tract level, the second row of description variables are deleted so that the data values started in row 2. The column identified as “GEOID” is then converted to a text format to it can be recognized by the ArcMap software. (Figure 3.3)

Using ArcPro, the US census tracts shapefile was imported to the map document. The “GEOID” column in this shapefile was then converted to a “Double” integer type in order for it to be joined to the American Community Survey fertility excel file. This process involves the creation of a new attribute field called “ID2” and used the Field Calculator to copy the content of the “GEOID” field to the new “ID2” field. Once finished, the American Community Survey fertility excel file is imported into the map document. The two files (census tracts and excel file)

are then spatially joined together using the “Join” function in ArcPro, based on the field called “ID2”.

Addressing spatial dependence. Due to the dependence these analyses have on spatial location, there are some census tracts that need to be removed from the contiguous United States before data analysis. Some census tracts in the United States do not represent locations where people live, such as census tracts over the great lakes and around coastal areas that define the extent of a state’s geopolitical boundary. Alaska and Hawaii were also separated from the contiguous United States so that the distance of these two states were not included in the spatial analyses that considered nearest neighbor (in this case, nearest census tract). By separating these two states and analyzing them individually, the accuracy of the observed spatial relationships was maintained. The total number of features included in the analysis of the contiguous United States was 72,483 census tracts. The total number of census tracts for analysis in Hawaii was 337, and for Alaska was 167.

Data analysis. Count variable models. Linear regression statistics were applied to the American Community Survey Fertility data in order to observe any linear relationships between the variables, which in this case referred to count values that reflect women with births based on sociodemographics said to be associated with disparities. Linear tests applied here were a Poissonian distribution, followed by a Negative Binomial distribution, quantitated using SAS 9.4.

Statistical significance in the Poisson regression was determined by a 95% confidence level, which was used to ascertain whether the proportions of *women with births* differed by sampled location (census tract). Poisson regression can be used for prediction, including forecasting of inference, hypothesis testing, and modeling of causal relationships (Haight, 1967). The regression analyses assumed independent counts (i.e., ni), taken at locations $i = 1, 2, \dots, n$, where

each of the estimated count values, was from a Poisson distribution. These counts were described by a set of explanatory variables denoted by matrix \mathbf{X}_i , a $1 \times p$ vector of covariate estimates for each census tract i . The expected value of these data was given by: $M_i(\mathbf{X}_i) = Ni(\mathbf{X}_i) \exp(\mathbf{X}_i \boldsymbol{\beta})$, where $\boldsymbol{\beta}$ was the vector of non-redundant parameters and the Poisson rates parameter was given by: $\Delta i(\mathbf{X}_i) = \mu_i(\mathbf{X}_i) / Ni(\mathbf{X}_i)$.

The rates parameter $\lambda_i(\mathbf{X}_i)$ were both the mean and the variance of the Poisson distribution for a estimated number of “*All women with births*” (fertility) within a census tract i . The dependent variable was the total count of *All women with births* (fertility). All of the estimates for the models were tested for multicollinearity using partial F test in SAS, and no problematic correlations were found. In statistics, multicollinearity (also collinearity) is a phenomenon in which one predictor variable in a multiple regression model can be linearly predicted from the others with a substantial degree of accuracy. In this situation, the coefficient estimates of the multiple regression may change erratically in response to small changes in the model or the data. Multicollinearity does not reduce the predictive power or reliability of the model as a whole, at least within the sample data set. It only affects calculations regarding the individual predictor (Belsley, 1991).

Extra-Poisson variation was detected in the residual variance estimates of the fertility model. Extra-Poisson variation occurs when discrete data comes in the form of counts or proportions that display greater variability than would be predicted when fitting a model (Haight, 1967). When sampled data are overdispersed, the square root and logarithmic transformations may be less effective at making the mean and variance independent (Hosmer & Lemeshow, 2000).

Overdispersed Poisson processes can be modeled in many alternative ways. The most common approaches used for count data include quasi-likelihood-based Poisson models (Wedderburn, 1974), random-effects models (Bolker, 2008), and negative binomial models

(McCullagh & Nelder, 1989), all extensively used in the literature and readily available in statistical software packages. In quasi-Poisson methods the amount of overdispersion is estimated under the assumption that the variance is proportional to the mean, after which, e.g., standard errors are corrected for the estimated overdispersion. On the other hand, mixed-effects Poisson models and typical negative binomial models assume that the extra-Poisson variance is a quadratic function of the mean. The statistics literature also proposes other types of overdispersed generalized Poisson models (Famoye, 1993) and zero-inflated variants of the Poisson and negative binomial models (Lambert, 1992).

Ver Hoef & Boveng (2007) made a comparison between quasi-Poisson and negative binomial regressions as two contrasting approaches for dealing with overdispersed count data. The authors showed that the choice of approach can affect the outcome of the analysis. The authors recommended sound scientific reasoning and graphical investigation of the data as the basis for model choice. Different processes underlying overdispersion in spatially dependent data may result in various mean–variance relationships (Griffith, 2003).

For this research, a negative binomial regression with a gamma distributed non-homogenous mean was constructed in PROC GENMOD to account for the overdispersion in the fertility model. The negative binomial distribution arises as a continuous mixture of Poisson distributions in a model where the mixing distribution of the Poisson rate is a gamma distribution (Hilbe, 2011). A specific parameterization of the negative binomial distribution can be used to approximate overdispersed Poisson processes with a wide range of mean–variance relationships (Haight, 1967). The negative binomial model is a quadratic function of the mean and the variance which commonly affect the weights in the iteratively weighted least-squares algorithm for fitting sampled data (Cameron & Trivedi, 1998). In probability theory and statistics, the negative

binomial distribution is a discrete probability distribution that models the number of failures in a sequence of independent and identically distributed Bernoulli trials before a specified (non-random) number of successes (denoted r) occurs (Lambert, 1992). A Bernoulli trial (or binomial trial) is a random experiment with exactly two possible outcomes, *success* and *failure*, in which the probability of success is the same every time the experiment is conducted (Papoulis, 1984).

Employed here is the negative binomial regression model with a non-homogenous gamma distributed mean to linearly adjust the sampled extra-Poissonian variation in the fertility data. An analytical solution to this integral exists when τ_i is assumed to follow a gamma distribution. This solution is the negative binomial distribution. When the model contains a constant term, it is necessary to assume that $E(e^{E_i}) = E(\tau_i) = 1$, in order to identify the mean of the distribution (Haight, 1967). Thus, it is assumed that τ_i follows a gamma(θ, θ) distribution with $E(\tau_i) = 1$ and

$V(\tau_i) = 1/\theta$. $g(\tau_i) = \frac{\theta^\theta}{\Gamma(\theta)} \tau_i^{\theta-1} \exp(-\theta \tau_i)$ where $\Gamma(x) = \int_0^\infty z^{x-1} \exp(-z) dz$ was the gamma function and θ is a positive fertility-related parameter. Then, the density of y_i given \mathbf{x}_i was derived as

$$\begin{aligned} f(y_i|\mathbf{x}_i) &= \int_0^\infty f(y_i|\mathbf{x}_i, \tau_i) g(\tau_i) d\tau_i \\ &= \frac{\theta^\theta \mu_i^{y_i}}{y_i! \Gamma(\theta)} \int_0^\infty e^{-(\mu_i + \theta)\tau_i} \tau_i^{\theta + y_i - 1} d\tau_i \\ &= \frac{\theta^\theta \mu_i^{y_i} \Gamma(y_i + \theta)}{y_i! \Gamma(\theta) (\theta + \mu_i)^{\theta + y_i}} \\ &= \frac{\Gamma(y_i + \theta)}{y_i! \Gamma(\theta)} \left(\frac{\theta}{\theta + \mu_i} \right)^\theta \left(\frac{\mu_i}{\theta + \mu_i} \right)^{y_i} \end{aligned}$$

Making the substitution $\alpha = \frac{1}{\theta} (\alpha > 0)$, the negative binomial fertility distribution was then

rewritten as $f(y_i|\mathbf{x}_i) = \frac{\Gamma(y_i + \alpha^{-1})}{y_i! \Gamma(\alpha^{-1})} \left(\frac{\alpha^{-1}}{\alpha^{-1} + \mu_i} \right)^{\alpha^{-1}} \left(\frac{\mu_i}{\alpha^{-1} + \mu_i} \right)^{y_i}$, $y_i = 0, 1, 2, \dots$ In so doing, the

negative binomial distribution was derived as a gamma mixture of Poisson random variables.

For this research, the assumption about equality of mean and variance (i.e., Poisson distribution property) is relaxed. In our fertility model the variance of negative binomial was equal to $\mu + k \mu^2$, when $k \geq 0$ was a dispersion parameter. The key criterion for using a Poisson model is after accounting for the effect of predictors, the mean must equal the variance (Haight, 1967). The maximum likelihood estimation method was used to estimate k as well as the parameters of the regression models for $\log(\mu)$. Since the Poisson regression model can be generalized by introducing an unobserved heterogeneity term for observation i (McCullagh & Nelder, 1989), individual sampled estimate of “*All Women with Births*” were assumed to differ randomly in a manner that was not fully accounted for by the Poissonian values.

In this research the unobserved heterogeneity term was independent. Overdispersion results from neglected unobserved heterogeneity (Cameron & Trivedi, 1986). The Poisson regression model was generalized by introducing an unobserved heterogeneity term for the *fertility* classified observation i . This was formulated as $E(y_i | \mathbf{x}_i, \tau_i) = \mu_i \tau_i = e^{\mathbf{x}_i' \boldsymbol{\beta} + \varepsilon_i}$ where the unobserved heterogeneity term $\tau_i = e^{\varepsilon_i}$ was independent of the vector of regressors \mathbf{x}_i in the model. In so doing, the distribution of y_i conditional on \mathbf{x}_i and τ_i was Poissonian with conditional mean and conditional

variance $\mu_i \tau_i$: $f(y_i | \mathbf{x}_i, \tau_i) = \frac{\exp(-\mu_i \tau_i) (\mu_i \tau_i)^{y_i}}{y_i!}$ in the fertility model output letting $g(\tau_i)$ be the probability density function of τ_i . Then, the distribution $f(y_i | \mathbf{x}_i)$ (no longer conditional on τ_i) was obtained by integrating $f(y_i | \mathbf{x}_i, \tau_i)$ with respect to τ_i : $f(y_i | \mathbf{x}_i) = \int_0^{\infty} f(y_i | \mathbf{x}_i, \tau_i) g(\tau_i) d\tau_i$ (see Haight, 1967).

Because the Poisson distribution is a special case of the negative binomial distribution, coefficients estimated using Poisson regression will not differ significantly from coefficients estimated using negative binomial regression, although the standard errors estimated by the

negative binomial regression may not be as efficient (Haight, 1967). As a result, this research offers the caveat that some factors identified as significant, using Poisson regression, may or may not become insignificant when using negative binomial regression.

The fertility model output suggests the negative binomial may be used for handling overdispersion in fertility data. Negative binomial regression models can estimate a dispersion parameter that can remove the effects of overdispersion from a model (Neter et al., 1993). When the negative binomialized fertility data were fitted by the maximum likelihood method, the model outputs were considered to be convenient and practical. They handled the overdispersion and allowed the likelihood ratio and other standard maximum likelihood tests to be implemented with robust properties. Inappropriate imposition of the Poisson in fertility data may underestimate the standard errors and overstate the significance of the regression parameters, and consequently, giving misleading inference about the regression parameters.

Spatial autocorrelation. The prior analyses observed the interaction between overall fertility and fertility based on predefined sociodemographics identified in the literature. Spatial autocorrelation in this research includes statistical analysis of autocorrelation using PROC VARIOGRAM in SAS (Moran's I) and using the Optimized Hotspot Analysis (Getis-Ord G_i^*) function in ArcPro. All spatial analyses using latitude and longitude coordinates were computed in the Lambert Conformal Conic geographic projection, which is appropriate for the analysis of Getis Ord G_i^* in ArcPro when the span of analysis exceeds 30° - otherwise calculations will automatically use Chordal distance, which is not as accurate beyond 30° (ESRI, 2020a).

Moran's I statistic. Spatial autocorrelation will observe the interaction of these variables while also taking into account the geographic location of each census tract, based on latitude and longitude coordinates. An autoregressive model was employed that used a sampled Y value [i.e.,

an autoregressive response (AR) or spatial linear (SL) specification] and/or the residuals of Y as a function of nearby Y residuals [i.e., an AR or SE specification]. Sampled spatialized fertility variables were defined in terms of an n-by-n geographic weights matrix, C, whose c_{ij} values will be 1 if the sampled covariate and coefficient values i and j respectively, are located adjacent in geographic regression space and 0 otherwise. Alaska and Hawaii were separated from the contiguous United States so that the distance of these two states were not included in the spatial analyses that take into account nearest neighbor (in this case, centroid from the coordinate data).

The formulation for the Moran's index of spatial autocorrelation used in this research was as follows: where with $i \neq j$ as in Jacob, et al, (2013). Moran's I is a product moments correlation coefficient that can detect latent positive/negative autocorrelation (i.e., similar /dissimilar aggregation of attributes in geographic space) Spatial autocorrelation is the correlation among values of a single variable strictly attributable to their relatively close locational positions on a two-dimensional surface, introducing a deviation from the independent observations assumption of classical statistics (Griffith, 2004).

Spatial analysis frequently employs model-based statistical inference, the dependability of which is based upon the correctness of posited assumptions about a model's error term. One principal assumption in the fertility model construction was that that individual error terms came from a population whose entries were thoroughly mixed through randomness. Moreover, the probability of a sampled parameter estimator value in a autocorrelation paradigm taken on by one of a fertility model's error term entries may not affect the probability of a value taken on by any of the remaining error term entries (i.e., the violation of independent observations assumed in classical statistics). Non-zero spatial autocorrelation would violate this assumption (see Jacob et al., 2009). Without detecting autocorrelation in a fertility time series national dataset, few

variables would exhibit a geographic expression when mapped. Most variables would exhibit some type of spatial organization across space. Zero spatial autocorrelation means geographically random phenomena and chaotic landscapes (Griffith, 2003).

Did the directional distribution of the fertility-related variables in order to observe raw spatial trends based on the count data alone and 1 standard deviation from the mean center.

The standard deviational ellipse is given as:

$$C = \begin{pmatrix} var(x) & cov(x, y) \\ cov(y, x) & var(y) \end{pmatrix} = \frac{1}{n} \begin{pmatrix} \sum_{i=1}^n \tilde{x}_i^2 & \sum_{i=1}^n \tilde{x}_i \tilde{y}_i \\ \sum_{i=1}^n \tilde{x}_i \tilde{y}_i & \sum_{i=1}^n \tilde{y}_i^2 \end{pmatrix}$$

where

$$var(x) = \frac{1}{n} \sum_{i=1}^n (x_i - \bar{x})^2 = \frac{1}{n} \sum_{i=1}^n \tilde{x}_i^2$$

$$cov(x, y) = \frac{1}{n} \sum_{i=1}^n (x_i - \bar{x})(y_i - \bar{y}) = \frac{1}{n} \sum_{i=1}^n \tilde{x}_i \tilde{y}_i$$

$$var(y) = \frac{1}{n} \sum_{i=1}^n (y_i - \bar{y})^2 = \frac{1}{n} \sum_{i=1}^n \tilde{y}_i^2$$

. In this equation, x and y refer to latitude

and longitude coordinates of the feature i , $\{\bar{x}, \bar{y}\}$ are the Mean Center for the features, which can be specified by a variable in the dataset, and n is the total number of features. In this research, the overall trend of “All Women with Births” is compared to the distributions of the each of the other fertility variables based on sociodemographics (specified in the Case Field option). The covariate matrix is represented by eigenvalues and eigenvectors, where the standard deviations for these are

$$\sigma_{1,2} = \left(\frac{(\sum_{i=1}^n \tilde{x}_i^2 + \sum_{i=1}^n \tilde{y}_i^2) \pm \sqrt{(\sum_{i=1}^n \tilde{x}_i^2 - \sum_{i=1}^n \tilde{y}_i^2)^2 + 4(\sum_{i=1}^n \tilde{x}_i \tilde{y}_i)^2}}{2n} \right)^{1/2}$$

computed using:

which includes scaling of variance using an adjustment factor so the ellipse includes an accurate representation of datapoints (ESRI, 2020b).

Observing the raw values of the fertility data based on socio-demographics allowed some visual spatial trends of the data, but the directional ellipse makes those spatial relationships more clear because it calculates the x and y directions separately – defining the axis of the ellipse based on standard deviations of the x- and y-coordinates (Chew, 1966). Should the autocorrelation reveal statistical significance, a directional distribution can give insight into a directional significance based on standard deviations of the raw values from the mean center of each feature (Fisher et al., 1987).

Getis-Ord G_i^* statistic. Statistical significance of maternal fertility demographics in this research was observed both linearly, with the aforementioned Poissonian and Negative Binomial distributions, and spatially with the Moran's I statistic. Although the Moran's I statistic calculated in SAS can indicate significance between variables using coordinate data, it does not provide the ability to observe the spatial boundaries the data represent, such as , census tracts in the United States. The difference between these two spatially-based statistics is that the Moran's I is a global statistic observes the overall trend in the data, which works best when the data are consistent over space (Goodchild, 1986; Griffith, 1987). The Getis Ord G_i^* statistic is a local statistic that observes the relationships of neighboring features, comparing the local to the global (Arthur Getis & Ord, 1992).

Within ArcPro 2.4, the Getis Ord G_i^* statistic is calculated using an Optimized Hot Spot Analysis which observes the count values of features and compares them to the values of neighboring features in the dataset. The Getis-Ord G_i^* statistic is given as:

$$G_i^* = \frac{\sum_{j=1}^n w_{i,j}x_j - \bar{X} \sum_{j=1}^n w_{i,j}}{S \sqrt{\frac{n \sum_{j=1}^n w_{i,j}^2 - \left(\sum_{j=1}^n w_{i,j}\right)^2}{n-1}}}$$

where x_j is the attribute value for the feature (j), $w_{i,j}$ is the spatial weight between features i and j , n is equal to the total number of features, and \bar{X} and S are

respectively: $\bar{X} = \frac{\sum_{j=1}^n x_j}{n}$, $S = \sqrt{\frac{\sum_{j=1}^n x_j^2}{n} - (\bar{X})^2}$. Statistical significance is based on

z-scores, where positive z-scores indicate high clustering of high values (hot spots), and negative z-scores indicate high clustering of low values (cold spot).

The variable observed is the total number of women with births within the last 12 months (coded: AllBirths). Analysis of this variable alone was done to observe the overall spatial trend of births in the United States in order to have a reference for analysis of women with births based on certain sociodemographics. Also this was to done to have a reference for a national spatial analysis of infertility or use of infertility services. Future analysis might consider Optimized Hot Spot analyses for the fertility variables based on sociodemographics.

Part 2b: Spatial Analysis of CDC-Reporting Fertility Clinics in the United States.

Collection of ART clinic data in the United States began in 1986, shortly after the establishment of the SART in the early 1980s. In 1992, the Federal Trade Commission condemned fertility clinics of false advertisement of success rates which resulted in the passing of the Fertility Clinic Success Rate and Certification Act of 1992 (FCSRCA), Section 2(a) of P.L. 102–493 (42 U.S.C. 263a-1(a)). This Act required clinics to report yearly to the CDC their information about ART cycles performed at their clinic. In 1997, the first ART Success Rates Report was published from

data in 1995. Clinic reports are available online through the CDC from 1995-2017. As of June 2020, the 2018 data are available as summaries, but is not available for download (CDC, 2019b).

This research utilized ART Success Rate clinic data from 2017, since that is the cut-off date for the American Community Survey Fertility data (representing 2013-2017). Although the clinic data from 2013, 2014, 2015, and 2016 were also downloaded, it was found that the number of clinics did not vary greatly, so only 2017 – being the year with the most clinics – was used for this research.

Data collection. Clinic data were obtained through the CDC website, in the NASS archived reports (<https://www.cdc.gov/art/reports/archive.html>). Data were downloaded in MS Excel format and converted to shapefiles through the geocoding process.

Data preparation. Addresses and geolocated clinics were not available through the CDC's archived clinic tables. In order to obtain the geographic locations of each clinic, the clinic name was searched in Google and matched with the state and city disclosed on the CDC website. To triangulate the accuracy of the address of each clinic, the website FertilityIQ was referenced to check the status of the clinic and the address. Status was important as some clinics closed or reorganized since the previous year, so they may no longer be in service, or have a new name. If a clinic changed or was reorganized, it was identified in the Excel file downloaded by the CDC. This process was conducted for all clinics between the years of 2013-2017, as disclosed by the CDC. Earlier years had more instances of closed clinics and more incidences of reorganized clinics. The 2017 dataset had the least of both at 0.

Once the addresses were obtained, the data were georeferenced in ArcPro 2.4. The initial results were 444 matched (99.11%), 1 unmatched (0.22%), and 3 tied (0.67%). All unmatched and

tied results were reconciled by reviewing them individually and placing them in the correct locations or confirming they were in the correct locations.

Data analysis. For this research, observation of the spatial locations of the clinics was used to answer the research questions relating to the spatial relationship between reporting fertility clinics, population density, and birth density. There were variables relating to success rates, types of services offered, and accreditation and memberships of the clinics, but these were not observed in the analyses.

Select by location. With over 72,000 census tracts and less than 450 ART clinics, it was presumed that the majority of census tracts would not have a clinic, a census tract would have no more than one clinic if there was one, and that the clinics would be located in areas of high population density. To test this concept, the Select by Location tool was utilized so that census tracts that had a clinic could be selected. A new shapefile and excel file were created for the census tracts that had at least one clinic. In this way, the data from all census tracts with clinics could be compared to all census tracts without clinics.

Kernel density. Observation of spatial density was conducted using the Kernel Density tool in ArcPro, which is a predicted measurement of the magnitude-per-unit area from a point. The measurement uses a kernel function to create a smoothed raster surface to observe spatial clustering with a gradient image. Calculation of density is based on the following formula:

$$Density = \frac{1}{(radius)^2} \sum_{i=1}^n \left[\frac{3}{\pi} \cdot pop_i \left(1 - \left(\frac{dist_i}{radius} \right)^2 \right)^2 \right]$$

For $dist_i < radius$

, where $i=1, \dots, n$ are input points, pop

is an optional parameter for a population field, and $dist_i$ is the distance between point i and (x,y) location (Silverman, 1986). Within ArcPro 2.4, this analysis used the Planar method of analysis

with square meters since the data in ArcPro 2.4 and from the Census are automatically in meters. Also the default search radius is calculated using

$$SearchRadius = 0.9 * \min \left(SD, \sqrt{\frac{1}{\ln(2)} * D_m} \right) * n^{-0.2}$$

, where D_m is the weighted median

distance from the mean center, n is the number of points, and SD is the standard distance. The default search radius was 412,323.06 meters (256.21 miles).

Getis-Ord Gi statistic.* The Optimized Hotspot analysis was also utilized with the fertility clinic data points. This analysis required the creation of a grid, or fishnet, to have a spatial boundary from which to determine spatial density. More points within a grid cell indicated higher density. The grid cell size was automatically calculated in ArcPro 2.4 at 43,289 meters (26.9 miles). Statistical significance was based on z-scores, where positive z-scores indicate high clustering of high values (hot spots), and negative z-scores indicate high clustering of low values (cold spot) (ESRI, 2020a; Getis, 2001). Parameters of the Getis-Ord G_i^* statistic used here is the same as described earlier, with the exception that the spatial parameters are the grid cells rather than census tracts.

Chapter Three Tables

Table 3.1 Sociodemographics chosen to observe with qualitative and quantitative data

Independent Variables	References to Support Inclusion
Geographic	
State	(King & Meyer, 1997; National Conference of State Legislatures, 2017)
Census Tract	(Dragičević, 2004; Dustin T. Duncan et al., 2018)
Sociodemographics	
Ethnicity	(M. P. Bitler & Schmidt, 2012; M. Bitler & Schmidt, 2006; Dieke et al., 2017; Kissil & Davey, 2012; Seifer et al., 2010)
Sexual Orientation	(Bergmann, 2011; Greenfeld & Seli, 2016; Jin & Dasgupta, 2016; The Ethics Committee of the American Society for Reproductive Medicine, 2013; Wu et al., 2017)
Age	(Albertini et al., 2017; Chandra et al., 2013; Lemoine & Ravitsky, 2015)
Income	(Jacqueline R. Ho et al., 2017; Mehta et al., 2016; Seifer et al., 2010; The Ethics Committee of the American Society for Reproductive Medicine, 2015)
Religion	(Greil et al., 2011; Kee et al., 2000; Klitzman, 2018)
Education	(Jacqueline R. Ho et al., 2017; Kunicki et al., 2018; The Ethics Committee of the American Society for Reproductive Medicine, 2015)
Employment	(Langher et al., 2019; Nicolette, 2016; Simoni et al., 2017)
Nativity	(Kronenfeld, 2017; Luke et al., 2016)
Insurance	
Private insurance	(Dieke et al., 2017; Mutcherson, 2017)
Public insurance	(Adashi & Dean, 2016; Kulkarni et al., 2017; Mutcherson, 2017)
Presence of infertility insurance mandate	(Bitler & Schmidt, 2012; Bitler & Schmidt, 2006; Boulet et al., 2019; Schmidt, 2007)

Table 3.2 Infertility Self-Efficacy (ISE) Scale

TABLE 3. Characteristics of the 16 ISE items.

ISE Item	Mean score (range 1–9)	Mean expert rating (range 1–7)
Ignore or push away unpleasant thoughts that can upset me during medical procedures	6.35 (2.16)	4.43 (1.72)
Keep a sense of humor	6.90 (2.01)	5.57 (1.40)
Make meaning out of my infertility experience	5.80 (2.47)	4.00 (2.00)
Handle mood swings caused by hormonal treatments	5.65 (2.02)	4.71 (1.38)
Keep from getting discouraged when nothing I do seems to make a difference	5.04 (2.22)	4.86 (1.35)
Accept that my best efforts may not change my/our infertility	6.30 (2.39)	5.14 (1.35)
Control negative feelings about infertility	5.36 (2.29)	4.14 (1.77)
Cope with pregnant friends and family members	5.59 (2.56)	5.00 (1.16)
Handle personal feelings of anger or hostility	6.36 (1.71)	5.57 (1.13)
Keep a positive attitude	6.56 (1.93)	5.29 (0.95)
Lessen feelings of self-blame, shame, or defectiveness	5.78 (2.47)	5.71 (1.38)
Stay relaxed while waiting for appointments or test results	5.03 (2.50)	4.29 (0.49)
Do something to make myself feel better if I am sad or discouraged	6.81 (1.95)	5.71 (1.11)
Feel good about my body and myself	5.74 (2.45)	5.86 (1.07)
Keep active with my usual life routine	6.81 (2.03)	4.29 (1.60)
Feel like a sexual individual	5.75 (2.66)	4.86 (1.07)

Cousineau. [Infertility](#) Self-Efficacy scale. Fertil Steril 2006.

*adapted from (Cousineau et al., 2006)

Table 3.3 American Community Survey 2013-2017: Fertility (S1301)

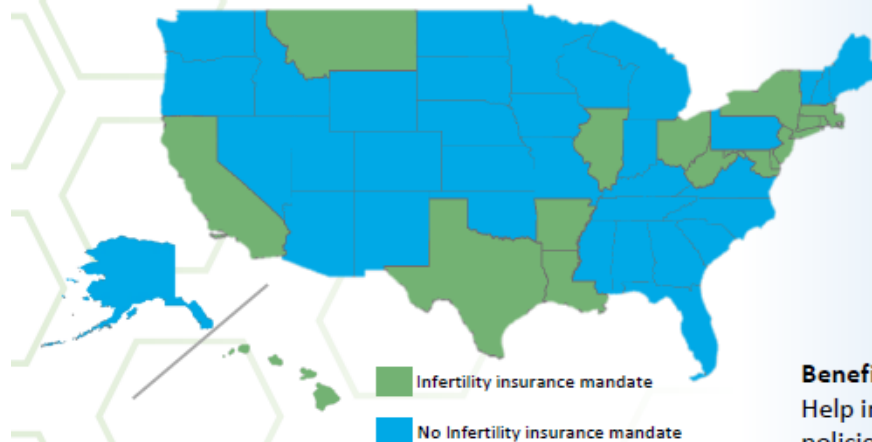
United States	Total		Women with births in the past 12 months					
			Number		Percent Distribution		Rate per 1,000 women	
	Estimate	Margin of Error	Estimate	Margin of Error	Estimate	Margin of Error	Estimate	Margin of Error
Women 15 to 50 years	76,416,928	+/-12,601	3,994,223	+/-20,838	(X)	(X)	52	+/-1
15 to 19 years	10,359,412	+/-5,575	157,388	+/-2,685	3.9%	+/-0.1	15	+/-1
20 to 34 years	32,739,120	+/-5,658	2,979,339	+/-16,878	74.6%	+/-0.2	91	+/-1
35 to 50 years	33,318,396	+/-9,542	857,496	+/-8,559	21.5%	+/-0.2	26	+/-1
RACE AND HISPANIC OR LATINO ORIGIN								
One race	74,075,571	+/-30,513	3,871,392	+/-19,302	96.9%	+/-0.1	52	+/-1
White	53,241,216	+/-19,470	2,728,858	+/-15,855	68.3%	+/-0.2	51	+/-1
Black or African American	10,778,133	+/-11,790	579,871	+/-6,335	14.5%	+/-0.1	54	+/-1
American Indian and Alaska Native	666,447	+/-5,081	41,764	+/-1,311	1.0%	+/-0.1	63	+/-2
Asian	4,942,390	+/-7,117	258,381	+/-3,533	6.5%	+/-0.1	52	+/-1
Native Hawaiian and Other Pacific Islander	158,031	+/-1,887	10,011	+/-757	0.3%	+/-0.1	63	+/-5
Some other race	4,289,354	+/-24,402	252,507	+/-3,773	6.3%	+/-0.1	59	+/-1
Two or more races	2,341,357	+/-23,741	122,831	+/-3,274	3.1%	+/-0.1	52	+/-1
Hispanic or Latino origin (of any race)	14,938,405	+/-4,877	889,228	+/-7,740	22.3%	+/-0.2	60	+/-1
White alone, not Hispanic or Latino	43,509,770	+/-8,118	2,146,670	+/-13,573	53.7%	+/-0.2	49	+/-1

Table 3.3 (continued)

United States	Total		Women with births in the past 12 months					
			Number					
	Estimate	Margin of Error		Estimate	Margin of Error		Estimate	Margin of Error
NATIVITY								
Native	63,572,289	+/-36,161	3,204,452	+/-18,611	80.2%	+/-0.2	50	+/-1
Foreign born	12,844,639	+/-40,383	789,771	+/-7,294	19.8%	+/-0.2	61	+/-1
EDUCATIONAL ATTAINMENT								
Less than high school graduate	13,105,452	+/-44,727	516,785	+/-6,231	12.9%	+/-0.2	39	+/-1
High school graduate (includes equivalency)	16,069,512	+/-76,049	920,398	+/-8,708	23.0%	+/-0.2	57	+/-1
Some college or associate's degree	24,932,063	+/-33,883	1,258,848	+/-8,881	31.5%	+/-0.2	50	+/-1
Bachelor's degree	14,765,055	+/-69,703	811,834	+/-10,902	20.3%	+/-0.2	55	+/-1
Graduate or professional degree	7,544,846	+/-63,402	486,358	+/-8,445	12.2%	+/-0.2	64	+/-1
POVERTY STATUS IN THE PAST 12 MONTHS								
Below 100 percent of poverty level	11,484,450	73,281	883,722	+/-14,932	22.4	+/-0.3	77	+/-1
100 to 199 percent of poverty level	13,176,393	77,293	797,006	+/-15,777	20.2	+/-0.4	60	+/-1
200 percent or more above poverty level	48,041,799	+/-117,261	2,147,404	+/-21,015	53.9%	+/-0.3	45	+/-1

Infertility Services and Health Insurance

16 states in the U.S. have insurance mandates for infertility services, but do they help alleviate the high cost of those services? Does your health insurance increase **your** ability to pay for those services?



Benefits of Participating

Help inform new and current policies to increase financial accessibility to infertility services

Purpose of this research

Add context to the accessibility and use of different types of health insurance for infertility services.

Eligibility

Adults 19+ yrs who are looking for, using, or previously used infertility services

Participation

10 min Survey

and

Informal interview about your experience accessing infertility services

\$30 Amazon Gift Card for completing an interview

Access survey through QR code or click

[Policy in Context](#)



An interview request is at the end of the survey, or send an interview inquiry to

nbs@usf.edu



IRB Study # STUDY000110

Figure 3.1. Survey and interview recruitment flyer

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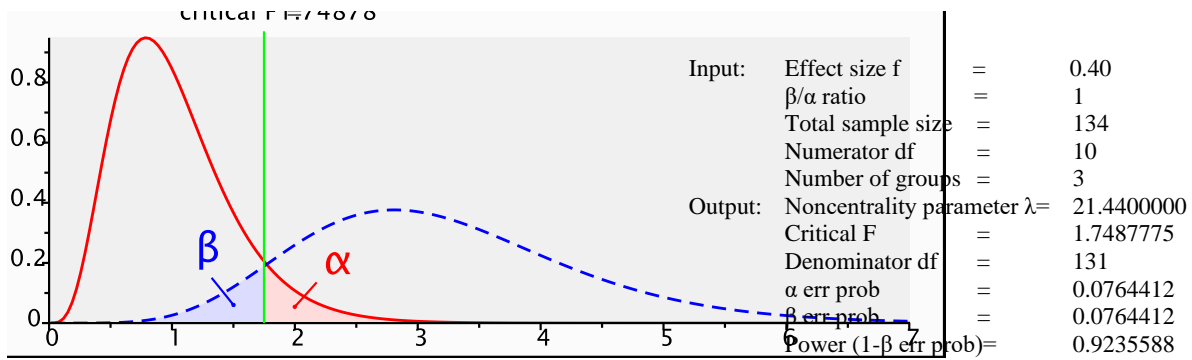


Figure 3.2. Power analysis for Infertility Self-Efficacy Scale

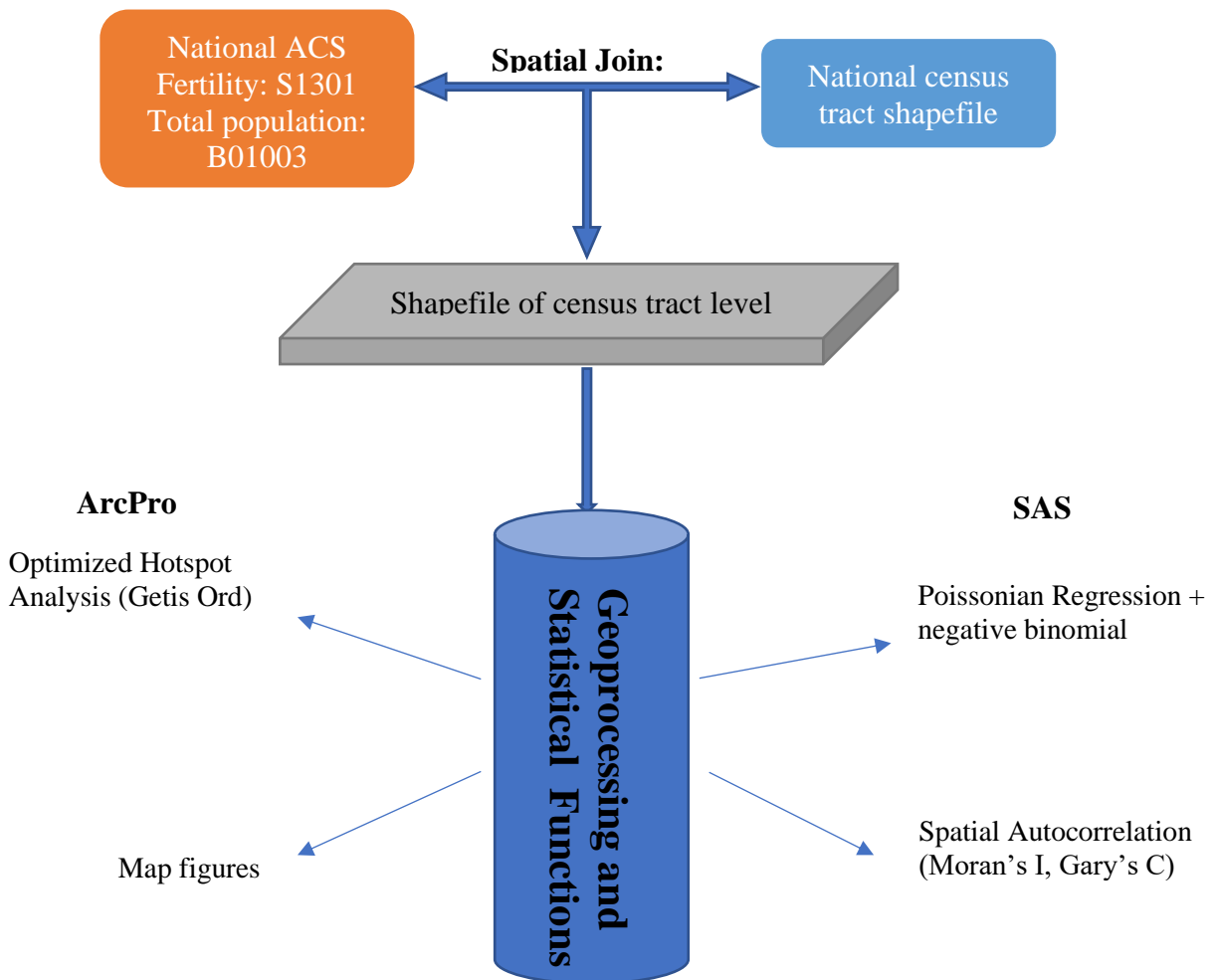


Figure 3.3. Geoprocessing of census data

CHAPTER FOUR:

RESULTS

This chapter provides the results of both the qualitative and quantitative data analyses for this research. Descriptive results are presented first, followed by results based on each of the seven research questions. By organizing the results by research question, all data sources (qualitative and quantitative) used to answer each research question can be observed simultaneously, either triangulating results or adding contextual information to further explain the results of one source. This follows the guidelines for a multiphase mixed method research design (Creswell & Plano-Clark, 2011). Some of the results of this dissertation have been published in conference abstracts from the 2020 American Society for Reproductive Medicine Scientific Congress and Expo (Stanley, 2020; Stanley & Foti, 2020). Use of the previously published material is allowed due to the user agreement of the journal Fertility and Sterility (Appendices H and I).

Descriptive Statistics

Qualitative Interviews

Informal interviews. *Demographics.* Table 4.1 lists the informal interview demographics. Bring next sentence forward for this paragraph. There were a total of 66 interviews completed between September 2019 – February 2020. The length of the interviews ranged from 9-28 min, with a total of 1,023 min (17.05 hours) of recorded interview time.

Regarding state representation, 51.5% of participants lived in a state with an infertility health

insurance mandate, and 48.5% lived in a state without an infertility health insurance mandate.

There were 16 states without a mandate, and 11 states with a mandate – representing 61% of the 18 states with an infertility health insurance mandate. States with mandates included California (3), Colorado (3), Illinois (5), Louisiana (1), Maryland (3), Massachusetts (3), New Jersey (3), New York (9), Rhode Island (1), Texas (4), and West Virginia (2). The states identified as having a mandate only reflect the mandated states as of January 2020.

Regarding the stages of infertility service use (Prospective, Active, Past), 51.5% were currently using infertility services (Active), 43.9% had previously used infertility services and either had successful pregnancies or were seeking other options (Past), and 4.6% were not yet accessing services but seeking information about infertility services in anticipation of using them (Prospective). The majority was female (92.4%), however there were also three men and two individuals identifying as non-binary or gender queer. Age ranges were between 21-43, with a mean of 32.7 (4.09). Estimated household income was self-reported, ranging between \$30,000 - \$700,000 with a mean of \$155,107.69. Of the reported income, 86.4% was joint income between married or cohabitating partners. The majority of participants was married (92.4%), heterosexual (83.3%), identified with no religion (54.6%), were Caucasian (86.4%), and employed full time (72.7%).

There were 16 different employment industries identified by interviewees. The three most common were healthcare (21.1%), higher education/adult education (16.7%), and non-profit sector (10.6%). The majority of participants had a master degree (42.4%), followed by bachelor degree (30.3%), and the next most common was the PhD (16.8%). PhD and professional doctorates (MD, DVM, PharmD, etc.) were identified separately. Regarding health insurance, 87.9% of participants reported having private health insurance through their employer or individually.

Expert interviews. Demographics. A total of eight organizations participated in an expert interview. Regarding the type of financial or other assistance provided by the organizations, five organizations specifically offered one or more grants to help with infertility services, ranging in amounts from \$500-\$10,000. The other three were particular to the organization. One was described as offering insurance benefits, one described a shared risk and medical savings management program, and one was described as offering insurance and case management. The types of organizations were also variable, where four were certified 501c3 non-profits, and the other four had their own descriptions (Table 4.2).

All but two of the organizations had residency requirements for persons seeking their assistance. Residency restrictions included U.S. resident or naturalized citizen (n=4), both U.S. resident and resident of Philadelphia, PA (n=1), and one that specified that the employer must be based in the United States (n=1). Of the eight organizations included, six offered services directly to individuals or couples, one offered services to individuals, couples, and clinics, and one offered to only employers as an insurance benefits package.

Baby Quest Foundation. The Baby Quest Foundation is a 501c3 non-profit that offers grants to two applicants per year to cover up to \$500 of associated costs for infertility services. Their main restriction is based on age, where persons over the age of 55 are not eligible for the grant, based on guidelines from medical professionals of the patient and those on the selection board. As of April 2020, the Baby Question Foundation has been able to fund 117 families in 29 states – 10 of which are states that have an infertility insurance mandate (Baby Quest Foundation, 2020).

The Tiniana Q. CADE Foundation. Founded in 2005 by a couple with personal experience using infertility services, The CADE Foundation is a 501c3 non-profit that offers two \$10,000

grants per year for people with diagnosed infertility. There are three grants they offer. These include 1) the Dr. Stephen Greenhouse Grant, founded in 2018 by physicians and staff of Shady Grove Fertility in memory of Shady Grove Fertility physician and reproductive health leader Stephen Greenhouse, MD; 2) the Family Building Grant, funded in part by donations from EMD Serono for medical infertility treatment and child adoption; and 3) the Savannah Grant, which is specifically for Shady Grove Fertility patients and was made in honor of a baby born at a Shady Grove who died in 2010 (Tiniana Q. CADE Foundation, 2020). Although people who require infertility services for reasons other than diagnosed infertility do not qualify for this grant, the foundation has raffle prizes for certain services or some money provided through various events that are open for anyone to receive. As of April 2020, the foundation has been able to provide funding for 12 families.

The Hope for Fertility Foundation. This 510c3 non-profit organization was founded in 2016 by a couple who went through the process of using infertility services and wanted to provide more funding “hope” for other couples who need infertility services to start a family. The foundation provides one grant between \$250-\$5,000, and since 2016 they have awarded 31 grants totaling \$122,650, resulting in three current pregnancies and 13 babies born or adopted (The Hope for Fertility Foundation, 2020).

Progyny. Progyny is described as a “fertility benefits administrator” that directs their fertility benefits to employers who self-insure their employees, utilizing a network of reproductive endocrinologists throughout the country (Progyny Representative, 2020). The benefits provided through Progyny are standalone or secondary insurance if the person either already has insurance or is on his or her partner’s insurance. By focusing on self-insured employers, Progyny is not affected by the state-based infertility insurance mandates. However, they adhere to the fertility

benefits included in the respective state mandates. “Progyny itself, the company, is not subject [to the state-based infertility mandate]. But, let’s say we were a self-funded employer and the mandate in New York State is three IVF cycles for infertility – even though Progyny wouldn’t have to adhere to it [the state-based infertility mandate], we do.” (Progyny Representative, 2020). The benefits they provide affect employers the same way as other types of insurance. “They’re [self-insure employers] paying deductible co-insurance and co-pay. But, there’s no added fee for them [employers] to access Progyny.” (Progyny Representative, 2020).

The Jewish Family and Children’s Service (JFCS) Fund. The Jewish Family and Children’s Service was first founded as an orphanage in 1855. Then in 1941 the orphanage in conjunction with the Association for Jewish Children (ACJC) and the Jewish Family Service (JFS), merged to become the Jewish Family and Children’s Service (JFCS, 2020). The organization created a grant program, called The Fertility Fund: A Gift from the Heart, for persons of Jewish ancestry living in the Philadelphia region needing infertility services. Applications for the grant are assessed by an external panel of physicians and funders of the grant, which is funded through donation from individuals and couples. The foundation also has partnering physicians who assist their members with navigating the fertility treatment process and pay clinics directly after verifying treatment recommendations from physicians.

Parental Hope. Parental Hope is a 510c3 non-profit organization founded in 2016 by a couple who used infertility services to start their family. After experiencing the high financial costs directly, they decided to create this organization that includes an online support group community, and two grants to support funding for infertility services. These are the Parental Family Hope Grant, which covers costs related to in vitro fertilization (IVF) or one frozen embryo transfer (FET); and the Embryo Adoption Grant, which offers a one-time award of \$5,000 to a couple who

qualifies for embryo adoption with the National Embryo Donation Center (Parental Hope, 2020). Since 2016, Parental Hope awarded 41 grants totaling \$370,900, resulting in 18 babies born and 4 on the way as of August 2020 (Parental Hope, 2020).

ART Risk Solutions. ART Risk agency was founded 15 years ago by a woman with personal experience navigating the use of surrogacy services in the United States. As she became very knowledgeable on the topic she began to identify trends in insurance coverage there surrogacy ends up not being covered, and from that created ART Risk Solutions that functions to either provide or direct clients to the sources of insurance or other financing they would need for surrogacy services (ART Risk Solutions Representative, 2020). ART Risk Solutions is described as a financial insurance solutions company that provides financial case management to individuals and couples using infertility services related to surrogacy. They also provide insurance groups available to individuals, gestational carriers, clinic offices, and employers (ART Risk Solutions, 2020). The agency is based in California, but they have an approximately 50% international client base (ART Risk Solutions Representative, 2020).

IntegraMed Fertility. IntegraMed Fertility is a division of IntegraMed America that functions as a medical savings account (MSA) crisis management association that provides discounted fertility services at their clinic partners throughout the United States and Canada. The company does not provide loans, but acts as a third party between self-pay patients and the clinics to process payment for services in a type of shared risk program (IntegraMed Representative, 2020). Self-pay patients are those who may have health insurance, but it does not cover infertility services beyond diagnostics. They offer “bundles” of fertility services and provide refunds up to 100% of costs if the cycles do not result in a baby, based on the type bundle program. The entity

that processes the payments between patients and clinics is a subsidiary of IntegraMed Fertility called Attain Fertility.

Survey Instrument

Demographics. There were a total of 134 survey responses included in this research, collected between September 2019 – January 2020. The majority of survey respondents heard about the research through Reddit (89.6%), and the next highest was through a friend (6.7%). Regarding the stages of use, there were 12 Prospective (9%), 71 Active (53%), and 51 Past (38.1%). Table 4.3 shows the demographics for the survey responses. All of the interviewees also completed a survey, and their data were also reflected in these results.

The majority of respondents was female (95.5%), between the age of 31-35 (47.8%), and married (90.3%) with annual household incomes above \$100,000 (70.1%). The majority were also heterosexual (82.1%) and Caucasian (88.1%), identifying with no religion (51.5%), and employed full time (83.1%). There were, however, a variety of employment levels. Some had only part-time jobs (2.9%), multiple jobs (1.5%), were unemployed but had a partner who was working (8.2%), were a student (1.5%), or were self-employed (3.7%).

Due to the supposition that employers might play a role in facilitating access to infertility services, this research also included information about the employment industry to show the variety of places that have employees who utilize infertility services. There were 16 different industries identified by survey respondents. The three most common industries were Healthcare (26.9%), Higher Education/Adult Education (10.5%), and K-12 education (8.2%). The majority of participants had a Masters degree (35.8%), followed closely by Bachelors degree (34.3%). The

next most common degree was the Doctorate (13.4%). The doctorate includes PhD, SciD, DrPH, EdD, DDiv, etc., but not professional degrees such as MD, DVM, DDM, PharmD, etc.

The following are descriptive statistics based on the following sections in the survey: Health Education, Online Communities, and the Infertility Self-Efficacy Scale.

Health education. There were two questions about health education related to human infertility. Tables 9 and 10 show the responses for these questions. When asked about the grade in which they received information about the risks of fertility decreasing with age, the majority of respondents responded that they never received that information in any level of school (56%), and 20.6% did not remember if they received that information in any level of school (Table 4.4). No one reported hearing this information in elementary school, 1 remembered hearing about it in middle school (0.8%), followed by high school (3.8%), and 12 heard about those risks in college or university (8.7%) (Table 4.4).

When asked about their opinion on the earliest grade at which people should learn about the risks of fertility decreasing with age, 24.8% did not think it was a topic to provide in any level of school, however the majority thought that high school (45.1%) was the best time to introduce this type of health education (Table 4.5).

Online communities. In an effort to gauge the use and perception of online support communities, the survey contained three questions related to the use of these online spaces, and types of information shared. These questions are based on Likert-type scales ranging from 1 (Strongly Agree) to 5 (Strongly Disagree) (Table 4.6). When asked to respond with their level of agreement to the prompt “I use online ART/infertility support forums to help me make decisions about what infertility services to use”, 41.8% responded “Agree”, followed by “Strongly Agree” at 31.3%. When asked to respond with their level of agreement to the prompt “I talk about my

experience with using infertility services more online than I do with people in person”, 44% respond with “Strongly Agree”, however the responses for Agree, Neutral, and Disagree were close at 19.4%, 8%, and 15% respectively. When asked to respond with their level of agreement to the prompt “I prefer to access online support forums for ART/infertility before talking to a physician”, 32.8% responded “Neutral”, followed by “Agree” at 28.4%, and “Disagree” at 22.4%.

Future analyses could determine if there are demographic differences among the respondents to these survey questions, based on characteristics such as age, ethnicity, education, and income.

Infertility Self-Efficacy Scale. The mean scores for each item of the ISE scale are located in Table 4.7. Using a GML model, comparisons in mean ISE score were measured against residence in a state with or without an infertility insurance mandate, stage of use, age, ethnicity, and responses to questions about infertility health education and the use of online infertility support communities. There were no differences between ISE mean score and residence in a state with or without an infertility insurance mandate, stage of use, age, online community use about making decisions, or preference to talk to people in online community forums before speaking to a physician about infertility services (Prospective, Active, Past) (Table 4.8). There were significant differences in ISE mean scores between ethnicities ($F=3.19$, $Pr>F=0.009$), responses to health education ($F=2.53$, $Pr>F=0.032$), and preferences for discussing infertility related issues in online forums ($F=5.01$, $Pr>F=0.0009$). Post-hoc analysis using the Tukey’s test to control for Type 1 experiment wise error rate found statistically significant differences in ISE mean scores at 95% confidence between Asian and Caucasian groups (Table 4.9), as well as the mean ISE scores between those who responded “Strongly Agree” compared to “Disagree” or “Strongly Disagree” to the prompt “*I talk about my experience with using infertility services more online than I do with*

people in person” (Table 4.10). Significant difference in ISE mean scores with the the health education responses were not significant after the post hoc analysis.

American Community Survey: Fertility of Women Age 15-50, Census Tract

National fertility statistics between the years of 2013-2017 show that there were estimated to be 76,416,928 (+/- 12,601) women between the age of 15-50, of which 3,994,223 (+/-20,838) gave birth, at a rate of 52 (+/- 1) per 1,000 women (Table 3.3). Among the age ranges, women age 20-34 had the highest number of women with births (n=32,793,120), highest fertility rate (91 +/- 1 per 1,000 women), and the highest percent distribution of women with births among all the age ranges (74.6%). For race/ethnicity, Caucasian women with (n=53,241,216, 68.3%) and without (n=43,509,770, 53.7%) Hispanic/Latin ancestry reported giving birth the most and had the highest percent distribution. However, those two groups had the lowest fertility rate per 1,000 women, where Caucasian women with Hispanic/Latin ancestry had a rate of 51 +/- 1 per 1,000 , and Caucasian women without Hispanic/Latin ancestry had a fertility rate of 49 +/- 1 per 1,000. The highest fertility rates were among racial groups with the lowest estimates of women with births, which were Native Hawaiian and Other Pacific Islander (63 per 1,000 +/- 5) and American Indian and Alaska Native (63 +/- 2 per 1,000). Foreign born women had higher fertility rates than native born women, at 61 +/- 1 and 50 +/- 1, respectively. Women with a graduate or professional degree had the lowest estimated pregnancies that led to live birth (n=7,544,846), but they had the highest fertility rate (64 +/- 1 per 1,000) compared to the rest of the education variables. Among the poverty variables, women who were below 100% of the poverty level had the highest fertility rate per 1,000 women with births at 77 +/- . The comparison was women with births who were 100%-

199% of the poverty level and women who were 200% above the poverty level. These groups had the fewest number of women with births at 11,484,450 (Table 3.3).

The spatial scale the data were obtained is at census tract level, and there are 72,483 census tracts included in this research. Interestingly, the mean number of women who had a birth between states with and without an infertility insurance mandate were very close, where states without a mandate had a mean of 53.71 women with births (n=2,137,744) and states with a mandate had a mean of 55.9 (n=1,856,479) (Table 4.11). The number of census tracts between states with/without an infertility insurance mandate was also close, where states without a mandate had 39,798 census tracts and states with a mandate had 33,198. Examining the population density between these groups gives context to that close difference, where states without an infertility insurance mandate have a lower population density of 2,669.1 per mi² compared to states with a mandate where population density is 9,152.2 per mi². Since the fertility data reflects the years 2013-2017, these analyses are based on the 16 states that had infertility insurance mandates during those years.

Before calculating spatial autocorrelation, the first step in the analysis was to determine the relationships between the variables based on linear regression using the Poissonian distribution (Table 4.12), which showed some overdispersion. To account for the overdispersion, a negative binomial regression was utilized to account for unequal mean and variance (Table 4.13), as recommended by Haight (1967). The negative binomial reduced the Akaike information criterion (AIC) from 1,640,741.0079 to 645,221.8708, effecting a 60.7% reduction in prediction error. A reduction in the AIC indicates a reduction in the out-of-sample prediction error (Hurvich et al., 1998), so this negative binomial distribution shows a more accurate description of the relationship between these variables. The negative binomial removed statistical significance from five

variables: African American, American Indian/Alaska Native, Asian, Two or more ethnicities, and Hispanic.

The spatial autocorrelation utilized the significant variables from the Poissonian and also for significant variables from the negative binomial to show their effect on the spatial autocorrelation output. This experiment is encouraged due to the high degree of overdispersion, where a reduction in the number of variables should affect the output due to the iterative analysis included in autocorrelation (Griffith, 1987).

CDC-Reporting Fertility Clinics

There was a total of 448 fertility clinics reporting information to the CDC in 2017 (Table 4.14). The majority of the clinics provided all services described in the report from the CDC, which includes: use of donor eggs (89.1%), donor embryos (62.3%), embryo cryopreservation (100%), egg cryopreservation (98%), see single women (99.1%), and use gestational carriers (88%). Every state but Alaska and including the territory of Puerto Rico, had at least one ART clinic. Of those 448 clinics, 82% were SART member clinics, and 92% were accredited labs through one of three organizations: (1) the College of American Pathologists/American Society for Reproductive Medicine (CAP/ASRM), (2) the Joint Commission on Accreditation of Healthcare Organizations (JACHO), or (3) the New York State Tissue Bank certification for ART laboratories (NYSTB) (CDC, 2019a) (Table 4.15)

Place as a Risk Regulator for Infertility Service Use

Research Question 1: Reasons for accessing infertility services

R1: Why do people access infertility services in the United States?

Survey. At the time of the survey, the majority of respondents were not currently parenting (76.7%), and those who had children (n=31) had between 1 (n=19) and 3 (n=1) (Table 4.3). Only people who used infertility service in the past reported having children as a result of using assisted reproduction (n=25). Many of the participants had more than one reason for needing infertility services. The most common reason for people prospectively seeking infertility services was unexplained infertility (n=5). For those actively seeking infertility services, the most common reasons were unexplained infertility (n=35) and female factor (n=25). For those who sought infertility services in the past, reasons were for female factor infertility (n=16) and dual male/female factor (n=10) (Table 4.3). Overall, the most common reported reasons for seeking infertility services were split between unexplained (26.7%) and female factor for infertility (26.7%).

Informal interviews. At the time of the interviews, the majority of participants were not pregnant (89.4%) and had no children (80.3%). Of those who were pregnant, four were due to IVF (6.1%), one from IUI and one from using egg retrieval. There was one instance of twins from using IVF, and one instance of adoption (Table 4.2). There were 11 (16.7%) interviewees who reported having children from using assisted reproductive technology. Many of the participants had more than one reason for seeking infertility services, especially those who had some form of diagnosed or unexplained infertility. Primary reasons for those actively seeking infertility services were unexplained infertility (27.3%) and female factor (25.8%), and the secondary reasons for seeking services were reversed, with female factor at 6.1% and unexplained infertility at 3%. There were

also other non-infertility related reasons, such as being in a same-sex relationship (10.6%), infertility due to cancer (4.6%), and avoidance of transgenerational inheritance of recessive genes (1.5%).

Research Question 2: Aspects of travel

R2: What influence does geographic location have on access to infertility services?

Survey. There are seven survey questions related to travel for infertility services. These questions inquire about instances of, or intentions to, travel either domestically or internationally to access infertility services. The questions also inquire into reasons for and where persons want to travel to seek services.

When asked about inter-state travel, the majority of respondents indicated they have not and do not intend to move out of state to access infertility services (90.3%), while nine (6.7%) indicated they are considering moving out of state, 3 (2.2%) indicated actually moving out of state, and 1 (0.75%) indicated traveling out of state for services, but did not move residence (Table 4.16). When asked about potential reasons for traveling out of state to access infertility services to access better services, 94% indicated having not and not intending to move out of state to access a better physician or fertility clinic, while three respondents (2.2%) moved out of state to access better services, and four respondents (3%) are considering moving out of state to access better services (Table 4.17).

When asked about instances or intentions to travel internationally for infertility services, 83% indicated they have not and do not intend to travel internationally to access infertility services, while 20 respondents (15%) reported considering traveling internationally, two respondents (1.5%) traveled internationally to access infertility services, and one respondent intends to travel

internationally (Table 4.18). For those who travelled internationally to access infertility services, reasons were because of lower cost of services. For the person who intended to travel internationally, the reason was specifically because of a greater availability of egg and embryo donors, compared to the United States. The two countries identified as having been visited specifically to use infertility services were the Republic of Georgia and Czech Republic. The countries people indicated considering travelling to were: Republic of Georgia, Czech Republic, Barbados, Croatia, Canada, Greece, Israel, Tunisia, Finland, Mexico, Cayman Islands, and some were undecided.

Informal interviews. When observing the relationships between the code “Travel” and the SCT construct codes, the code that intersects most frequently with “Travel” is “Facilitator” (Figure 4.1). This suggests that, when discussing aspects of travel, most interviewees tended to discuss travel as a facilitating aspect of accessing infertility services. Within the discourse related to “Travel”, two main themes developed: *distances* people travel to access infertility services; and making *clinic decisions* based on travel, cost, quality of services, and restrictions based on insurance and provider networks. In the following quotes, state’s that are **bold** represent states with an infertility insurance mandate.

Distances. Distances traveled to clinics were not explicitly asked of the interviewees, but 22 (33%) reported distances traveled in minutes, one way. Distances ranged from 5 minutes to 240 minutes, and modes of transportation reported by interviewees included travel by foot, motor vehicle, train, boat, and airplane. There were responses from persons in both state’s with and without infertility insurance mandates that clinics were within an appropriate proximity of where someone lives.

“...it’s [the clinic] actually like eight blocks away or something. It’s very convenient.” (Interview 006, Female, Caucasian, Pennsylvania)

“...it’s really only six miles, although in south Florida, that’s about 30 minutes, depending on traffic” (Interview 026, Female, Caucasian, Florida)

“ Our office that we utilize is within our same city. It’s actually very close to our house. We don’t drive very far” (Interview 048, Female, **Louisiana**)

“We’re very lucky because we live in southern California, so there’s many clinics in our immediate area. We actually ended up going to three different ones because we weren’t happy with the first two. So, we had a lot of options. They were all in our same county” (Interview 052, Female, Caucasian, **California**)

There were instances where distance was described as the proximity of the fertility clinic to the person’s place of employment, rather than the proximity of the clinic to the person’s residence.

“Oh, it [clinic] was really close. It was less than five minutes from work.” (Interview 001, Female, Caucasian, **New Jersey**)

“Actually, the clinic is a mile from my job. It’s just one of two in the area.” (Interview 043, Female, Caucasian, Wisconsin)

“It’s [the clinic] actually really close by, the same campus where I work, so a 10-minute walk from my office” (Interview 057, Caucasian, Georgia)

Clinic decisions. The rationale for selecting a clinic varied and was never just one reason. Proximity to home and work were main drivers for clinic selection, as well as recommendations from primary physicians or OBGYNs, and some decisions included cost of services and reputation of the clinic or attending physician. When travel was discussed along with clinic selection, the choice of clinic was marginally based on proximity.

“It’s quite close. It’s a 15-minute drive. It is the only one in the city”
(Interview 024, Female, Caucasian, Virginia)

“We have a local clinic here... This is within the same city, but if I wanted to go to any other one, I would have to leave the city roughly two hours away” (Interview 015, Non-binary, Multiracial, Minnesota)

There were sentiments relating to the lack of other closeby clinic options that provided the full range of services people required, and the majority of those responses was from people living in non-mandated states.

“So, it’s in state. So, the clinic I use has a satellite office about 20 minutes from me, but the main office where they do their more extensive procedures is an hour away from me... So, even though there’s a location I can drive to 20 minutes away, it’s nowhere near as well-equipped as the main one. So, I think options are a bit limited. Of course, for people who live closer to the metro ***** area, there’s tons of options to choose from. But in this area, you either have to be willing to spend a lot of time in the car or maybe opt for a clinic that’s a little less than desirable. So, that’s been interesting” (Interview 012, Female, Caucasian, Michigan)

“We drove to *****, so there’s the University of ***** has a women’s health group, they’ve got a reproductive medicine office that does IUI, IVF, egg and sperm freezing. So, we drove about two hours to get to those services. And it would have been a two- or three-hour drive anywhere we needed to go or to get to that service” (Interview 029, Female, Caucasian, Kansas)

Others reported network-imposed restrictions forcing them to use clinics within the network of the person’s insurance provider in order to have any type of insurance coverage for infertility services.

“I live in ***** and there are three clinics in the city... I have to go to the clinic that’s affiliated with the network that I work for. It’s in the same city but it is like an hour away. It’s not necessarily close. It was a

significant burden to have to go there. Especially every other day for monitoring during the IVF process...I actually ended up traveling to Texas **** in **** and sought care from their clinic. My insurance actually did pay for it there because they're in network, apparently" (Interview 039, Female, Caucasia, Pennsylvania)

"We started off at **** Fertility Clinic because I worked for ****. So, that's the only clinic that they [insurance] would cover, but they don't cover IVF. So, when we reached that point in our path and I switched onto my husband's insurance, we went to a private clinic that was in network for his insurance, but also nearby, so super lucky" (Interview 016, Female, Caucasian, North Carolina)

It is important to note that although the "Travel" code was found along with facilitating factors more than barriers, there were instances of travel that still involved moving out of state, traveling out of state, or traveling out of the country to access infertility services. Travel was a facilitating factor, but only when there were financial benefits to traveling. There were three instances where people traveled from a mandated to another mandated state; two instances of people traveling from a mandated state to a *non*-mandated state; and one instance of someone traveling from non-mandated state to non-mandated state,

"We actually do travel. We're located in Virginia, but we travel to New York for our IVF clinic...because of the cost." (Interview 019, Female, Caucasian, Virginia)

"So, I found an amazing clinic up in – I was living in Florida at the time – up in Michigan and this clinic had an amazing success rate and it happened to be located right next to my aunt's house...So, we ended up going with that clinic based on its success rate and the fact that I could stay at my aunt's house next to it" (Interview 037, Female, Caucasian, Florida)

It is also important to note that some people who lived in a mandated state still required travel to another state to access infertility services.

“So, I was originally in Massachusetts – living in Massachusetts – and working in Massachusetts. And that is where I started fertility treatment and I did one. I did one embryo transfer before going to law school in Illinois, but all my embryos were in Massachusetts and it’s kind of like expensive to start with a new doctor and to transfer them over. So, I kept flying back to Massachusetts” (Interview 007, Female, African American, **Illinois**)

“Initially, I went in-state with the IUIs and they could not figure out what was wrong. They did not consider me a candidate for IVF. At that point, I moved to out-of-state services and so I traveled to Maryland, which is four hours from my home...I did because they have a money-back guarantee, the ‘shared risk’ program” (Interview 051, Female, Caucasian, **West Virginia**)

In instances of surrogacy, travel was required if the individual or couple had residence in a state where surrogacy was not legal, such as in New York prior to April 2020 when the couple below were using surrogacy services,

“Yeah, I did have to go out of state. It’s [surrogacy] not legal in New York City yet...I mean every time you have – I mean the agency can do everything online or over the phone, Skype. For the clinic, obviously, you have to go [out of state], yes. And since she [surrogate] was in Connecticut not too far, I also went to meet her in person three or four times...I mean some people they have a surrogate in Ohio or I actually was offered a surrogate in Ohio, another one in North Carolina. So, yeah, you have to be prepared for travel – either you or the surrogate – to the clinic, you know?” (Interview 004, Male, Middle Eastern, **New York**)

In the two instances of international travel, one of the couples lived in a state with an infertility insurance mandate and the other lived in a non-mandated state, however their reasons for seeking services internationally were the same: to reduce the cost. Even though health insurance was not an issue, international travel was perceived as more cost effective,

“For the workup, like diagnostic testing, it was in the same state. So, I do have insurance coverage for – I mean not complete coverage, but pretty good coverage for the diagnostic tests. And my policy also covers up to six IUIs per attempt at pregnancy. So, a lot of that was covered. But I don’t have any coverage for IVF so we decided to travel abroad to do IVF. We ended up flying to the Czech Republic. That’s where we did IVF” (Interview 049, Female, Caucasian, Minnesota)

“So, I guess it wasn't strictly necessary, but I've been going to Tbilisi, Georgia; Republic of Georgia. And part of that is the cost factor because we're trying to keep everything under the \$20,000 reimbursement... I guess I would say the care is different in Georgia. It's a little bit more consumer-focused, we could just pay for whatever we want. Where in the U.S., most of the – actually we spoke to a doctor in Canada too, they really wanna push you into one type of treatment, or they kind of have a timeline of how you do things” (Interview 035, Female, Caucasian, **California**)

There were also responses from people in both mandated and non-mandated states about considering traveling abroad to access services, including receiving medications, although those individuals had not traveled at this point in time.

“I have looked at some of the other states. I’ve also looked at some other countries. So, I’ve just kind of gotten a gauge for the pricing and the success rates and stuff in different places, but no official decisions have been made about if we’ll do any of that” (Interview 010, Male, Caucasian, **Texas**)

“I have looked into a lot of ways to pay for it. We looked into going abroad to Greece or Prague because it’s a lot cheaper there to do IVF. But, it is a time investment from work by taking off a lot of time. You’re kind of putting all of your eggs in one sort of IVF basket. We have looked into a lot of things like that and ultimately decided our local ones – although they’re more expensive – would just be easier” (Interview 024, Female, Caucasian, Virginia)

“I sometimes talk about going down to Mexico to get IVF, but I don't think I'm really serious about it. But sometimes I think about it”(Interview 013, Female, Caucasian, Arizona)

“I think if we wound up having to do this again though, we might look into purchasing drugs internationally. Because we did some calculations and it looks like it’s actually way cheaper to go to Mexico, like, including the flight there to go spend a weekend to Mexico City and get medications within Mexico and then fly back with them, and save a few thousand dollars actually on the medication, which is wild” (Interview 057, Female, Caucasian, Georgia)

“I'm from [North Africa], so I'm thinking about going there because it would be cheaper and I'll have the support at home” (Interview 020, Female, Middle Eastern, **Massachusetts**)

Although traveling out of state or internationally were not common occurrences, there were responses about knowing that extensive travel was often part of people’s experiences, empathizing with those and being thankful they were not in the same situation,

“I know plenty of people who had to do crazy amounts of travel and I was very thankful that I was not one of those” (Interview 001, Female, Caucasian, **New Jersey**)

“So, travel, I mean we had to travel across the city, but we were not traveling out of state like other people have. But I feel like we’re pretty lucky because I do know that people do travel out of state to come to this doctor” (Interview 003, Female, Caucasian, **Colorado**)

“I think that it is becoming a larger trend for people to travel for IVF because of different costs, which is really unfortunate because it's becoming more common” (Interview 019, Female, Caucasian, Virginia)

Expert interviews. The knowledge of travel being a requirement for some people who are seeking infertility services was also mentioned in the expert interviews, where some representatives gave examples of patients they came across where some went to the extent of changing residences or jobs in order to get better access to infertility services,

“And there are patients that will literally leave their state, or leave their job, or go wherever they have to go to either get a job that offers access care or to go to a state that will give them access to care” (IntegraMed, MSA crisis management company)

Based on the responses from the survey, informal interviews, and expert interviews, the influence of travel on infertility services can be described as a facilitative nuisance. Few people reported wanting to travel, or thinking about travel for infertility services, however qualitative responses express travel is a common requirement for people using these services – even if it was not experienced by them. Interestingly, “Travel” was never coded along with “Expectations” or any associated outcomes, as evidenced by the lack of lines connecting “Travel” to “Expectations” or “Outcomes” in the Code Map (Figure 4.1). Travel was, however, distantly linked with “Self-efficacy” and “Behavioral Capability”, suggesting that when participants discussed self-efficacy or exhibited behavioral capability to access infertility services, it was rarely related to travel associated with infertility services.

The decision to travel for infertility services can be forced due to environmental restrictions, such as when the required services are either not offered in the area, illegal in the state, or there are not any fertility clinics nearby that are in network. Also, it can be voluntary, albeit based on the desire to reduce the high financial burden and have behavioral capability to identify methods to circumvent high costs.

Research Question 3: Influence of residence

R3: What influence does living in a state with mandated insurance have on access to infertility services?

Survey. There were two questions related to residence in this survey (Appendix B). There are 32 states represented in this research. Of those 32, 13 (40.1%) have an infertility insurance mandate (Table 4.19). When asked if their state of residence is the same state in which they access infertility services, 88.3% responded “Yes”, and 11.7% (n=15) responded “No” (Table 4.20). There were 12 states identified by those who responded “No”, and 8 of those 13 (67%) were states that have an infertility insurance mandate – meaning 67% of the people who accessed infertility services in a state other than their state of residence did so in a state that had an infertility insurance mandate (Table 4.21).

Health insurance coverage. There were seven questions related to health insurance and the knowledge of an infertility insurance mandate in the respondent’s state of residence (Appendix B). When asked whether their state of residence had an infertility insurance mandate, 48.5% responded “No”, 38.1% responded “Yes”, and 13.4% reported being unsure (Table 4.22). Of those who responded “Yes”, 47% were *not* able to apply the state-mandated infertility insurance to their situation, 20.4% were able to apply the mandate and have 100% of infertility-related expenses

covered, and 32.6% were able to have partial coverage from the mandate (Table 4.23). This means that 47% of people who accessed infertility services in a state with an infertility insurance mandate were disqualified from accessing that mandate for one reason or another.

When asked about their health insurance status, 86% reported being covered by private insurance (without Medigap) either individually or through their employer (Table 4.24). When asked about the presence of private health insurance specifically for infertility services, 41.8% said “Yes”, and 41.8% said “No”, while 10 responded “Not Sure” and 12 indicated that while they do not have that coverage on their health insurance, their partner’s insurance does have that coverage (6%) (Table 4.25). When asked about the presence of employer coverage for infertility services, 50% responded “Yes” 40% responded “No”, and 6% indicated that while their employer does not, their partner’s employer does (Table 4.26). When asked about the presence of any health insurance that specifically covers infertility services, 52.2% responded “Yes” s (Table 4.27). There were 17 different providers who provided infertility insurance coverage, but the most frequent were BlueCross/BlueShield (n=14), Aetna (n=13), and United Healthcare (n=10). There were also three entities that were insurance or loan companies that offered financial options specifically for infertility coverage: Progyny (n=5), WINFertility (n=1) and Freedom Fertility (n=1) (Table 4.28).

Informal interviews. The overarching narrative surrounding the use of infertility insurance mandates is that if you live in a state with an infertility insurance mandate, you will have greater access to coverage. However, this research found such an assumption to be false. Data from these interviews suggest that living in a state with an infertility insurance mandate will only benefit you if you meet certain requirements. There were two major themes that developed based on the influence of residence on access to infertility services: *role of the employer*, highlighting instances where it was the employer that influenced the approval or denial of infertility services and

applicability of the state’s infertility insurance mandate; and *perception of the mandate*, which were unsolicited reflections about the infertility insurance mandates. Based on review of the frequency of the coded segments in each document using the Code Relations Browser in MaxQDA, both the employer and infertility insurance mandates are described as barriers more often than facilitators (Figure 4.2).

Role of the employer. Employers were discussed as both facilitators and barriers in accessing infertility services, and that pattern existed in states both with and without infertility insurance mandates. The code map showing the relationship between the codes employer, mandate, and the SCT constructs in Figure 4.3 shows that employers are described more as barriers than facilitators, and that the infertility insurance mandates are discussed more along with barriers and also with employers. The most striking barrier had to do with both the employer and the infertility insurance mandate, where either residents in mandated states would be disqualified from accessing their state’s mandate because their employers’ headquarters is based in a non-mandated state, or people in non-mandated states would still be disqualified from accessing the mandate coverage in the state of their employer’s headquarters,

“So, we live in Massachusetts where there is a mandate, however, I work in New Hampshire, and my husband works in Massachusetts for an employer that is self-insured. So, from May of 2018 when we got our – when we got the azoospermia diagnosis up until January 1, 2020, we were entirely out-of-pocket. New Hampshire passed their fertility mandate that went into effect on January 1st of this year and my employer was subject to the mandate, so they are now offering coverage.” (059, Female, Caucasian, **Massachusetts**)

“I guess Texas has one of the lower types of mandates as far as fees go. They just say that they have to offer infertility coverage on insurance

plans. My company is based in California, so they don't have to obey that law. They are also self-insured, which is a way that they don't have to offer it. My husband works for a religious employer, so I think they choose not to offer it" (063, Female, Caucasia, **Texas**)

"The company that my husband works for is actually based out of New York, but they are independently insured, so they don't have to follow the state mandate" (019, Female, Caucasian, Virginia)

However, the same type of residence loopholes that disqualified some people, also qualified others.

"When we originally started pursuing this we were living in Washington, D.C. We've since moved to Maryland but it's still in the Washington metropolitan area. It's [husband's employer] actually a really small company. And I think that we're in a little bit of a loophole because his company is based in Massachusetts. They have a satellite office here in D.C. And I think because it's based in Massachusetts, that's why we have the mandated infertility coverage" (050, Female, Caucasian, **Maryland**)

"So, we dropped my employer coverage and I got on my husband's employer coverage because his company is based in California and therefore IUI coverage is required by law" (031, Female, Caucasian, Florida)

In yet another example, a couple living in New York was getting insurance from the employer based in New Jersey, but when the company changed, their insurance fell under the New York mandate – which did not offer as much coverage as the New Jersey mandate,

"So, we briefly went to another clinic because we had this New Jersey insurance that a lot of New York clinics didn't take, and we found one that did. We did one IUI there and it was unsuccessful. Then, our insurance changed so we unfortunately found out that we no longer had any coverage. Because when it was a New Jersey insurance, New Jersey is a

mandated state. They covered up to four rounds of IVF. We lost that when our insurance switched to New York insurance. And then even though New York is now a mandated state, we work for companies that don't qualify for the mandate because they are less than 100 employees for New York state" (038, Female, Caucasian, **New York**)

There were also barriers related to the type of insurer the employer had due to being self-insured and small companies under 100-500 employees (depending on the state) being exempt from the majority of the infertility insurance mandates.

"I live in New Jersey – which is a state mandated state – but there's the loopholes. So, my employer who provides my insurance is a self-insurer and is therefore exempt from having to cover infertility treatments. (Interview 001, Female, Caucasian, **New Jersey**)

"The company that my husband works for is actually based out of New York, but they are independently insured, so they don't have to follow the state mandate" (019, Female, Caucasian, Virginia)

"It's out of New York. But unfortunately, it's a very small company so all of the mandates that were recently introduced in terms of fertility and coverage do not apply to my company because it's such a small organization" (042, Female, Caucasian, **New Jersey**)

"And then even though New York is now a mandated state, we work for companies that don't qualify for the mandate because they are less than 100 employees for New York state" (Int 038, Female, Caucasia, **New York**)

"We work for a pretty small company. They are I feel like our insurance plan is pretty barebones. Our plan's kind of vague. It says, "Oh, some infertility benefits are covered." But then when you go and actually talk to them or you know get more in detail about it, you find that most of the

things after diagnostics are not covered at all. Some of the diagnostics stuff is also not covered, so pretty limited in scope” (010, Male, Caucasian, **Texas**)

“Originally, how we had New Jersey state insurance even though we lived in New York and then losing that was a pretty unique experience. Going into this process thinking ‘We were gonna have four rounds covered’, and then because of job change or a company being spun off basically losing that coverage. Then having the hope that we were gonna be able to qualify for the New York mandate and then finding out that the mandate doesn’t apply to us because we work for small companies and our company doesn’t have to opt into the mandate. So, that was kind of painful” (038, Female, Caucasian, **New York**)

Decisions made by employers were among the barriers to accessing infertility services. There was one instance where an interviewee explained a situation where both her and her husband’s employers had the opportunity to apply a new infertility insurance mandate in New York, but they opted not to based on the self-insure opt out – even though the husband’s employer was in the medical field. In this case, the decision to not add infertility services is based on a financial barrier perceived by the employer.

“So, we’re in New York state...And we were waiting to see if either of our companies, because they are both headquartered in New York, would adhere to the law, but because they are self-insured companies, they didn’t choose to add that fertility coverage...we were working with a rewards reinvention program for my work with our benefits team, and I did find out that in order for my company to add the IVF coverage, it would have been a total of \$1,500.00 for each in the organization. But I think there was just a fear of – what I was told, which is kind of disheartening to hear, is that they would have to then pay for more people. If they paid for the IVF coverage, then more people would be getting pregnant, and then

they'd end up having to pay for more maternity leave and more services like that. And even my husband's – he works for a health system here. And the president is a reproductive endocrinologist, but they decided not to opt in this year, either” (017, Female, Caucasian, **New York**)

And in another situation, the employer decision was to remove infertility coverage while a couple was still using them, which cost them financially,

“I don't know exactly how this works. But he [employer] decided that infertility no longer count towards out of pocket maximum. So, we had hit our out of pocket maximum, and that should have meant that the second cycle was essentially covered 100%, but because my husband's company just decided, and with no warming, we no longer could count towards out of pocket max. And so, we were suddenly stuck once again paying 50%. So, that decision cost us personally at least \$10,000.00” (028, Female, Caucasian, **California**)

In the instances where employer-based insurance policies included infertility services, the knowledge that infertility benefits existed through the place of employment was at times not known – and almost missed out on.

“We weren't aware that there's a separate infertility group. So, on my plan, it says like you have a \$100,000 maximum for fertility benefits. And it was like "Oh, cool. That's really amazing and really good." But I didn't realize there was a separate group within the insurance that you had to contact *first*. And so, the short version is it was almost not covered, but they let me slide because I didn't know” (018, Female, Caucasian, **Illinois**)

“The big thing for me in all of this was that I found it very frustrating to know that my insurance changed in I want to say June of 2018. And we were told at the time that there were no major changes to it. I want to say it was like three or four months later, I happen to call my insurance about

something else and the customer service rep was the one to tell me that I had practically full benefits. And so, I guess it was a little – on one hand I'm grateful that I do have this coverage from my employer, but I really think that the employer did not do a good job in rolling out. And obviously when you're older, time is of the essence” (054, Female, Caucasian, **New Jersey**)

“My husband’s company originally did not offer insurance at all – fertility coverage. They were exempt from the mandate because they had an office of less than 50 people. The office grew within two years to about I guess 75 and so they were then required to offer it” (007, Female, African American, **Illinois**)

Besides the presence or absence of an infertility insurance mandate, employer flexibility was a facilitative factor for some people because of the need to go to frequent appointments required for some services that also follow strict scheduling and cannot be missed, and at times need to be scheduled with short notice.

“I have a very flexible work schedule, so if I have to go in an hour late, I just stay an hour late and it's not a big deal. So, I still get paid. I just kind of shuffle my work hours around accordingly” (021, Female, Caucasian, **Colorado**)

“I have a lot of flexibility with my job. I’m able to be honest with my boss and tell her I’m gonna be a little late because I have an appointment. When I have to go into the clinic for monitoring and stuff, which is two times a cycle, their hours for monitoring are 7:00 a.m. to 8:30 a.m. It makes for a long day. But, I’m able to go and still get to work on time. (027, Female, Caucasian, **New York**)

“The biggest problem is that you usually don’t know until last minute when they’re gonna be. So, it’s hard to plan around. But I’m fortunate in

that my company is pretty understanding. I've worked there for almost five years" (042, Female, Caucasian, **New Jersey**)

"Well, my dad is my boss. I'm his only employee. He's pretty forgiving about when I need to go places. He understands that I've gotta do what I've gotta do. I have a pretty unique situation" (062, Female, Caucasian, Iowa)

There was an instance where it was the type of work and associated early schedule that would make going to appointments difficult at times.

"Because I work within the hospital system, I have very early hours as well. So, even like a 7:00 a.m. appointment means going in late to work. So, that makes it a lot harder" (032, Female, Asia, **New York**)

There were some instances where people described examples of trying to work with employers to cover infertility services. In some cases, the advocacy for those services worked, but in other instances they were not successful.

"My husband started this job at this small company and their insurance was really bad at first. And so, he tried to work with his boss to get better insurance going on. And it's this weird thing...you usually offer a couple plan options to your employees, and if you offer one plan with infertility, then all the other plans have to have infertility coverage. And it does bump up the cost of the plan significantly. And so, it's this weird thing of my husband couldn't ask for a plan that we might have been able to utilize because it would have forced everyone else to pay \$100.00 more a month so that he could have the option" (028, Female, Caucasian, **California**)

"I did send an email to my HR department saying that I thought they should cover it you know kind of laying out some heuristic arguments, policy arguments, and they did not change their policy" (033, Female, Caucasian, Michigan)

“At my new job, it's just something that they, unfortunately there is kind of some loopholes that they can say that infertility treatment doesn't, they are allowed to find a loophole to get out of FMLA or any kind of medical leave that you would need to take. So, it was discussed, and ultimately, I think was up to the company, and they were able to find a way to make me use my own personal time” (019, Female, Caucasian, Virginia)

“And all through 2019 anytime my company had – I work for a health care company – anytime they had any surveys asking how they were doing; I would use a little bit of a template and then my own research from the RESOLVE webpage advocating that they cover it. And they did up their coverage” (053, Female, Caucasian, Minnesota)

One person described an instance where her employer was about to remove infertility benefits, but since she knew people in her company's HR department, she was able to get them to keep the benefits before they completely removed them.

“The funny part was I'm actually close with a few people are in our HR department. And I let them know that I discovered this [full infertility coverage] and that they hadn't rolled it out properly. They were in the midst of trying to remove that benefit – because they had thought that no one had caught on. And so, when they were told that I had done a round of IVF by that point, they decided to keep it as part of our benefits for this year 2019. And so, when they had the open enrollment session and they were announcing the benefits and the changes since like from last time, they had to underscore not only the fact that we had full fertility coverage, but also they had to talk about the mandate the New York state mandate from I guess this year. So, they did eventually come around to announcing it properly but something like someone made a mistake. I don't know if it was intentional or if it was like truly an oversight, but it was not handled properly” (054, Female, Caucasian, **New Jersey**)

For people who worked in the federal government or military, fertility benefits were variable but mainly consisted of diagnostic coverage and initial IUIs, but nothing beyond those services – which were often the most expensive.

“I work for the federal government, so I have insurance through my employer. That covers 50% of diagnostic for infertility and then it covers 50% of IUIs and then my Tricare insurance they cover 100% of diagnostic, but they don’t cover any infertility services. If they’re treating the infertility, then it’s no” (008, Female, African American, **Maryland**)

“I wish I had known a little bit better when I was picking coverage and plans because you get a pretty wide variety of plans to choose from with the federal government when we had open season. When we had open season, I was at the point where I thought I wanted to try to find a plan that has some kind of better fertility coverage. Looking back, I think I would consider changing plans the next open season because of it being pretty limited. It would definitely make a difference” (023, Female, Caucasian, **Texas**)

“I’m dual insured. My primary insurance does not cover anything infertility related. My secondary insurance is Tricare. They cover diagnostics. The clinic that we’re going to now is in-network with Tricare for diagnostic. That was enough of a reason for us to go with them. Tricare is not covering the IUI now, but they did cover everything up until this point. (062, Female, Caucasian, Iowa)

Perception of the infertility insurance mandates. The most prominent aspect about sentiments regarding the infertility insurance mandates were the differences in expressed self-efficacy and behavioral capability related to the use of these mandates between people living in mandated vs non-mandated states. There were some instances where people had to argue with clinics and insurance companies to apply the mandated coverage to their situation, where

sometimes it was due to the experimental nature of some procedures. Other times it was an issue of the organization not being up to date on the current infertility insurance mandates they need abide by. In these instances, the individuals displayed a high degree of self-efficacy and behavioral capability to preserve through the red tape. To observe the relationship between mentions of the infertility insurance mandate and expressions of self-efficacy and behavioral capability, code maps were created for people living in mandated (Figure 4.4) and non-mandated states (Figure 4.5).

Both of these code maps show the relationship between the codes “Mandate”, “Self-Efficacy”, and “Behavioral Capability” but their co-occurrence in the interview between people in mandated and non-mandated states show they are not discussed in the same ways. In mandated states, talk related to the infertility insurance mandates co-occur along with statements coded as self-efficacy and behavioral capability (Figure 4.4). However, in non-mandated states there are fewer mentions of the mandate and none of those mentions co-occur with self-efficacy or behavioral capability (Figure 4.5). This shows that the mandates that exist are not cut-and-dry applications to every situation. There are times where people must fight for their coverage, even when it is being mandated to be covered or offered.

This example shows how doctors’ offices are not always up to date on what infertility services will and will not be covered. It is then left to the patient to go through their often-vague insurance policy and then follow up with the insurance company before going through certain procedures due to the high cost and necessity of coverage.

“We a couple times have had to even some tests done and we were told by our doctor, ‘Hey, yeah, it looks like you’re covered’ and then we get a bill for it later and we’re like, ‘Uh, I thought this was covered’ and they’re like, ‘Oh, actually sorry, no. It wasn’t.’ I’ve had to kind of go into the insurance

plans and try to read as much fine print and then – when it’s not listed or not clear – I’ll call and ask before we do any of that” (010, Male, Caucasian, **Texas**)

In a similar example, a woman working for the federal government and living in a mandated state needed to have preimplantation genetic testing for Sickle Cell, and although the information on the lab’s website said that procedure was covered, she kept being denied. Through her own education in law, she was able to get the procedure covered.

“The weirdest thing about going through this entire process was that – at some point – it seemed that the insurance companies were less aware of the requirements of the mandates than I was and that happened fairly often. I actually had to report the lab testing company that did my PGT testing to the Board of Massachusetts Health Insurance because they just refused to bill my insurance or go through them, even though they had a contract with each other. I eventually got the PGT testing covered, but it took a year and a half and it actually only got covered because I went to law school and I found out who I needed to contact in order to get it through” (007, Female, African American, **Illinois**)

The infertility insurance mandates often disqualified people from accessing services. Disqualifications often centered around the need for a diagnosis of infertility, which at times disqualified people who were single and those in same sex relationships when there was not an infertility related issue, or required them to use more services than are needed in order to qualify for their state’s insurance coverage,

“So, for 2014 and I want to say 2017, it did say that there was an infertility mandate if I’m not mistaken. However, because the caveat to that was, I needed to have some something wrong with me and I needed to be female. I needed to have problems carrying a child holding a child or conceiving

a child. Unfortunately, with two men, that doesn't, you know, there are no problems unless there's something wrong with the sperm” (044, Male, Hispanic, **New York**)

“Yeah, so, Colorado’s talking about a law that would mandate infertility coverage and one of the questions I have about it is ‘Is this gonna cover queer people?’ Because one of the things that happens is that a lot of times there will be a requirement that you have to try for a year or six months or whatever it is, depending on your age. And so, typically for straight people you go in and say, ‘I’ve been trying’ And often for a same-sex couple they’ll end up requiring medicated IUIs monitored by a doctor. Which basically means your spending \$12,000.00 in the first year trying to get pregnant, possibly more if you’re buying sperm. So, you’re spending \$12,000.00 on medical intervention before you’re even eligible for IVF or for the fertility coverage that you’re supposed to get” (061, Female, Caucasia, **Colorado**)

Some instances were not necessarily disqualifications, but rather limited coverage, vague verbiage in the insurance policies and descriptions of the mandates, or a lack of insurance companies and clinic personnel updating their policies as the new infertility mandates are passed.

“When we were first starting, I just started googling, just to see what, as a state – to see if there were any mandates or any – I don’t know – and then I also looked at my actual insurance policy to see what was covered, what was excluded. Louisiana is one of the mandated states. However, it doesn’t mandate coverage of treatment. It only states that a person cannot be denied coverage, I guess, as a pre-existing condition. That was not easy to see online because Louisiana is in the list of pretty much every website that lists mandated fertility coverage for states, but it actually does not cover very much at all. I don’t think it’s very specific to our unique case, where we’re not actually a mandated state for treatment coverage. That is difficult, I think, if someone was just starting out and they were looking

they would, maybe, misinterpret that information to mean that they would have the coverage in this state and that's just not the case" (48, Female, Caucasian, **Louisiana**)

"So, it [New York mandate] changed in 2018, but insurance didn't actually update their policy online or anywhere. So, even though it was supposed to be covered it took me talking to my infertility services nurse trying to figure out what the hell I could do to try to cobble together some coverage because I knew was running out of time and I needed to access services that I didn't have \$3,000 to pay out of pocket for each round, and it took three rounds of IVF to get any viable embryos. She literally found a piece of paper that had the updated 2018 policy. This was just a piece of paper, a single piece of paper that had this policy change on it and that wasn't updated anywhere internally. That was in, I think, like April of that year. So, we had gone four months of having this coverage with insurance just whoopsie forgetting to update it everywhere. Like they didn't update it online, they didn't update it in their own system. You cannot make this shit up" (011, Female, Caucasian, **New York**)

Residence continued to be an issue, where people living in mandated states were not able to access the fertility benefits of that state's mandate because their employer was located in a different state or territory,

"Yeah. I find it really frustrating that I pay taxes in Maryland and I don't get the benefit of Maryland's infertility mandate. It's very frustrating that my life is being dictated by insurance companies. And, I'm trying to figure out if my work will let me become a remote employee from Maryland, and whether or not I can scam some coverage that way. But, it's fairly crazy making" (056, Female, Caucasian, **Maryland**)

"I am pretty well-informed person on these kinds of things, but I just assumed if there was a mandate that we have coverage because my

husband worked in Massachusetts. I didn't know how many loopholes there were and that was probably the most frustrating thing for us related to it" (059, Female, Caucasian, **Massachusetts**)

There were, however, some instances where people were able to apply the mandate of their state to their situation after deductibles were met, or assumed that they would be able to have services covered after their deductible was met based on conversations with financial counselors or by reading their respective policies.

"We live in Massachusetts, which is one of the mandated states. So, we're lucky for that, as well as coverage infertility diagnosis and services, and treatment. We have a \$1000 deductible, so for now, we've been paying towards that. But after, it's gonna cover everything" (020, Female, Middle Eastern, **Massachusetts**)

"My company was one of the companies that meets the criteria, that they have to have the coverage. I work in benefits administration for the HMO that I have. I kind of have a little more knowledge of exactly what's covered and why and things like that. Illinois essentially covers for women who meet the criteria for infertility for egg retrievals or the policy in the life science. We were very lucky to have that. We still had deductibles and things like that. But, the IVF and all that were covered" (025, Female, Caucasian, **Illinois**)

"I'm not sure if IVF will be covered. It seems the way the law is written that it should be. Yeah, that's one of those things that I figured I'll ask once we get there. I know last year that it would've been covered up to \$10,000 for IVF. And, anything else would've been out-of-pocket for us. When I first read into our insurance, I didn't realize that [insurance treats IUI differently than IVF]. I was really nervous. But we sat down with the financial coordinator. They told us that the IUI is completely covered by our insurance. There aren't caps on how many IUIs we can have. We don't

have to have an IUI before going to IVF” (027, Female, Caucasian, **New York**)

Some perceptions of the mandates took the form of frustration with the unequal attention that infertility receives when politicians discuss healthcare coverage for reproductive health, often focusing on contraception and abortion – methods to circumvent having children – while infertility services are rarely discussed.

“I work in politics and I’m excited to hear about how everyone’s going to fix health care. But it’s been frustrating to not hear anyone talk about this at all, like this isn’t healthcare. And, folks keep calling it “elective,” as if this is something I chose for myself, which has been infuriating. Everyone talks about one side of choice, but there’s a whole other side of, “I would very much like to start a family,” and I cannot. I have no choice right now” (056, Female, Caucasian, **Maryland**)

“Well and the sad thing is, too, actually, when they were first devising the Affordable Care Act, that my understanding was that they were intending to have in there more fertility benefits. But that got was one of the things that got on the chopping block” (053, Female, Caucasian, Minnesota)

Expert interviews. There were confirmations from four of the expert interviews regarding the applicability of a state-based infertility insurance mandate being denied based on a person’s employer headquarters or main office being located in a non-mandated state. In two of those instances, the scenario was posed to them and they responded in affirmation that they experienced that type of situation with some patients, and the other two brought it up organically as they were explaining the services their organization provides.

“I think that at some point legislation will change, and maybe it’ll become more specific to where the patient lives. But at this point, it’s depending

on where the business is at” (IntegraMed, MSA crisis management company)

“Correct. Correct. What we run into is the fact that some insurances won't cross state lines...when the employer base is in New York, but the baby's going to be born in, you know, Texas. But the baby would have no coverage in Texas, and that's, you know, a hard concept for people to understand” (ART Risk Solutions, Financial insurance solutions company)

In response to the research question “What influence does living in a state with mandated insurance have on access to infertility services?”, the main synopsis is that personal residence is often negligible, and in fact what is most influential are two aspects about one’s employer: 1) employer headquarter residence, and 2) decisions the employer makes about what types of health insurance are available. This conclusion is based on the evidence from both informal and expert interviews that the way insurance companies interpret “residence” is not necessarily the same way that residence is interpreted in the infertility insurance mandates, and that even in non-mandated states, if the employer has infertility benefits then the employees can access those infertility insurance benefits.

There were more examples of how the existing infertility insurance mandates were not able to be applied to people’s situations than examples of successful use of the infertility insurance mandates. Even in the presence of accessing those insurance benefits, there were examples of interstate and international travel specifically to reduce the cost of services. A common theme was that mandated coverage would only extend to diagnostic services, but when an intervention was required there was limited to no coverage, requiring people to sacrifice house savings, all savings, dig into health savings accounts, get creative with credit card balance transfers, or apply for types of loans they may be eligible for and also have the credit for approval.

Research Question 4: Role of Organizations

R4: What are the roles of specialized infertility specific insurance or other financial aid organizations in increasing access to infertility services in the United States?

Survey. Another financial aspect missing from the literature are the uses of the various grant and scholarship programs to support an individual or couple with their infertility expenses. To observe the use of those services, there are two questions related to the knowledge and use of scholarships or grants for infertility services. Two of the organizations who provide these services are among the “expert interview” sources in this research. When asked if they heard of grants or scholarships that provide financial assistance for infertility services, 70.1% responded “Yes” they have heard of them. When asked if they ever applied for and received a grant or scholarship, five received one (5.3%), 16 applied for but did not receive a grant or scholarship (16.8%), and 77.9% said they never applied for either a grant or scholarship.

Informal interviews. There were a total of six different fertility specific insurance, grant, or financing organizations utilized among the interviewees. These included Progyny (n=5), Freedom Fertility (n=3), Baby Quest Foundation (n=2), Walgreens Specialty Pharmacy (n=1), ArcFertility (n=1), and Prosper Healthcare Lending (n=1). Two of these organizations are represented in the expert interviews (Progyny and Baby Quest Foundation). A lexical search in MaxQDA allowed for these organizations to be searched among the corpus of documents, and then allows the user to create a de novo code based on those search hits. After reviewing the search hits for these organization names to confirm their context, the code map was generated with the code “Organizations”, representing the named insurance, financial, or non-profit organizations used by the interviewees. Figure 4.6 shows the code map of the frequency of instances these organizations were discussed and observes them based on their co-occurrence with SCT constructs. Based on

the code map lines connecting to the code “Organizations”, these organizations are discussed directly along with (in order of proximity): “Self-Efficacy”, “Facilitator”, “Environmental”, “Behavioral Capability”, and “Barrier”. The organizations are coded along with “Facilitator” more than “Barrier,” suggesting that those who had something to say about these organizations expressed facilitative experiences that helped them access infertility services.

The interactions with these organizations were described as largely facilitative in terms of how people expressed their ability to access infertility services by these organization. Some of these organizations were described as facilitative specifically to cover medications, as some of these them were specialty pharmacies that offer discounts on certain medications, such as the Compassionate Care Program through Freedom Fertility,

“I applied for the Compassionate Care Program, which gives a discount on some medications for people who don’t have insurance coverage. So, I did get a discount on my meds through that. I used it with Freedom Fertility, which is the name of a pharmacy where you can order the medications over the phone and they mail them to you” (Interview 012, Female, Caucasian, Michigan)

The variability of cost for the same medication at different pharmacies of the same company caused some concern. In one description, there were pharmacy locations of the same company that had variable prices for the same medication. This was concerning when it was required that medication be purchased from a particular pharmacy based on one’s insurance.

“So, the other thing that we found out that was surprising that I didn't really realize was how the cost of medications even if you're paying out-of-pocket how they can vary so much from one pharmacy to another. So, for example, there's a pharmacy in **** that has those discounted medications. The Walgreens in **** or **** or any of those nearby cities,

their prices are higher. So, I didn't realize that prices could vary even between one location to another, even if it's the same company” (053, Female, Caucasian, Minnesota)

There was one instance where a person was told it would be four times cheaper to purchase medications through a specialty pharmacy than through the pharmacy her insurance uses, which she did. She did not regret the decision due to needing multiple attempts at IVF that included those medications.

“So, we chose to pay for all the medication out-of-pocket. So, it technically would have been covered but we were advised that the price of the medication would have been like four or five times higher than it would have been out-of-pocket. So, we would have used up our – the lifetime benefit of the \$25,000.00 really quickly, so we chose to pay for the medication out-of-pocket, which I’m glad we did, because if we only needed one IVF cycle, it would have been fine, but now that we’re going into our second cycle now, I’m glad we saved that benefit. I’ve heard that from other people too, that Aetna would require a CVS Caremark and it’s just a lot more expensive through CVS than it is through the specialty pharmacy that we use” (057, Female, Caucasia, Georgia)

GoodRx was brought up once, and it was used to specifically reduce the cost of medications not covered by health insurance.

“Since insurance did not cover treatment, they wouldn't cover that medication, so I used a prescription saving program, GoodRx, to help cut the cost on the prescriptions. I didn't know I could do it for the first round. So, for the second round I cut the cost about in half for the pills. The trigger, which is an injection, went to a specific pharmacy that they're ex-contracted with, so that stayed the same, but the other portion was significantly lower” (066, Female, Caucasian, **Texas**)

The two individuals who received the Baby Quest grant reported still needed to use out of pocket savings for things such as lawyer fees since they were using surrogates, but the grant money was able to reduce some of the cost related to clinic fees.

“...through Baby Quest – I had a small grant. Then that helped a little bit. It was \$10,000.00 (Interview 004, Male, Middle Eastern, **New York**)

“We applied for the Baby Quest Grant and were approved. We got the grant for like \$8,000. And then the rest of the money was out of pocket savings that we had for the process. The lawyer was partially covered, but most of it [grant] was just for the clinic” (Interview 044, Male, Hispanic, **New York**)

An unanticipated organizational facilitator *and* barrier that came up in these interviews was the use of medical coding for medications, surgeries, bloodwork and general doctor visits for health insurance claims. Sometimes, medical recoding was successful in “tricking” insurance to approve a medication or doctor visit. In other instances, the recoding was not successful, or the interviewees were just experiencing the denial of medications, bloodwork, or doctor visits that were previously covered, but not when they started using IVF.

In the instance of medical coding of doctor visits, it was explained that physicians will input a Current Procedural Terminology (CPT) code in the patient’s file, and that code is what insurance companies use to determine if the visit will be covered by the patient’s health insurance. In this example, the woman had difficulty determining whether to disclose all of her medical history with her physician, or not mention the use of infertility services as to avoid the physician coding the visit as a fertility related consultation.

“When I go to see my regular doctor just for regular human stuff, not reproductive stuff, often the doctors will ask you questions, ‘Oh I see

you're taking this drug' for whatever. And then I'm like, 'Yeah we're doing fertility stuff' And then they start asking you questions about it. And then once they ask you questions about it, then they probably put in their notes, "Oh, talked to the patient about whatever." And then when it comes to putting the CPT code, they end up putting something like 'preconception counseling' or 'fertility counseling' or something like that. And then a regular insurance doesn't cover it. And you're just put in this position where you have to tell the doctor, 'I don't wanna talk about that with you' Or something just to make sure my normal office visit is going to be covered" (035, Female, Caucasian, **California**)

Medications, surgeries, and bloodwork are similar in that they require physicians to code them based on the treatment the medication is for, or the reason for the surgery or bloodwork. In some cases, the infertility-related medication or bloodwork could also be used for other types of diseases that tend to be covered by most insurance.

"Both **** and my prior clinic will try to code everything they can differently to try to get it covered. There's also a tendency to prefer Letrozole for ovulation induction over Clomid for ovulation induction – both for medical reasons and because Letrozole is a cancer drug and therefore is almost always covered" (031, Female, Caucasian, Florida)

"I visit a local clinic, and they'll do like bloodwork and exams a couple times a week sometimes. My clinic will code those so that they're not related to IVF so that my insurance will then cover them. They code them as ovarian dysfunction which is something that most insurances cover. I'm not sure if that's what it's actually supposed to be coded as but I've heard people talking about asking for it to be coded that way so that their insurance will cover it" (042, Female, Caucasian, **New Jersey**)

"My doctor does – I don't know if it's creative medical coding but I know for some of the medications it's not sent to the pharmacist as infertility. It

will be sent under endocrine disorder or I forget the other term that he used, so that insurance would cover it. That has worked for some of the medications. They understand and I think that they are able to, I guess, get creative with their medical coding” (048, Female, Caucasian, **Louisiana**)

“So, our doctor actually was able to code things in certain ways so that it would be covered. For example, she coded my surgery so that it was for dysmenorrhea versus female infertility, which then we were able to apply the cost of that surgery to our deductible” (030, Female, Caucasian, Florida)

There was one instance where the person mentioned it was the insurance company, not clinic, that provided the medical *recoding* because they were knowledgeable of the fact that Lupron, a medication used for IVF, was also a cancer drug and therefore eligible.

“For example, Lupron is one medication that I’ve had to take that was covered by our insurance because it could also be used for something else that was non-IVF related. Like I was basically told it was also a cancer drug and that’s why that one was covered. But then, for example, Gonal-F and Menopur and Cetrotide which are very specific to IVF were not covered. All I was told by the representative from United Healthcare was that because it can also be, I guess, coded as a cancer drug, they approved it” (038, Female, Caucasian, **New York**)

There were also some examples where people were just experiencing denials on medications or services there were previously covered.

“As far as the doctor’s visits...there was a change in the way that the clinic did their coding and my insurance has been instructed to deny all claims regarding that code, even though it was previously covered under a different code” (015, Nonbinary, Multiracial, Minnesota)

“So, it includes medications if I am doing IUI. It does not include medications if I do IVF. So, the exact same Follistim that I used this past month for \$20.00 would then cost me \$1,000.00...just because it’s used for IVF instead of IUI, which is not a covered procedure” (056, Female, Caucasian, **Maryland**)

In one of those examples, the expenses paid out of pocket due to insurance claim denials were later recoded and the person received reimbursement. This example reveals an interesting perception of infertility by the insurance companies, where things that were covered as diagnostic procedures were then denied once there was a diagnosis of infertility,

“I have been fighting with our insurance company over a blood panel and certain medications that used to be covered. But now, because we have this diagnosis and we have sought out treatment, it won’t cover certain medications. So, we have to pay for things out of pocket. They said because of the treatment now. Because I sought out treatment for infertility, then those were things that were now excluded. I actually just got a couple of checks in the mail from them because the provider was able to recode some of it, and then resubmit it, and get them to review it, and then reapprove it” (043, Female, Caucasian, Wisconsin)

Expert interviews. The roles of these organizations, as described by their representatives, were similar in that the services they offer to help with the costs associated with infertility services exist only because of the high cost of infertility services. However the types of financial assistance are not the same (Table 4.2). There were three themes that developed through analysis of these expert interviews: *Prior insurance*, responses about the effect that having health insurance with some sort of infertility coverage would have on the financial services offered; *Personal history and advocacy*, which were sentiments regarding a personal experience with infertility that affected the creation of the organization or decision to engage in non-profit work related to infertility; and

Perception of the mandate, which were the representatives' opinions regarding the current state-based infertility insurance mandates.

Prior insurance. One of the questions asked to each representative was whether the presence of other health insurance would affect the ability to access the financial assistance their company provides. The responses to the effect of health insurance largely reflected the notion that the presence of health insurance was negligible due to the limited amount of coverage that exists for these types of services.

“It [prior insurance] generally covers testing, sometimes it covers the bloodwork and the testing up to the diagnosis, and then most of the people who approach us have a diagnosis of infertility, but no insurance that covers it” (Baby Quest Foundation, non-profit)

“We do ask about their insurance coverage, and the reason we ask is because we wanna know about the resources that they have already have access to. But, if you have someone, for instance, who has insurance coverage, but they're out of pocket is \$5,000, or let's just call it an amount that would make fertility treatment beyond something that they would be able to cover financially, that person may still qualify. We look at their taxes and look at their pay stubs, and we look at their financial background, in addition to what resources they bring to their treatment, or adoption. We make a decision based on all of that information” (CADE Foundation, non-profit)

“It may be something that we take into consideration, but it's not an eliminating factor. But it could be a deciding factor if it comes down to decide between two applicants. It also depends. We have seen that most insurances, if they do offer any sort of infertility coverage, has a lifetime cap on it. It's usually around \$5,000, \$5,000 to \$10,000. So, may take that

into consideration, whether or not they already used that benefit in previous treatments” (The Hope for Fertility Foundation, non-profit)

“They [recipients of the grant] do [have health insurance], but in Pennsylvania, it’s not covered. It doesn’t cover IVF. So, they do have some insurance technically, but infertility is not covered. The treatment isn’t covered” (The JFCS Fertility Fund, Jewish Human Service Agency)

There was one response from a non-profit organization that health insurance would make someone ineligible. However, after providing an example from the informal interviews about how some people with insurance will get coverage for things like diagnostics but not actual procedures themselves like IVF, it was clarified that insurance coverage for services beyond diagnostics would make someone ineligible, not the presence of insurance alone,

“So, yeah, that’s a good clarification. So, for example, in Ohio, you can have coverage – most people have coverage for the diagnosis of infertility. That is okay. What we do not allow is if there is insurance for the treatment of infertility. And that would be IVF or embryo transfers, and that kind of stuff” (Parental Hope, non-profit)

In some instances, such as with surrogacy, the process of how insurance applies becomes more complicated due to there being a third party who may also have some type of insurance. In the case explained below, both party’s insurance must be reviewed to determine what resources are available.

“So, if an individual or couple comes to us and says, you know, ‘We need to go through surrogacy, what do we do?’ basically it starts with ‘Do you have a surrogate selected, yes or no? If you have a surrogate selected, what type of insurance does your surrogate have?’ It’s important to note that the surrogate’s insurance would not cover any portion of the IVF because she is not, by definition, infertile. So, even though her policy may have fertility

benefits, it doesn't matter because she's never going to need that definition of infertility. So, then we would start with her insurance. Will it cover a surrogate pregnancy? Yes or no? If the answer's yes, that's fabulous news because it saves into the parents' fund. If not, then we start looking for alternatives for them” (ART Risk Solutions, Financial insurance solutions company)

In the case of IntegraMed and Progyny, the person seeking help is a “self-insure” client, meaning they pay all of the treatment for infertility services (not including diagnostics). Progyny is essentially a type of insurance benefit that can be added on to the company’s insurance plan through the employer – but it does not cost the employer more to have the Progyny benefits.

“Progyny is a fertility benefits administrator. So, what that means is, we work with self-insured employers, US only, and for those employers, we administer the fertility benefits...So, payback to the company, that’s a really good question. Our members, the employees who access our services, they pay their premium to their employer, so they pay their monthly premium, just like anybody would, obviously some of our employers have \$0.00 premiums, but they pay their monthly premium and then they pay their financial responsibility in the same exact way they would if they were having ACL surgery. They’re paying deductible co-insurance and co-pay. But, there’s no added fee for them to access Progyny” (Progyny, fertility benefits administrator)

In the case of IntegraMed, the presence of health insurance would not disqualify someone, but it might influence the types of services from which they could benefit. That influence will be based on the insurance offered by the employer, not necessarily the state in which the patient is a resident.

“So, what happens is that typically patients go into a fertility clinic with medical insurance, regular health insurance, and they bill us for a consultation as a diagnostic. Typically, most of the insurance companies

across the nation do cover the initial consultation. Say in Connecticut, [a mandated state]...they may have the diagnostic coverage, but if it turns out that the patient needs to do IVF, that's not something that their insurance would pick up because their employer is 100 employees or less [in a mandated state]. And so, that would make them a self-pay patient” (IntegraMed, MSA crisis management company)

Personal history and advocacy. Interestingly, six of the eight representatives, all of whom hold high administrative roles in their organization, expressed personal experiences using infertility services. Some described their experience using infertility services to empathize with people going through the same process and experiencing the same denials of insurance coverage.

“And I speak to this personally because I went through it myself. So, I lived in Connecticut. I worked for this company based out of New York, and they didn't have insurance coverage for IVF. They did cover IUI. So, when I was doing IUI, it was totally fine, and my IUI medication was even paid for. But the minute I found out I needed IVF, the services were no longer covered” (IntegraMed, MSA crisis management company)

Representatives from 3 different types of organizations mentioned how theirs or the founder’s personal experience fueled their passion to create the organization they are representing,

“So, the CADE foundation was founded in 2005 by my husband and myself. Our vision was to originally provide one family with a grant of \$10,000 for fertility treatment or adoption. That has evolved to the point where we’ve given out 121 grants to families of up to \$10,000 throughout the country” (CADE Foundation, non-profit)

“So, my wife and I have our own infertility story, I guess you can say. We now have five-year-old twins, boy/girl twins. However, I had male factor infertility; my wife had female factor infertility. And we had to go through IVF in order to conceive our kids...in the beginning, we were very

concerned about how we were going to pay for it. But luckily for us, my wife happened to be working for a **** based out of ****. And Illinois, at the time, was one of eight states that mandated that employers provide coverage for infertility. And so, her insurance plan allowed us to have up to four rounds of IVF and retrievals. Once the kids were born, we wanted to give back to that infertility community, kind of pay forward the blessing that we had with respect to that insurance” (Parental Hope, non-profit)

“There was a couple in the community who went through this themselves. And they knew how exorbitant the costs were. And they wanted to help other couples. So, they donated some money. And then, kind of fund raised in the community, and then found that there were a lot of other couples with similar situations. And just kind of fund raised throughout the past few years” (The JFCS Fertility Fund, Jewish Human Service Agency)

“So, **** is the owner of Art Risk. She has been in charge for about 25 years at this point. So, she became more of an expert on using major medical trends for surrogacy and...kind of looking through people's benefits essentially and seeing what potentially their insurance paper, either any portion of infertility and then also with the surrogacy fees. So, that's really how it started, and then it just grew from there. A lot of teaching engagements kind of helped clarify the law with the attorneys. Kind of get them to understand what was going on in the insurance world so that their contracts could mirror that and not be facing some contracts that insurance could not do” (ART Risk Solutions, financial insurance solutions company)

One had a personal experience with infertility services in the family that influenced them to pursue non-profit work rather than strictly political advocacy due to the direct benefit their grant program has on people who are trying to overcome infertility issues..

“I made a choice when I started this foundation. This is based on our daughter going through four IVFs with miscarriages every time, and eventually, now, having two daughters via surrogacy. We were very fortunate to be able to financially afford that or help them with it. I made a choice at that time. I could put my efforts into working towards political reform, or I could put my efforts into raising money so that people along the way would get help. I’ve chosen the latter because we funded 117 families now. Those are 117 families representing 85 babies that would not have been born if I hadn’t chosen this route” (Baby Quest Foundation, non-profit)

There were both political advocacy efforts and patient advocacy efforts expressed by two of the representatives. In the case of Progyny, their advocacy was geared towards the patients, to the extent that their program includes “patient care advocates” (PCAs) who act in a similar fashion to patient navigators. They assist patients with health education, treatment reminders, and services as are the patient’s main point of contact throughout the use of their services,

“It’s very similar to a patient navigator service yeah...let’s say in the example of IVF, a member and their partner are trying to become pregnant. Their OBGYN tells them that they should really seek fertility care. They call their HR department and ask about the benefits and they’re transferred over to Progyny and they’re matched with a one-to-one, we call them Patient Care Advocates or PCA’s. So, they’re matched with a dedicated Patient Care Advocate who is their main point of contact and offers emotional support, logistical support in terms of organizing appointments, following up on appointments, offers education about what all the different treatments mean and what all that entails, and how the medications work and is their main point of contact throughout the process. In some cases, helping them get second opinions, or if the service they’re getting at their provider, if they want a different type of service or

a different type of provider, making sure that they're getting what they need throughout their journey” (Progyny, fertility benefits administrator)

It was also brought up by Progyny that PCAs are so intertwined with the infertility journey of the patient that some advocates have children named after them,

“We have babies named after PCAs. And, obviously, for a lot of people, it's a really close relationship that's formed because members understand that A.) That they are getting something a lot of people don't have access to and they're grateful and B.) There's still a stigma that surrounds it [infertility services] and a woman who's going through IVF and maybe recurrent pregnancy loss isn't necessarily open with her friends or her family or certainly her colleagues about her experience. And, even when she is, not everybody understands it because while there is an incidence of one in eight, not everyone's gone through it, and even someone who has, hasn't had your exact experience. So, having that Patient Care Advocate who understands what you're going through and can talk you through it, and also serves as an expert, you really form close bonds” (Progyny, fertility benefits administrator)

In the case of IntegraMed, their advocacy was political, where one of the representatives who held an administrative role in the organization was an advocate with RESOLVE and gave presentations to some policy leaders that led to some policy changes.

“So, I'm an advocate for RESOLVE. I've been doing it for a few years, and I've gone to a few of their Advocacy Days. And there have been a couple of occasions where I've had to present in front of some of the staffers. And they recently got to some victories [passing new mandates]. New Jersey was one of the more recent ones. I was part of the Connecticut one. I think Rhode Island is working on one. So, New York recently, too. I think California” (IntegraMed, MSA crisis management company)

Perception of mandate. Almost every representative had an opinion of the efficacy of the current infertility health insurance mandates, and none of them were completely positive. While there were negatives raised, there were also some solutions proposed. Negative opinions of the infertility insurance mandate included the slow process of passing legislation, and the perceived greater positive effect their grant program had on immediate financial help – albeit for one person per year.

“I know there are people who are doing a great job in the political arena, and we’re trying to change the laws. But that’s not our focus. My focus is to get money to help people who need it right now, and who can’t wait till the laws change...I just know how slowly the wheels of progress move, and they’re going backwards in insurance in many ways. So, it’s just not, it doesn’t give the rewards that as immediate as what we’ve seen that we’re able to help people have babies right away” (Baby Quest Foundation, non-profit)

Representatives from three different organizations brought up reasons why people get denied, and much of it has to do with the language within the mandates themselves. This includes: 1) some mandates still maintain heteronormative language that exclude same-sex couples; and 2) there is an unequal perception of “medical need” for infertility services, highlighting the way the insurance industry perceives infertility as something closer to a cosmetic surgery – wanted but not medically necessary.

“But I also feel like there should be at least an equal, the way that the insurance company view infertility, I think, needs to be treated as equal as any other disease out there. I don’t think that the insurance companies are doing that” (The Hope for Fertility Foundation, non-profit)

“The problem is, with these plans, is that they tend to be very heterogeneous. So, even New York that recently passed legislation, was not bad legislation, they passed it last summer [2018], and it opened up

the infertility world a bit more. But it still didn't address same-sex couples – it was a great step forward, it stopped short of really where it should be. And there's only 16 states that have any type of a mandate. And of those 16, there's really only 3 good ones. So, California loves to say, “We have a mandate’, but all they really mandate is that you're going to test to see if you are infertile. And if you are infertile, you're done. There's no coverage for treatment” (Progyny, fertility benefits administrator)

“But I think that to say then ‘We're [insurance company] not going to cover this disease’ which truly is a disease – if you're infertile, you are infertile for a variety of reasons – is, I think, wrong, and wrong on the part of the insurance companies, and I think there are ways that we can start limiting the cost” (ART Risk Solutions, financial insurance solutions company)

The fact that employers must bear an extra cost for adding infertility services, leading to those services not being offered, was brought up by two different organization representatives.

“When you look at the companies that are voluntarily providing this coverage, such as Proctor & Gamble, or Fifth Third Bank, or Starbucks, for example, they are large companies that can afford to take on that additional cost voluntarily because there’s gonna be a higher percentage of their employees who are gonna actually access that care” (Parental Hope, non-profit)

“The cost of IVF is very prohibitive [for employers]. But if there was insurance coverage for it [infertility services], the price would come down because you're only going to get reimbursed so much by the insurance company. I think we'd start seeing equalization of the prices, which then would make it more affordable, so then the fear on the part of the employers that it's going to be too expensive would go away. I think it's a multi-faceted solution” (ART Risk Solutions, financial insurance solutions company)

Representatives from the different types of organizations expressed how insurance for infertility services could be done differently. This is based on their experience working with patients, couples, clinics, or employers on infertility insurance benefits – such as lowering the costs of infertility services, rather than create more mandates for insurance companies, or just providing more coverage for the wide spectrum of services.

“I worry that the more mandates we put on insurance companies just ultimately causes our insurance rates to go up, making it more difficult for people to get insurance in the first place. I feel like the solution, well, then on top of that, the amount that doctors end up charging ends up going up. So, I feel, if there was a way for treatments to be cheaper to begin with, I think that would probably be a more effective approach than mandating insurance on the insurance companies” (The Hope for Fertility Foundation, non-profit)

“And even in states with really decent mandates like Massachusetts or Illinois, again, if you're company does not provide benefits, whether it's because their headquarters are in another state without a mandate, or it's because they have 100 employees or less, or you're self-employed, you're a contractor with five people that work for you, you need to go with somebody like Attain, or you're gonna pay the clinic for each single cycle. So, patients like this exist. And even though 16 states right now offer some sort of a mandate, they're not all perfect, and still a really small number” (IntegraMed, MSA crisis management company)

“If insurance could cover more it would be definitely more beneficial because people pay so much out of pocket for the cost even prior to doing the IVF. And there's no guarantee when people pay for IVF that they're gonna have a child” (The JFCS Fertility Fund, Jewish Human Service Agency)

“I think actually the state-mandates need to change, because if the state mandates were to change, which actually we're making progress on, especially with medically necessary fertility coverage, the state mandates could get rid of the heterogeneous language, and the insurance companies would have to follow” (Progyny, fertility benefits administrator)

“But if there was insurance coverage for it, the price would come down because you're only going to get reimbursed so much by the insurance company. I think we'd start seeing equalization of the prices, which then would make it more affordable, so then the fear on the part of the employers that it's going to be too expensive would go away. I think it's a multi-faceted solution” (ART Risk Solutions, financial insurance solutions company)

Some representatives expressed giving much thought into the effect of the mandates and their role in facilitating increased access, but still feel they cannot tell if the mandates are truly facilitative. More often than not, respondents felt that the mandates were not effective as they are now. They identified gaps in coverage after an infertility diagnosis is confirmed, and in the role of the state in increasing access to infertility services in a more equitable manner,

“I put a lot of thought into it, and I think I've bounced back and forth between my opinion and I've sat down with some of our local political leaders and talked to them about it. To be honest I'm still on the fence a little bit. It might be that I feel that I'm more surprised at the things that insurance companies are willing to provide coverage for but tend to ignore infertility. Most insurance companies will pay to have infertility diagnosed, but then they won't pay for any of the treatment” (The Hope for Fertility Foundation, non-profit)

“I really think that the states have to dictate the coverage and dictate the language. The insurance companies are not going to do this [offer cheaper services] voluntarily because they're not going to want to take on the

risk...I think once the state sets the framework, I think the insurance companies will step up in a positive way. But they're not going to do it if it's not mandated” (Progyny, fertility benefits administrator)

All of these organizations exist due to the *lack* of insurance coverage for infertility services. Due to this, increased insurance coverage could mean that some of organizations would suffer through the loss of their own clientele. The representative from IntegraMed reflected specifically on the longevity of the company’s subsidiary, Attain Fertility, if access to infertility services increases to the extent that their services are no longer utilized (as much). This highlights the philosophy under which the organization operates: to help patients.

“Years ago, not all oncology services were covered. A number of years, most bariatric coverages were not covered. Most of the time, they are now. I think most employers are going to begin covering fertility treatment. And that is fantastic for IntegraMed. That is fantastic for patients. That's fantastic for practices financially. It does really, frankly, hurt Attain, but that's fine. We're here to help patients. So, if they have coverage, they have coverage. That's perfectly fine. And we'll continue to be here and help them – help those that don't have coverage” (IntegraMed, MSA crisis management company)

The representative from Progyny had a similar philosophy that increased access to infertility services is good no matter the effect on the company,

“We believe that state mandates are great. Because we are serving the self-insured groups, and that means that there are a lot of fully insured people out there and they should have access too. And, we live our vision and believe our vision for us and our employers, but we believe it for everybody. So, just because someone doesn’t have access to Progyny doesn’t mean they shouldn’t have access to benefits. And so, state mandates are good because it’s improving and increasing access for

people. I think the New York State one was very good. In some ways, they're small amounts. I would love that they cover fertility preservation more and things of that nature. But, any increase in coverage and increase of access is always a good thing, whether it directly affects Progyny or not. We believe across the board that people who want to have a child should be able to have a child or children if that's their thing" (Progyny, fertility benefits administrator)

In sum, the role of organizations on increasing access to infertility services in the United States is to be advocates for both the patients and the policies meant to help them. This is a type of collective efficacy to make positive changes in favor of increased access to infertility services, and to function as a type of safety net for people who cannot achieve insurance coverage for infertility services. Although most of the survey and interview responses show low usage of these organizations, those who were able to access them were able to achieve some degree of financial assistance for infertility services when their insurance would not cover. Many of those expenses were for medications and actual treatment of infertility beyond IUI or diagnostic services.

The personal histories expressed from these representatives shows that empathy is a powerful motivation to make change, even in the face of opposition. A type of community advocacy could also be argued to be present in the support given to fund the different grant programs. These grants were funded almost 100% on donations from other individuals and couples who deal or dealt with infertility – who also endured the high cost of infertility services, but still wanted to give their money to help someone else. Patient advocacy efforts by Progyny with their PCAs are an example of how informed businesses can provide the full spectrum of services required, regardless of legislative support.

Political advocacy expressed through these expert interviews shows that these organizations are not static, but dynamic. They responded to new knowledge (new to legislators

and insurance companies) that more than heterosexual couples require infertility services; the definition of infertility within these mandates *is* disqualifying people, such as surrogates who will never fall under the designation of “infertile” and be will disqualified from insurance coverage and that going through these processes is uniquely stressful and expensive. The founders of these organizations responded to this knowledge by trying to make access to fertility resources to start a family easier, more affordable, and by influencing policies by advocating that those policies that exist are not good enough. Also they help by providing guidance on what needs to be done better.

Research Question 5: Spatial dimensions of fertility

R5: What is the spatial relationship between fertility of women between the years of 2013-2017 based on age, education, ethnicity, nativity, and income?

ACS fertility data. Data used for these analyses are from the American Community Survey (ACS) 2013-2017 5yr data on Fertility, reflecting an estimated number of women with births in the past 12 months between the years of 2013-2017 based on census tract level estimations. Figures 4.7 – 4.26 show the spatial distribution of women with births based on the selected sociodemographics (Table 3.1). Figure 4.27 represents population density, and Figure 4.28 represents birth density. For the map showing all women with births (Figure 4.7), the lowest possible number of observations was set to 0 so that they would not be combined with observations of 1 or more. For the rest of the frequency maps, the lowest possible observation was set automatically using the Equal Breaks (Jenks) option, which automatically sets the distribution of values based on the values themselves within the number of levels specified.

Spatial distribution of “All Births” shows some higher birth estimates in large metropolitan areas. This follows the construction of census tracts, which are based on population numbers

(Census Bureau History Staff, 2020). The smaller the census tract, the higher the population, and thus the higher the number of women who could give birth, as seen in their plotted linear relationship ($y = 55.07784 + -0.00936x$; $R^2 = 0.00155973949$) (Figure 4.29). The variables with the most distinct spatial associations that could be observed spatially were the race/ethnicity related variables. Figure 4.30 shows a dot density map of the fertility data based on census-based racial groups to observe how there are spatially distinct areas where some racial groups are having births with greater frequencies than in other areas. As can be seen on the map, there are distinctly higher and isolated counts of African American women with births along the southeastern United States, and higher and isolated counts of Hispanic women with births along the southern and western United States, with some density locations in Florida, New York, and Washington state (Figure 4.30).

Spatial autocorrelation. Spatial autocorrelation of the dependent variable “All Women with Births” revealed significant spatial autocorrelation ($p < 0.0001$) for All Women with Births and population density (Table 4.29), Age (Table 4.30), Ethnicity (Table 4.31), Nativity (Table 4.32), Education (Table 4.33), and Income disparity (Table 4.34). In spatial autocorrelation, the direction of autocorrelation is also important to observe – whether positive or negative. Interpretation of Moran’s I is that, for the Moran’s I coefficient, $I > E[I]$ indicates positive autocorrelation – indicating the neighboring census tracts have similar values. Interpretation of Gary’s c is that when $c < E[c]$, there is positive autocorrelation (SAS Institute Inc, 2020). Negative autocorrelation means that the neighboring census tract values are dissimilar (SAS Institute Inc, 2020). All independent variables showed significant positive autocorrelation for Moran’s I and Gary’s c , except for African American (Table 36) and Graduate and Professional Degree (Table 38) which both exhibited significantly negative spatial autocorrelation for the Gary’s c statistic.

This may suggest that census tracts containing women with births between the age of 15-50 who are either African American or who have a graduate or professional degree are located adjacent to census tracts with few women with births identifying with those sociodemographics. This could indicate that women with births having those demographics are both fewer and spatially constrained.

The Moran's I and Gary's c statistics did not change when using the significant variables identified by either of the linear regression statistics (Poissonian and negative binomial), or when using the Randomized assumption opposed to the default Normalized assumption (Table 4.35). This occurrence could be due to the highly autocorrelated nature of this data and the fact that it observes all census tracts within the contiguous United States. Spatial autocorrelation within state boundaries could give different results.

Optimized hot spot analysis. Previously it was discovered that the fertility variables are all significantly autocorrelated and that the majority show positive spatial autocorrelation. These values do not, however, show where spatially these values are autocorrelated. To observe the clustering of women with births over space, this research utilized the Optimized Hot Spot Analysis in ArcPro 2.4. Analyses on Hawaii and Alaska were computed separately from the contiguous United States. The cartographic output of the Optimized Hot Spot Analysis also uses the data package "U.S. Major Cities" created by ESRI and the U.S. Census Bureau (ESRI & U.S. Census Bureau, 2020).

The Optimized Hot Spot Analysis revealed the maximum number of women with births within a census tract to be 1,370 with an average of 54.9 (50.5) women with births. There were 1,287 outliers, which were not included in the optimal fixed distance band used to observe "neighboring" features. The program did not detect an optimal scale for analysis, so the optimal

fixed distance band was based on the average distance to 30 nearest neighbors, 17,574m (10.9mi). The FDR correction detected 27,164 statistically significant census tracts, which included the corrections for multiple testing and spatial dependence (Figure 4.31). Nearly 14% of features had less than eight neighbors based on the distance band of 17,547m (10.9mi). Based on observation, the majority of significantly high or low estimates of women with births were in metropolitan areas with populations above 250,000 persons.

Directional distribution. To observe the spatial directions in which these data are distributed, a directional distribution ellipse was calculated for each of the fertility variables. The ellipses are based on one standard deviation from the mean center of the data observation. Figure 4.32 shows the directional distributions for all of the fertility variables, and Figures 4.34 – 4.38 show the directional distributions based on each demographic domain (age, ethnicity, education, nativity, income disparity, and densities).

Based on these quantitative spatial analyses, fertility in the United States is highly spatially autocorrelated. When investigating the directional distributions, the demographic category with the greatest diversity is Ethnicity, suggesting that some of the spatial autocorrelation may be based on ethnicity-specific factors.

Research Question 6: Observing fertility in relation to states with/without mandated infertility insurance coverage

R6: What is the spatial relationship between fertility of women between the years of 2013-2017 and states with or without infertility insurance mandates?

ACS fertility data. There are now 18 states with infertility insurance mandates, however this research observes the 16 states that had infertility insurance mandates as of December 2017. To observe fertility to states with an infertility insurance mandate to those without, a new

dichotomous variable called “Mandate” was added to the Fertility dataset – where 1 = mandate present, and 2=mandate absent. When looking at the total number of women with births between those groups, there is only a difference of 6,600 women with births (Table 4.11). This suggests that state’s that have mandates are states with higher populations, which also explains the extreme differences in average population density. States with mandates have an average population density of 9,152.2 (86,060.04) persons per square mile, whereas states without a mandate have an average of 2,669.1 (4,185.5) persons per square mile.

After testing for normality, it was discovered these data were positively skewed (Figure 4.39) so traditional two-sample t-test is not appropriate. This analysis used the Wilcoxon rank-sum test. Results comparing the means of “All Women with Births” between states with and without an infertility insurance mandate resulted in rejecting the null hypothesis – meaning there is a significant difference between the mean number of births between states with an infertility insurance mandate and states without an infertility insurance mandate ($Pr > \text{Chi-Square} = <0.0001$, $df=1$). The Poissonian and negative binomial regression also detected significant differences between “All Women with Births” in states with and without an infertility insurance mandate ($p < .0001$) (Table 4.36).

Research Question 7: Spatial dimensions of CDC-reporting fertility clinics

R7: What is the spatial relationship between fertility of women age 15-50 and the spatial distribution of SART reporting clinics between the years of 2013-2017?

Informal interviews. There was a total of 22 different clinics identified by the interviewees – clinics they personally used for some if not all of their services. The names of these clinics were searched in the clinic data sheet used for this research (accessed from the CDC), and

the clinic names were searched on the CDC's ART clinic search service (https://nccd.cdc.gov/drh_art/rdPage.aspx?rdReport=DRH_ART.FindAClinic&rdRequestForward=True). Regarding the differences between mandated and non-mandated states, seven people were living in and using a clinic in a mandated state, 13 people were living in and using a clinic in a non-mandated state, and 2 people lived in non-mandate states but used a clinic in a mandated state. Of the 22 clinics identified, four were not found in the database of clinics reporting their data to the CDC – two clinics in mandated states and two clinics in non-mandated states. One of the clinics not reporting their data was a military-based medical center, the other three were not associated with another entity such as military, academic, or within a hospital or university.

Fertility clinics, 2017. Of the 72,987 census tracts included in this research, 0.56% (408) of those have at least one of the 448 clinics included in this research. When observing fertility in relation to those clinics, the mean estimates of “All Women with Births” does not vary greatly between census tracts with clinics ($m=53.22$ (51.06)) and all census tracts ($m=54.73$ (50.55)), however the census tracts with fertility clinics represent 0.62% of the total population which could explain the similarity of the two averages: fertility clinics are located in places of high population density (Table 4.35).

Spatial distribution of fertility clinics across the United States shows some spatial restriction, where most clinics tend to cluster around large cities (Figure 4.40). Kernel density analysis using a defined search radius of 200 miles revealed some high-density clusters of ART clinics in metropolitan areas, such as San Francisco, Los Angeles, New York, and Chicago (Figure 4.41). Kernel density analysis did not include Hawaii or Alaska due to their distance from the contiguous United States.

An optimized hot spot analysis using polygon cell sizes of 25 miles revealed a similar pattern of spatial clustering (Figure 4.42). There were 147 (33.41%) fertility clinics within a significantly closer distance to each other than the others, based on FDR correction and multiple testing for spatial dependence. Based on the automatic distance band of 54 miles, 4.3% of fertility clinics had less than eight nearest clinics. There were no cold spots identified, which could suggest that the clinics not included in the analysis are so spatially distant that they do not have neighboring features that could be detected by the algorithm.

Chapter Four Tables

Table 4.1. Informal interview demographics (n=66)

Variable	n	Total (%)
Stage of Using Infertility Services		
Currently using	34	51.52%
Previously used	29	43.94%
Not using yet	3	4.55%
Gender Identity		
Female	61	92.42%
Male	3	4.55%
Nonbinary	1	1.52%
Gender Queer	1	1.52%
Age		
Mean (<i>sd</i>)	32.7 (4.09)	
Range	21-43	
Estimated Annual Household Income		
Mean (<i>sd</i>)	\$155,107.69 (107,281.77)	
Range	\$30,000 – \$700,000	
\$30,000 – \$84,999	13	19.70%
\$85,000 – \$134,999	25	37.88%
\$135,000 – \$189,999	13	19.70%
\$190,000 – \$299,999	4	6.06%
\$300,000 – \$700,000	10	15.15%
Do not know	1	1.52%
Joint or Single Income		
Joint income	57	86.36%
Single income	8	12.12%
No answer	1	1.52%
Marital Status		
Married	61	92.42%
Single	2	3.03%
In a relationship, living together	2	3.03%
Divorced	1	1.52%
Sexual Orientation		
Heterosexual	55	83.33%
Homosexual	6	9.09%
Bisexual	5	7.58%
Ethnicity (with Hispanic ancestry)		
Hispanic or Latin Decent (n=3)		4.55%
Caucasian	2	3.03%
Puerto Rican	1	1.52%
Ethnicity (without Hispanic ancestry)		
Caucasian	57	86.36%
African American	2	3.03%
Middle Eastern	2	3.03%
Indian	1	1.52%

Table 4.1 (Continued)

More than one ethnicity	1	1.52%
Religion		
None	36	54.55%
Christian	10	15.15%
Catholic	6	9.09%
Jewish	6	9.09%
Agnostic	3	4.55%
Atheist	1	1.52%
Buddhist	1	1.52%
Muslim	1	1.52%
Bahá'í	1	1.52%
Hindu	1	1.52%
Employment		
Full-time	48	72.73%
Self-Employed	8	12.12%
Multiple jobs	4	6.06%
Part-time	3	4.65%
Student	3	4.65%
Industry		
Hospital, Healthcare, Social assistance	14	21.21%
College, University, Adult Education	11	16.67%
Non-profit	7	10.61%
Primary/Secondary Education	6	9.09%
Government (locale, state, federal)	6	9.09%
Arts, Entertainment, Recreation	3	4.55%
Pharmaceuticals	3	4.55%
Business (Marketing, Advertising, Consulting, Manufacturing, Retail/Wholesale, Corporate)	3	4.55%
Information Technology (IT)	2	3.03%
Real Estate	2	3.03%
Science/Engineering	2	3.03%
Construction	1	1.52%
Travel and Leisure	1	1.52%
Legal Services	1	1.52%
Insurance	1	1.52%
No answer	3	4.55%
Education		
Associates degree	3	4.55%
Bachelors degree	20	30.30%
Masters degree	28	42.42%
Professional (MD, PharmD)	2	3.03%
Doctorate (PhD)	11	16.67%
Graduate/Postgraduate Diploma	2	3.03%
Currently Pregnant?		
No	59	89.40%
Yes (IVF)	4	6.06%
Yes (IUI)	1	1.52%
Yes (Egg retrieval)	1	1.52%
Parity		

Table 4.1 (Continued)

0	53	80.30%
1	9	13.64%
2	2	3.03%
3	1	1.52%
Losses	1	1.52%
Children from ART (n=11)		
1	9	81.82%
2	1	9.09%
3	1	9.09%
Primary Reason Seeking Infertility Services		
Unexplained	18	27.27%
Female factor	17	25.75%
Male factor	10	15.15%
Dual factor	10	15.15%
Same sex	7	10.60%
Cancer related	3	4.55%
Genetic	1	1.52%
Secondary Reason Seeking Infertility Services		
Female factor	4	6.06%
Unexplained	2	3.03%
Dual factor	2	3.03%
Genetic	1	1.52%
Inconsistent information from doctors	1	1.52%
Type of Health Insurance		
Private (individually or through employer)	58	87.88%
Private with Medigap (individually or through employer)	4	6.06%
Dual (employer + private insurance, spouse insurance + own insurance)	2	4.55%
Tricare/Veterans Affairs	1	1.52%
Residence		
Living in Mandated State	34	51.5%
Living in non-Mandated State	32	48.5%

Table 4.2. Expert interview organizational demographics (n=8)

Name	Type of organization	State based in	Residence requirement	Assistance type	Individuals or Employers?	Cost to Employer
Baby Quest Foundation	501c3 non-profit	CA	U.S. resident	Grant (\$500)	Individuals/ Couples	N/A
CADE Foundation	501c3 non-profit	MD	U.S. resident	Grant (\$10,000)	Individuals/ Couples	N/A
The Hope for Fertility Foundation	501c3 non-profit	UT	U.S. resident	Grant (up to \$5,000)	Individuals/ Couples	N/A
Progyny	Fertility benefits administrator	NY	Must work for U.S. based company	Insurance benefits	Employers	None extra
The JFCS Fertility Fund	Jewish Human Service Agency	PA	U.S. resident in Philadelphia, PA	Grant (dependent on services)	Individuals/ Couples	N/A
Parental Hope	501c3 non-profit	OH	U.S. resident	Grant (\$5,000)	Individuals/ Couples	N/A
ART Risk Solutions	Financial insurance solutions	CA	None	Insurance and case management	Individuals/ Couples and clinics	N/A
IntegraMed Fertility	MSA crisis management	National	None	Shared risk programs	Individuals/ Couples	No

Table 4.3. Survey demographics (n=134)

Variable/Stage of Use	Prospective (n= 12, 9%)	Active (n=71, 53%)	Past (n= 51, 38%)	Total (%)
	n	n	n	
Gender Identity				
Nonbinary	0	1	0	1 (0.8%)
Male	1	2	2	5 (3.7%)
Female	11	68	49	128 (95.5%)
Age				
20-25	1	2	3	6 (4.5%)
26-30	3	19	5	27 (20.2%)
31-35	6	30	28	64 (47.8%)
36-40	1	16	11	28 (20.9%)
41-45	1	4	4	9 (6.7%)
Marital Status				
Single	0	1	0	1 (0.8%)
Married	10	64	47	121 (90.3%)
In a relationship, not living together	0	1	0	1 (0.8%)
In a relationship, living together	2	5	1	8 (5.9%)
Divorced	0	0	2	2 (1.5%)
No answer	0	0	1	1 (0.8%)

Table 4.3 (Continued)

Sexual Orientation				
Heterosexual	9	59	42	110 (82.1%)
Homosexual	1	5	4	10 (7.5%)
Bisexual	2	7	5	14 (10.5%)
Ethnicity (with Hispanic ancestry)				
Hispanic or Latin Decent (n=4)				4 (2.9%)
Caucasian	0	0	1	1 (0.8%)
More than one ethnicity	0	1	1	2 (1.5%)
Puerto Rican	0	0	1	1 (0.8%)
Ethnicity (without Hispanic ancestry)				
Caucasian	9	62	47	118 (88.1%)
African American	1	1	1	3 (2.2%)
Asian	0	4	0	4 (2.9%)
Middle Eastern	1	2	0	3 (2.2%)
More than one	0	1	1	2 (1.5%)
Religion				
Christian	2	15	14	31 (23.1%)
Buddhist	1	2	2	5 (3.7%)
Catholic	3	6	6	15 (11/2%)
Jewish	0	6	5	11 (8.2%)
None	6	40	23	69 (51.5%)
Other	0	2	1	3 (2.2%)
Employment				
Full-time	9	60	41	110 (83.1%)
Part-time	1	1	2	4 (2.9%)
Multiple jobs	1	1	0	2 (1.5%)
Unemployed, but partner is working	1	4	6	11 (8.2%)
Student	0	2	0	2 (1.5%)
Self-Employed	0	3	2	5 (3.7%)
Annual Household Income				
<= 50,999	1	3	1	5 (3.7%)
51,000 – 65,999	1	5	1	7 (5.2%)
66,000 – 75,999	1	4	1	6 (4.5%)
76,000 – 85,999	1	2	1	4 (2.9%)
86,000 – 99,999	2	8	7	17 (12.7%)
>= 100,000	6	49	40	95 (70.1%)
Education				
HS Diploma	0	1	2	3 (2.2%)
AS	1	4	1	6 (4.5%)
Bachelors	6	26	14	46 (34.3%)
Masters	2	26	20	48 (35.8%)
Professional	1	6	6	13 (9.7%)
Doctorate	2	8	8	18 (13.4%)
Where heard about research				
RESOLVE	0	0	2	2 (1.5%)
Family Equality Council	0	0	1	1 (0.8%)

Table 4.3 (Continued)

Friend	1	1	7	9 (6.7%)
Reddit	10	69	41	120 (89.6%)
Facebook	1	1	0	2 (1.5%)
Industry				
Hospital, Healthcare, Social assistance	5	18	13	36 (26.9%)
College, University, Adult Education	0	8	6	14 (10.5%)
Primary/Secondary Education	0	6	5	11 (8.2%)
Information Technology	2	8	0	10 (7.5%)
Non-Profit	1	3	4	8 (6%)
Government (local, state, federal)	1	6	1	8 (6%)
Business (Marketing, Advertising, Consulting, Manufacturing, Retail/Wholesale, Corporate)	0	4	3	7 (5.2%)
Science/Engineering	0	2	3	5 (3.7%)
Arts, Entertainment, Recreation	0	2	2	4 (3%)
Construction	1	3	0	4 (3%)
Legal Services	0	3	1	4 (3%)
Finance	0	1	2	3 (2.2%)
Pharmaceuticals	0	1	2	3 (2.2%)
Real Estate	0	1	1	2 (1.5%)
Insurance	1	0	1	2 (1.5%)
Hotel and Food Service	0	1	0	1 (0.75%)
Travel and Leisure	0	0	1	1 (0.75%)
No answer	1	4	6	11 (8.2%)
Currently parenting?				
Yes	0	6	25	31 (23.1%)
No	12	65	26	103 (76.7%)
Parity				
0	12	65	26	103 (76.7%)
1	0	4	17	21 (15.7%)
2	0	2	6	8 (6%)
3	0	0	2	2 (1.5%)
Children from ART (n=25)				
1	0	0	19	19 (76%)
2	0	0	5	5 (20%)
3	0	0	1	1 (4%)
Reason Seeking Infertility Services (number exceeds total counts of each group because some people gave more than one reason)				
Unexplained	5	35	5	45 (26.7%)
Female factor	4	25	16	45 (26.7%)
Male factor	4	19	8	31 (18.3%)
Dual factor	1	16	10	27 (16%)
Same sex	2	7	6	15 (8.9%)
Cancer related	0	3	1	4 (2.4%)

Table 4.3 (Continued)

Single person	0	1	0	1 (0.6%)
Advanced age	0	1	0	1 (0.6%)
Type of Health Insurance				
Private (individually or through employer)	8	60	48	116 (87.9%)
Private with Medigap (individually or through employer)	2	3	1	6 (4.5%)
Affordable Care Act (ObamaCare)	1	0	0	1 (0.8%)
Tricare/Veterans Affairs	0	4	1	5 (3.8%)
Single Service Plan	1	0	1	2 (1.5%)
Dual (employer + private insurance, spouse insurance + own insurance)	0	1	0	1 (0.8%)
Not covered by any health insurance	0	1	0	1 (0.8%)
Residence				
Living in Mandated State	8	40	27	75 (56%)
Living in non-Mandated State	4	31	24	59 (44%)

Table 4.4. Health education survey responses: Personal experience (n=133)

Q2.1 - I received information about risks of fertility decreasing with age during health education courses in: (check all that apply)			
#	Answer	%	Count
1	Elementary school	0%	0
2	Middle school	0.75%	1
3	High school	3.76%	5
4	College/University	8.96%	12
5	I do not remember	21.64%	29
6	I did not receive this type of information at any level of schooling	55.97%	74
7	More than one grade	9.02%	12
	Total (missing 1)	100%	133

Table 4.5. Health education survey responses: Personal opinion (n=133)

Q2.2 - In your opinion, what is the earliest grade at which to learn about the risks of infertility?			
#	Answer	%	Count
1	1st - 3rd grade	0%	0
2	4th - 7th grade	15.79%	21
3	High School	45.11%	60
4	College	2.99%	9
5	More than one grade	7.52%	10
6	None	24.81%	33
	Total (missing 1)	100%	133

Table 4.6. Survey responses to online communities (n=134)

Prompt: Please select your level of agreement or disagreement with the following statement:						
Response	I use online ART/infertility support forums to help me make decisions about what infertility services to use.		I talk about my experience with using infertility services more online than I do with people in person.		I prefer to access online support forums for ART/infertility before talking to a physician.	
Strongly Agree	31.34%	42	44.03%	59	9.70%	13
Agree	41.79%	56	19.40%	26	28.36%	38
Neutral	9.70%	13	17.91%	24	32.84%	44
Disagree	12.69%	17	14.93%	20	22.39%	30
Strongly Disagree	4.48%	6	3.73%	5	6.72%	9
Total	100%	134	100%	134	100%	134

Table 4.7. ISE Score breakdown

Field	Mean (range 1-9)	Variance	Count
Ignore or push away unpleasant thoughts that can upset me during medical procedures	5.19 (2.02)	4.09	133
Keep a sense of humor	6.38 (1.95)	3.8	133
Make meaning out of my infertility experience	4.83 (2.31)	5.35	132
Handle mood swings caused by hormonal treatments	5.35 (2.02)	4.08	133
Keep from getting discouraged when nothing I do seems to make a difference	3.98 (1.99)	3.95	133
Accept that my best efforts may not change my/our infertility	5.27 (2.25)	5.07	133
Control negative feelings about infertility	3.76 (1.95)	3.81	133
Cope with pregnant friends and family members	4.53 (2.31)	5.35	133
Handle personal feelings of anger or hostility	5.21 (2.04)	4.17	133
Keep a positive attitude	4.83 (2.01)	4.05	133
Lessen feelings of self-blame, shame, or defectiveness	5.19 (2.18)	4.77	133
Stay relaxed while waiting for appointments or test results	4.05 (2.14)	4.6	132

Table 4.7 (Continued)

Do something to make myself feel better if I am sad or discouraged	5.7 (1.78)	3.17	133
Keep active with my usual life routine	6.03 (1.91)	3.65	133
Feel good about my body and myself	4.83 (2.12)	4.5	133
Feel like a sexual individual	4.69 (2.22)	4.95	133

Table 4.8. GLM and Tukey's test: ISE mean total score and stage of infertility service use

Source	DF	Sum of Squares	Mean Square	F Value	Pr > F
Infertility Mandate	1	9.26201	9.26201	0.02	0.8883
Stage of Use	2	892.34418	446.17209	0.96	0.3851
Ethnicity	5	6836.20620	1367.24124	3.19	0.0095
Age	4	1513.52589	378.38147	0.81	0.5203
Health Education	5	5591.52697	1118.30539	2.53	0.0320
Online Communities: decisions	4	1279.00173	319.75043	0.68	0.6052
Online Communities: discussions	4	8294.16154	2073.54039	5.01	0.0009
Online Communities: physician	4	524.01567	131.00392	0.28	0.8929

Table 4.9. ISE mean score and ethnicity – Tukey's post hoc analysis

Comparisons significant at the 0.05 level are indicated by ***.				
Ethnicity Comparison	Difference Between Means	Simultaneous 95% Confidence Limits		
Asian – African American	8.333	-37.405	54.072	
Asian - Hispanic	14.000	-52.954	80.954	
Asian - More than one ethnicity	29.750	-12.595	72.095	
Asian - Caucasian	33.983	3.537	64.429	***
Asian - Middle Eastern	41.333	-4.405	87.072	
African American - Asian	-8.333	-54.072	37.405	
African American - Hispanic	5.667	-63.483	74.816	
African American - More than one ethnicity	21.417	-24.322	67.155	
African American - Caucasian	25.650	-9.362	60.661	

Table 4.9 (Continued)

African American - Middle Eastern	33.000	-15.896	81.896	
Hispanic - Asian	-14.000	-80.954	52.954	
Hispanic - African American	-5.667	-74.816	63.483	
Hispanic - More than one ethnicity	15.750	-51.204	82.704	
Hispanic - Caucasian	19.983	-40.156	80.122	
Hispanic - Middle Eastern	27.333	-41.816	96.483	
More than one ethnicity - Asian	-29.750	-72.095	12.595	
More than one ethnicity - African American	-21.417	-67.155	24.322	
More than one ethnicity - Hispanic	-15.750	-82.704	51.204	
More than one ethnicity - Caucasian	4.233	-26.213	34.679	
More than one ethnicity - Middle Eastern	11.583	-34.155	57.322	
Caucasian - Asian	-33.983	-64.429	-3.537	***
Caucasian - African American	-25.650	-60.661	9.362	
Caucasian - Hispanic	-19.983	-80.122	40.156	
Caucasian - More than one ethnicity	-4.233	-34.679	26.213	
Caucasian -Middle Eastern	7.350	-27.661	42.362	
Middle Eastern - Asian	-41.333	-87.072	4.405	
Middle Eastern - African American	-33.000	-81.896	15.896	
Middle Eastern - Hispanic	-27.333	-96.483	41.816	
Middle Eastern - More than one ethnicity	-11.583	-57.322	34.155	
Middle Eastern - Caucasian	-7.350	-42.362	27.661	

Table 4.10. ISE mean score and online community: discussions – Tukey’s post hoc analysis

Comparisons significant at the 0.05 level are indicated by ***.				
Prompt: “I talk about my experience with using infertility services more online than I do with people in person” Comparison	Difference Between Means	Simultaneous 95% Confidence Limits		
Strongly Disagree - Disagree	8.750	-19.385	36.885	
Strongly Disagree - Neutral	15.708	-11.954	43.371	
Strongly Disagree - Agree	20.880	-6.687	48.447	
Strongly Disagree - Strongly Agree	27.492	1.282	53.701	***
Disagree - Strongly Disagree	-8.750	-36.885	19.385	
Disagree - Neutral	6.958	-10.078	23.995	
Disagree - Agree	12.130	-4.751	29.011	
Disagree - Strongly Agree	18.742	4.182	33.301	***
Neutral - Strongly Disagree	-15.708	-43.371	11.954	
Neutral - Disagree	-6.958	-23.995	10.078	
Neutral - Agree	5.172	-10.909	21.252	
Neutral - Strongly Agree	11.783	-1.840	25.407	
Agree - Strongly Disagree	-20.880	-48.447	6.687	
Agree - Disagree	-12.130	-29.011	4.751	
Agree - Neutral	-5.172	-21.252	10.909	
Agree - Strongly Agree	6.612	-6.817	20.040	
Strongly Agree - Strongly Disagree	-27.492	-53.701	-1.282	***
Strongly Agree - Disagree	-18.742	-33.301	-4.182	***
Strongly Agree - Neutral	-11.783	-25.407	1.840	
Strongly Agree - Agree	-6.612	-20.040	6.817	

Table 4.11. Comparison of births by presence or absence of state-based infertility insurance mandate

Variable	Mandate Present Census tracts: 33,198 All women with births: 1,856,479		Mandate Absent Census tracts: 39,798 All women with births: 2,137,744	
	mean	SD	mean	SD
All Women with Births	55.9	52.3	53.7	49.0
Age 15-19	2.1	7.7	2.2	7.6
Age 20-34	40.5	42.9	41.1	41.1
Age 35-50	13.3	19.4	10.5	17.1
Caucasian (HL)	36.0	40.2	38.5	39.6
African American	7.3	19.5	8.4	22.4
American Indian/Alaska Native	0.3	2.9	0.8	5.8
Asian	5.1	14.5	2.3	8.6
Native Hawaiian/Pacific Islander	0.2	2.6	0.1	1.8
Two or more ethnicities	1.8	7.1	1.6	6.2
Hispanic (any)	17.1	32.8	8.0	20.8
Caucasian (only)	25.1	32.5	33.0	36.0
U.S. born	41.7	42.6	45.8	43.2
Foreign born	14.3	25.4	7.9	18.9
Less than High School	7.7	21.8	6.6	15.5
High School Diploma or GED	12.8	21.8	12.5	20.5
Associate Degree	16.6	24.3	17.8	24.4
Bachelor Degree	11.4	19.2	10.9	18.0
Graduate or Professional Degree	17.7	12.1	16.0	10.9
100% below poverty line	13.6	23.4	13.8	22.7
200% above poverty line	30.9	36.9	28.1	33.7
Received public assistance income	3.2	9.8	2.7	8.6
Population density	9,152.2	86,060.04	2,669.1	4,185.5

Table 4.12. Poissonian distribution GENMOD procedure

Criteria for Assessing Goodness of Fit								
Criterion	DF	Value		Value/DF				
Deviance	72E3	1263859.0820		17.4422				
Scaled Deviance	72E3	1263859.0820		17.4422				
Pearson Chi-Square	72E3	1037929.7930		14.3242				
Scaled Pearson X2	72E3	1037929.7930		14.3242				
Log Likelihood		12717647.120						
Full Log Likelihood		-820347.5039						
AIC (smaller is better)		1640741.0079						
AICC (smaller is better)		1640741.0231						
Analysis of Maximum Likelihood Parameter Estimates								
Parameter		DF	Estimate	Standard Error	Wald 95% Confidence Limits		Wald Chi-Square	Pr > ChiSq
Intercept		1	3.4058	0.0011	3.4036	3.4081	8996605	<.0001
Population Density		1	0.0000	0.0000	-0.0000	0.0000	1.82	0.1776
Infertility Insurance Mandate	Present	1	-0.0055	0.0011	-0.0075	-0.0034	27.14	<.0001
	Absent	0	0.0000	0.0000	0.0000	0.0000	.	.
Age 15-19		1	0.0029	0.0001	0.0027	0.0031	623.46	<.0001
Age 20-34		1	-0.0020	0.0001	-0.0022	-0.0018	367.82	<.0001
Age 35-50		1	0.0012	0.0001	0.0010	0.0014	134.69	<.0001
White (HL)		1	-0.0017	0.0000	-0.0018	-0.0017	2789.76	<.0001
African American		1	0.0003	0.0001	0.0002	0.0005	21.75	<.0001
American Indian/Alaska Native		1	0.0044	0.0001	0.0043	0.0046	2216.60	<.0001
Asian		1	-0.0006	0.0001	-0.0008	-0.0005	57.94	<.0001
Native Hawaiian/Pacific Islander		1	0.0014	0.0002	0.0010	0.0017	46.44	<.0001

Table 4.12 (Continued)

Two or more ethnicities		1	0.0010	0.0001	0.0009	0.0012	172.79	<.0001
Hispanic		1	0.0012	0.0001	0.0010	0.0013	287.24	<.0001
White-only		1	0.0033	0.0001	0.0032	0.0035	2175.37	<.0001
Native (U.S.) born		1	-0.0022	0.0000	-0.0022	-0.0021	9263.15	<.0001
Foreign		0	0.0000	0.0000	0.0000	0.0000	.	.
Less than HS		1	0.0090	0.0001	0.0088	0.0091	18276.5	<.0001
High School diploma or GED		1	0.0058	0.0001	0.0057	0.0060	8035.53	<.0001
Associates degree		1	0.0093	0.0001	0.0092	0.0094	22107.1	<.0001
Bachelor degree		1	0.0085	0.0001	0.0084	0.0086	18395.9	<.0001
Graduate or Professional degree		1	0.0109	0.0001	0.0108	0.0111	25129.5	<.0001
100% below poverty line		1	0.0037	0.0000	0.0037	0.0038	24585.2	<.0001
200% or above poverty line		1	-0.0011	0.0000	-0.0011	-0.0011	2502.34	<.0001
Received public assistance		1	-0.0004	0.0000	-0.0005	-0.0003	109.06	<.0001
Scale		0	1.0000	0.0000	1.0000	1.0000		

Table 4.13. Negative binomial distribution GENMOD procedure

Criteria For Assessing Goodness Of Fit								
Criterion	DF	Value		Value/DF				
Deviance	72E3	97706.1967		1.3484				
Scaled Deviance	72E3	97706.1967		1.3484				
Pearson Chi-Square	72E3	41185.3369		0.5684				
Scaled Pearson X2	72E3	41185.3369		0.5684				
Log Likelihood		13215407.688						
Full Log Likelihood		-322586.9354						
AIC (smaller is better)		645221.8708						
AICC (smaller is better)		645221.8874						
BIC (smaller is better)		645442.4574						
Analysis of Maximum Likelihood Parameter Estimates								
Parameter		DF	Estimate	Standard Error	Wald 95% Confidence Limits		Wald Chi-Square	Pr > ChiSq
Intercept		1	2.7299	0.0058	2.7184	2.7413	218693	<.0001
Population Density		1	0.0000	0.0000	-0.0000	0.0000	0.52	0.4723
Infertility Insurance Mandate	Present	1	0.0258	0.0041	0.0177	0.0339	38.73	<.0001
	Absent	0	0.0000	0.0000	0.0000	0.0000	.	.
Age 15-19		1	0.0243	0.0007	0.0229	0.0256	1269.74	<.0001
Age 20-34		1	0.0237	0.0006	0.0225	0.0249	1517.94	<.0001
Age 35-50		1	0.0246	0.0006	0.0234	0.0258	1627.04	<.0001
White (HL)		1	-0.0013	0.0002	-0.0017	-0.0009	33.80	<.0001
African American		1	-0.0008	0.0005	-0.0017	0.0001	3.01	0.0828
American Indian/Alaska Native		1	0.0011	0.0006	-0.0001	0.0023	3.25	0.0714
Asian		1	-0.0005	0.0005	-0.0015	0.0005	0.96	0.3261
Native Hawaiian/		1	-0.0033	0.0012	-0.0057	-0.0009	7.00	0.0082

Table 4.13 (Continued)

Pacific Islander								
Two or more ethnicities		1	-0.0003	0.0005	-0.0013	0.0006	0.47	0.4949
Hispanic		1	-0.0002	0.0004	-0.0011	0.0006	0.32	0.5741
White-only		1	0.0021	0.0005	0.0012	0.0030	21.89	<.0001
Native (U.S.) born		1	0.0005	0.0002	0.0002	0.0008	11.40	0.0007
Foreign		0	0.0000	0.0000	0.0000	0.0000	.	.
Less than HS		1	-0.0061	0.0004	-0.0068	-0.0053	248.93	<.0001
High School diploma or GED		1	-0.0058	0.0004	-0.0065	-0.0051	256.55	<.0001
Associates degree		1	-0.0059	0.0004	-0.0066	-0.0052	278.28	<.0001
Bachelor degree		1	-0.0058	0.0004	-0.0065	-0.0051	249.97	<.0001
Graduate or Professional degree		1	-0.0065	0.0004	-0.0073	-0.0057	257.63	<.0001
100% below poverty line		1	0.0005	0.0002	0.0002	0.0008	10.56	0.0012
200% or above poverty line		1	-0.0003	0.0001	-0.0006	0.0000	3.71	0.0541
Received public assistance		1	0.0010	0.0002	0.0005	0.0015	15.77	<.0001
Dispersion		1	0.2530	0.0018	0.2495	0.2565		

Table 4.14. CDC-reporting fertility clinics in the United States, 2017 (n=448)

Service	Yes		No	
Donor Eggs	399	89.06%	49	10.94%
Donor Embryos	279	62.28%	169	37.72%
Embryo Cryopreservation	448	100%	0	0%
Egg Cryopreservation	439	97.99%	9	2.01%
Single Women	444	99.11%	4	0.89%
Gestational Carrier	394	87.95%	54	12.05%

Table 4.15. CDC-reporting fertility clinic membership and accreditation, 2017 (n=448)

	Yes		No	
SART Member	367	81.92%	81	18.08%
Lab Accreditation*	410	91.52%	34	7.59%

*Pending accreditation (n=4, 0.9%)

Table 4.16. Survey responses: Inter-state travel (n=134)

Prompt: Which of the statements below most applies to you, regarding inter-state travel for infertility services?	%	Count
I moved out of state to access infertility services	2.24%	3
I intend to move out of state to access infertility services	0.00%	0
I am considering moving out of state to access infertility services	6.72%	9
I have not and do not intend to move out of state to access infertility services	90.30%	121
I traveled out of state to access infertility services (did not change residence)	0.75%	1
Total	100%	134

Table 4.17. Survey responses: Interstate travel for higher quality services (n=134)

Prompt: Which of the statements below most applies to you, regarding inter-state travel for higher quality infertility services?	%	Count
I moved out of state to access a better physician or fertility clinic	2.24%	3
I intend to move out of state to access a better physician or fertility clinic	0.00%	0
I am considering moving out of state to access a better physician or fertility clinic	2.99%	4
I have not and do not intend to move out of state to access a better physician or fertility clinic	94.03%	126
I traveled out of state to access higher quality infertility services (did not change residence)	0.75%	1
Total	100%	134

Table 4.18. Survey responses: International travel for infertility services (n=133)

Prompt: Which of these statements below most applies to you, regarding international travel for infertility services?	%	Count
I traveled internationally to access infertility services	1.50%	2
I intend to travel internationally to access infertility services	0.75%	1
I am considering traveling internationally to access infertility services	15.04%	20
I have not and do not intend to travel internationally to access infertility services	82.71%	110
Total (missing 1)	100%	133

Table 4.19. Survey responses: States represented in survey responses (n=134)

State	%	n
New York*	11.94%	16
Illinois*	8.96%	12
Florida	6.72%	9
Massachusetts*	5.97%	8
Texas*	5.97%	8
Maryland*	4.48%	6
Michigan	4.48%	6
Pennsylvania	4.48%	6
California*	3.73%	5
Minnesota	3.73%	5
New Jersey*	3.73%	5
Ohio*	3.73%	5
Indiana	2.99%	4
Missouri	2.99%	4
Virginia	2.99%	4
Colorado*	2.24%	3
North Carolina	2.24%	3
Washington	2.24%	3
West Virginia*	2.24%	3
Arizona	1.49%	2
Georgia	1.49%	2
Iowa	1.49%	2
Louisiana*	1.49%	2
Nevada	1.49%	2
Tennessee	1.49%	2
Connecticut*	0.75%	1
Kansas	0.75%	1
North Dakota	0.75%	1
Oregon	0.75%	1
Rhode Island*	0.75%	1
South Carolina	0.75%	1
Wisconsin	0.75%	1

*=state with infertility insurance mandate

Table 4.20. Survey response: Residence when accessing infertility services (n=128)

Prompt: Is your current state of residence the same state where you accessed infertility services?	%	Count
Yes	88.28%	113
No	11.72%	15
Total	100%	128

Total is less than 134 because of skip logic, not all persons had accessed infertility services when answering this question

Table 4.21. Survey response: State accessed infertility services if different that current state of residence (n=16)

Prompt: What was your state of U.S. Territory of residence when you accessed infertility services?	%	Count
New York*	18.75%	3
Maryland*	12.50%	2
California*	6.25%	1
Connecticut*	6.25%	1
District of Columbia	6.25%	1
Florida	6.25%	1
Hawaii*	6.25%	1
Kentucky	6.25%	1
Massachusetts*	6.25%	1
Minnesota	6.25%	1
Rhode Island*	6.25%	1
Texas*	6.25%	1
Total	100%	16

Total is less than 134 because of skip logic, not all persons had accessed infertility services when answering this question

Table 4.22. Survey response: Knowledge of state-based infertility insurance mandate (n=134)

Prompt: Does your state of residence have mandated insurance coverage for infertility services?	%	Count
Yes	38.06%	51
No	48.51%	65
I am not sure	13.43%	18
Total	100%	134

Table 4.23. Survey response: Applicability of state-based infertility insurance mandate (n=49)

Prompt: Were you able to apply the infertility insurance mandate to cover your expenses?	%	Count
Yes, everything was covered	20.41%	10
No	46.94%	23
Yes, but not everything was covered	32.65%	16
Total (missing 2)	100%	49

Table 4.24. Survey response: Current health insurance (n=134)

Prompt: What is your current health insurance status?	%	Count
Currently covered by private health insurance individually or through your employer, without MediGap*	85.93%	116
Currently covered by private health insurance individually or through your employer, including MediGap*	4.44%	6
Currently covered through the Affordable Care Act (aka. ObamaCare)	0.74%	1
Currently covered by Tricare or through Veterans Affairs	3.70%	5
Currently covered by a single service plan. (SSP)**	1.48%	2
Not covered by any health insurance	0.74%	1
Other not listed: (2 student insurance, 2 dual insurance coverage)	2.96%	4
Total	100%	134

*Medigap is extra health insurance that you buy from a private company to pay health care costs not covered by Original Medicare, such as co-payments, deductibles, and health care if you travel outside the U.S.

**Single Service Plans are health insurance coverage paid for by an individual or an employer that provides for only one type of service

Table 4.25. Survey response: Private health insurance specifically for infertility services (n=134)

Prompt: Do you have private health insurance to cover any costs for medical help to become pregnant?	%	Count
Yes	41.79%	56
No	41.79%	56
Not Sure	7.46%	10
No, but my partner's insurance does	8.96%	12
Total	100%	134

Table 4.26. Survey response: Employer coverage for infertility services (n=134)

Prompt: Does your employer's insurance include coverage for infertility services?	%	Count
Yes	50.00%	67
Not Sure	4.48%	6
No	39.55%	53
No, but my partner's insurance does	5.97%	8
Total	100%	134

Table 4.27. Survey response: Presence of any insurance specifically for infertility services (n=134)

Prompt: Do you have health insurance that specifically covers infertility services?	%	Count
Yes	52.24%	70
No	47.76%	64
Total	100%	134

Table 4.28. Survey response: Respondent-disclosed insurance companies offering their infertility insurance coverage

Insurance Company	n
Blue Cross / Blue Shield	14
Aetna	13
United Healthcare*	10
Cigna	5
Progyny	5
Harvard Pilgrim	3
Always	1
Fallon	1
HAP	1
Hawaii Medical Service Association	1
HealthPartners	1
Kaiser	1
Medica	1
Tufts Health Plan	1
University of Pittsburgh Medical Center (UPMC)	1
Freedom Fertility	1
Win Fertility	1

*Two of the United Healthcare recipients specified their Fertility Solutions Program

Table 4.29. Spatial autocorrelation of fertility by census tract: All observations and population density

Variable	Assumption	Coefficient	Observed	Expected	Std Dev	Z	Pr > Z
All Women with Births	Normality	Moran's I	0.00862	-0.0000138	0.0000217	398.7 ⁺	<.0001
	Normality	Geary's c	0.94587	1.0000000	0.0013044	-41.5 ⁺	<.0001
Population Density	Normality	Moran's I	0.00588	-0.0000138	0.0000217	272.1 ⁺	<.0001
	Normality	Geary's c	0.88240	1.0000000	0.0013044	-90.2 ⁺	<.0001

*positive autocorrelation = ⁺, negative autocorrelation = ⁻

Table 4.30. Spatial autocorrelation of fertility by census tract: Age

Variable	Assumption	Coefficient	Observed	Expected	Std Dev	Z	Pr > Z
Age 15-19	Normality	Moran's I	0.00322	-0.0000138	0.0000217	149.1 ⁺	<.0001
	Normality	Geary's c	0.95767	1.0000000	0.0013044	-32.5 ⁺	<.0001
Age 20-34	Normality	Moran's I	0.00914	-0.0000138	0.0000217	422.8 ⁺	<.0001
	Normality	Geary's c	0.94222	1.0000000	0.0013044	-44.3 ⁺	<.0001
Age 35-50	Normality	Moran's I	0.00812	-0.0000138	0.0000217	375.4 ⁺	<.0001
	Normality	Geary's c	0.98328	1.0000000	0.0013044	-12.8 ⁺	<.0001

*positive autocorrelation = ⁺, negative autocorrelation = ⁻

Table 4.31. Spatial autocorrelation of fertility by census tract: Ethnicity

Variable	Assumption	Coefficient	Observed	Expected	Std Dev	Z	Pr > Z
White (HL)	Normality	Moran's I	0.0117	-0.0000138	0.0000217	541.6 ⁺	<.0001
	Normality	Geary's c	0.9341	1.0000000	0.0013044	-50.6 ⁺	<.0001
African American	Normality	Moran's I	0.0158	-0.0000138	0.0000217	732.2 ⁺	<.0001
	Normality	Geary's c	1.0416	1.0000000	0.0013044	31.9 ⁻	<.0001
American Indian or Alaska Native	Normality	Moran's I	0.0054	-0.0000138	0.0000217	250 ⁺	<.0001
	Normality	Geary's c	0.7582	1.0000000	0.0013044	-185 ⁺	<.0001
Asian	Normality	Moran's I	0.0188	-0.0000138	0.0000217	867.3 ⁺	<.0001
	Normality	Geary's c	0.9490	1.0000000	0.0013044	-39.1 ⁺	<.0001
Native Hawaiian or Pacific Islander	Normality	Moran's I	0.00217	-0.0000138	0.0000217	101 ⁺	<.0001
	Normality	Geary's c	0.80863	1.0000000	0.0013044	-147 ⁺	<.0001
Two or more ethnicities	Normality	Moran's I	0.00258	-0.0000138	0.0000217	119.8 ⁺	<.0001
	Normality	Geary's c	0.94223	1.0000000	0.0013044	-44.3 ⁺	<.0001
Hispanic (any)	Normality	Moran's I	0.0479	-0.0000138	0.0000217	2211 ⁺	<.0001
	Normality	Geary's c	0.8357	1.0000000	0.0013044	-126 ⁺	<.0001
White (only)	Normality	Moran's I	0.015	-0.0000138	0.0000217	695.5 ⁺	<.0001
	Normality	Geary's c	0.963	1.0000000	0.0013044	-28.7 ⁺	<.0001

*positive autocorrelation = ⁺, negative autocorrelation = ⁻

Table 4.32. Spatial autocorrelation of fertility by census tract: Nativity

Variable	Assumption	Coefficient	Observed	Expected	Std Dev	Z	Pr > Z
U.S. Born	Normality	Moran's I	0.0111	-0.0000138	0.0000217	514.7 ⁺	<.0001
	Normality	Geary's c	0.9496	1.0000000	0.0013044	-38.6 ⁺	<.0001
Foreign Born	Normality	Moran's I	0.0258	-0.0000138	0.0000217	1193.0 ⁺	<.0001
	Normality	Geary's c	0.9496	1.0000000	0.0013044	-38.6 ⁺	<.0001

*positive autocorrelation = ⁺, negative autocorrelation = ⁻

Table 4.33. Spatial autocorrelation of fertility by census tract: Education

Variable	Assumption	Coefficient	Observed	Expected	Std Dev	Z	Pr > Z
Less than HS Education	Normality	Moran's I	0.00628	-0.0000138	0.0000217	290.7 ⁺	<.0001
	Normality	Geary's c	0.94892	1.0000000	0.0013044	-39.2 ⁺	<.0001
HS Diploma or GED	Normality	Moran's I	0.00495	-0.0000138	0.0000217	229.4 ⁺	<.0001
	Normality	Geary's c	0.96748	1.0000000	0.0013044	-24.9 ⁺	<.0001
Associates Degree	Normality	Moran's I	0.00867	-0.0000138	0.0000217	400.8 ⁺	<.0001
	Normality	Geary's c	0.93523	1.0000000	0.0013044	-49.7 ⁺	<.0001
Bachelor Degree	Normality	Moran's I	0.00296	-0.0000138	0.0000217	137.4 ⁺	<.0001
	Normality	Geary's c	0.97185	1.0000000	0.0013044	-21.6 ⁺	<.0001
Graduate or Professional Degree	Normality	Moran's I	0.00719	-0.0000138	0.0000217	332.7 ⁺	<.0001
	Normality	Geary's c	1.01847	1.0000000	0.0013044	14.2 ⁻	<.0001

*positive autocorrelation = ⁺, negative autocorrelation = ⁻

Table 4.34. Spatial autocorrelation of fertility by census tract: Income disparity

Variable	Assumption	Coefficient	Observed	Expected	Std Dev	Z	Pr > Z
100% below poverty line	Normality	Moran's I	0.00613	-0.0000138	0.0000217	283.7 ⁺	<.0001
	Normality	Geary's c	0.97039	1.0000000	0.0013044	-22.7 ⁺	<.0001
200% above poverty line	Normality	Moran's I	0.00513	-0.0000138	0.0000217	237.6 ⁺	<.0001
	Normality	Geary's c	0.95670	1.0000000	0.0013044	-33.2 ⁺	<.0001
Received Public Assistance	Normality	Moran's I	0.00353	-0.0000138	0.0000217	163.5 ⁺	<.0001
	Normality	Geary's c	0.96837	1.0000000	0.0013044	-24.3 ⁺	<.0001

*positive autocorrelation = ⁺, negative autocorrelation = ⁻

Table 4.35. Spatial autocorrelation: Comparison of presence/absence of Poissonian and negative binomial non-significant variables on Moran's I and Gary's C

Variable	All Variables (normal assumption)		Poissonian significant variables		Negative binomial significant variables		Assumption: Randomization	
	Moran's I	Gary's C	Moran's I	Gary's C	Moran's I	Gary's C	Moran's I	Gary's C
Variable: Women with Births								
All women with births	0.00862	0.94587	0.00862	0.94587	0.00862	0.94587	0.00862	0.94587
Age 15-19	0.00322	0.95767	0.00322	0.95767	0.00322	0.95767	0.00322	0.95767
Age 20-34	0.00914	0.94222	0.00914	0.94222	0.00914	0.94222	0.00914	0.94222
Age 35-50	0.00812	0.98328	0.00812	0.98328	0.00812	0.98328	0.00812	0.98328
Caucasian (Hispanic/Latinx)	0.0117	0.9341	0.0117	0.9341	0.0117	0.9341	0.0117	0.9341
African American	0.0158	1.0416	0.0158	1.0416	0.0158	1.0416	0.0158	1.0416
American Indian or Alaska Native	0.0054	0.7582	0.0054	0.7582	-	-	0.0054	0.7582
Asian	0.0188	0.9490	0.0188	0.9490	-	-	0.0188	0.9490
Native Hawaiian or Pacific Islander	0.00217	0.80863	0.00217	0.80863	0.00217	0.80863	0.00217	0.80863
Two or more ethnicities	0.00258	0.94223	0.00258	0.94223	-	-	0.00258	0.94223
Hispanic (any)	0.0479	0.8357	0.0479	0.8357	-	-	0.0479	0.8357
Caucasian (non-Hispanic)	0.015	0.963	0.015	0.963	0.015	0.963	0.015	0.963
Native born	0.0111	0.9496	0.0111	0.9496	0.0111	0.9496	0.0111	0.9496
Foreign born	0.0258	0.9496	-	-	-	-	0.0258	0.9496
Less than High School education	0.00628	0.94892	0.00628	0.94892	0.00628	0.94892	0.00628	0.94892
High School Diploma or GED	0.00495	0.96748	0.00495	0.96748	0.00495	0.96748	0.00495	0.96748
Associates degree	0.00867	0.93523	0.00867	0.93523	0.00867	0.93523	0.00867	0.93523
Bachelors degree	0.00296	0.97185	0.00296	0.97185	0.00296	0.97185	0.00296	0.97185
Graduate or Professional degree	0.00719	1.01847	0.00719	1.01847	0.00719	1.01847	0.00719	1.01847
100% below poverty level	0.00613	0.97039	0.00613	0.97039	0.00613	0.97039	0.00613	0.97039
200% or above poverty level	0.00513	0.95670	0.00513	0.95670	0.00513	0.95670	0.00513	0.95670
Received public assistance	0.00353	0.96837	0.00353	0.96837	0.00353	0.96837	0.00353	0.96837
Population Density	0.00588	0.88240	-	-	-	-	0.00588	0.88240

Table 4.36. Poissonian and negative binomial regression: Dependent variable “All Women with Births”

Parameter		DF	Estimate	Standard Error	Wald 95% Confidence Limits		Wald Chi-Square	Pr > ChiSq
Poissonian								
Intercept		1	3.3863	0.0011	3.3841	3.3885	8760471	<.0001
Mandate	Present	1	-0.0087	0.0010	-0.0108	-0.0067	69.22	<.0001
	Absent	0	0.0000	0.0000	0.0000	0.0000	.	.
Negative Binomial								
Intercept		1	2.7242	0.0058	2.7128	2.7357	217006	<.0001
Mandate	Present	1	0.0229	0.0041	0.0148	0.0311	30.72	<.0001
Mandate	Absent	0	0.0000	0.0000	0.0000	0.0000	.	.

Table 4.37. Comparison of fertility in census tracts with fertility clinics and all census tracts

Variable	Census tracts with fertility clinic (406)				All census tracts (72,987)			
	mean	SD	min	max	mean	SD	min	max
All Women with Births	53.22	51.06	0	376	54.73	50.55	0	1,370
Population	8,311	19,366.40	83.37	222,215.64	5,617.12	58,204.47	0	12,516,155.73

Chapter Four Figures

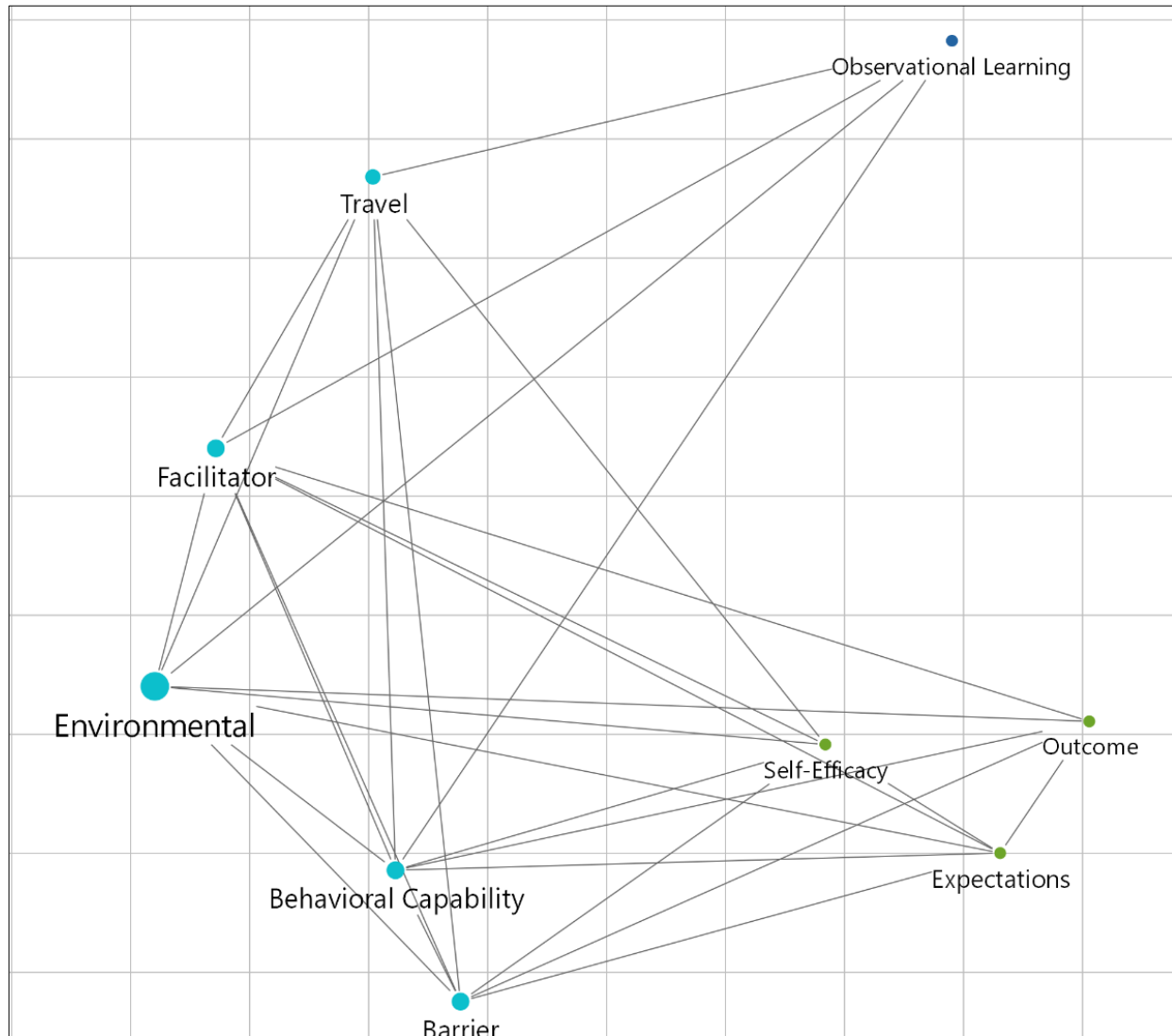


Figure 4.1. Thematic code map: Travel code and SCT constructs

Code System	Barrier	Facilitator	SUM
Mandate			29
Employer			91
Σ SUM	64	56	120

Figure 4.2. Code Relations Browser: Mentions of employer and infertility mandate as barriers or facilitators

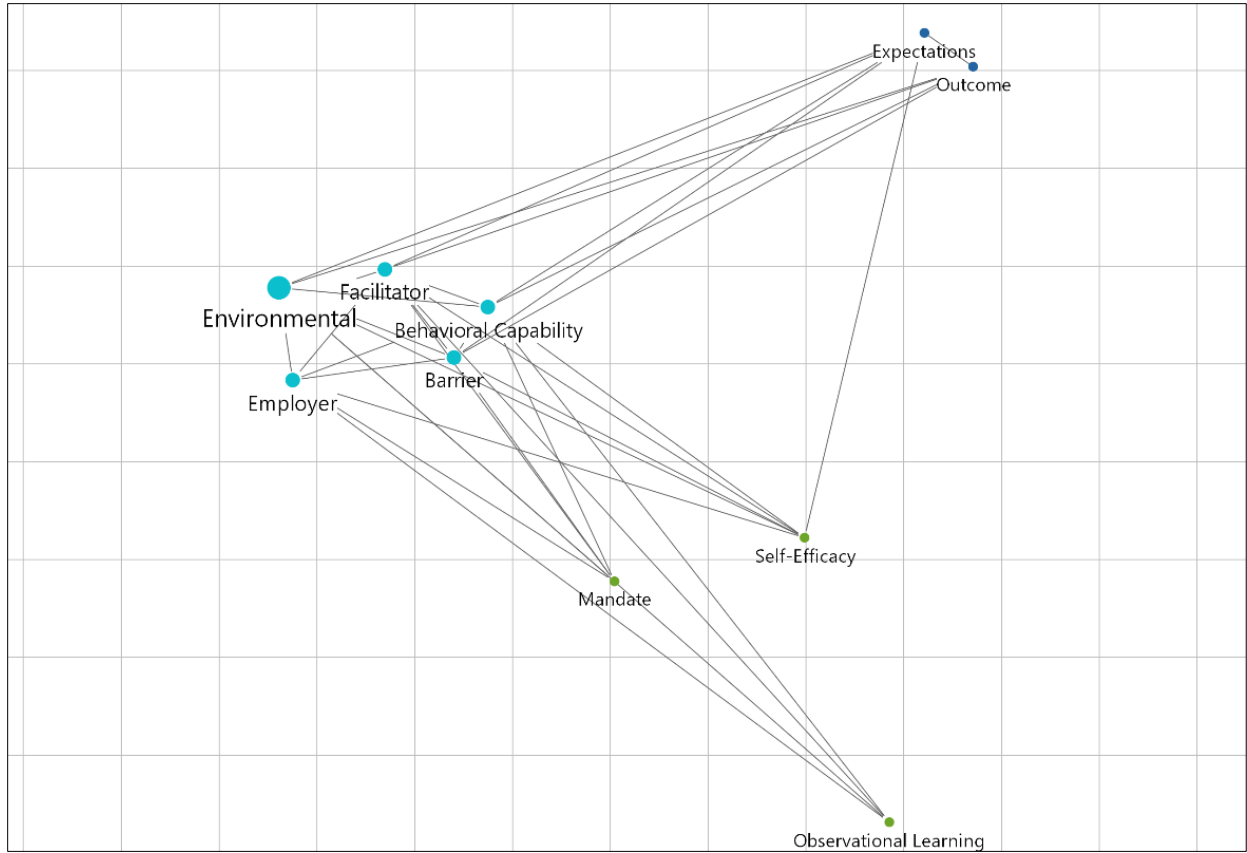


Figure 4.3. Thematic code map: Employer code, mandate code, and SCT constructs



Figure 4.4. Thematic code map: Mandate code, self-efficacy, and behavioral capability in mandated states



Figure 4.5. Thematic code map: Mandate code, self-efficacy, and behavioral capability in non-mandated states

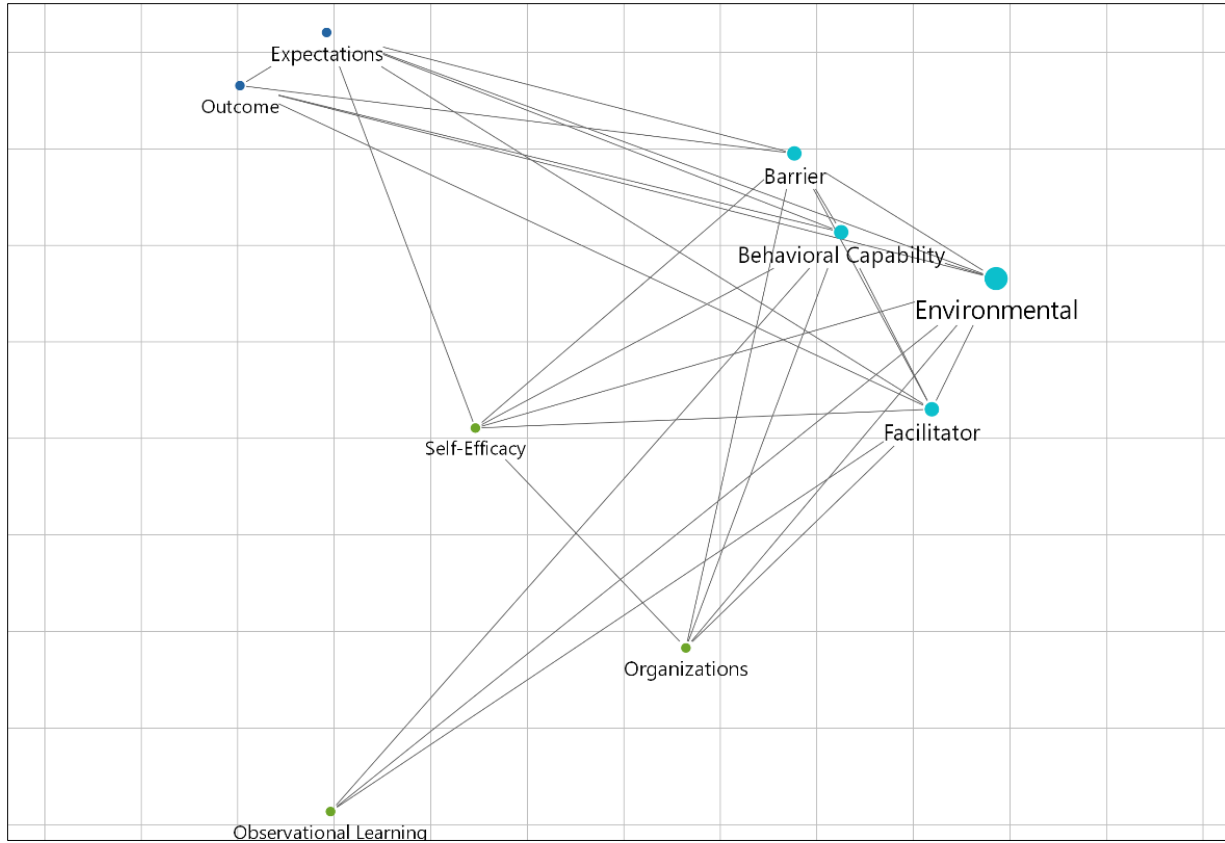
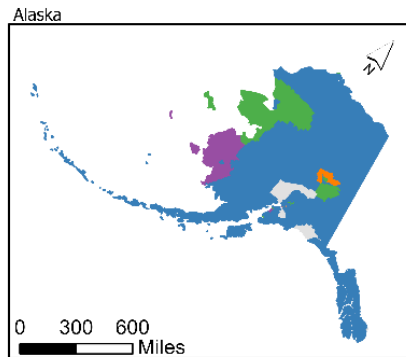
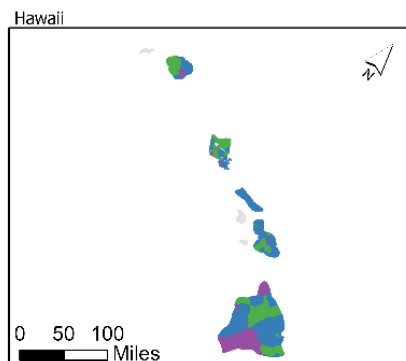


Figure 4.6. Thematic code map: Financial code, non-profit organizations and SCT constructs



2013-2017 American Community Survey
All Women with Births (Census tract)



2013-2017 American Community Survey: Fertility of Women Age 15-50

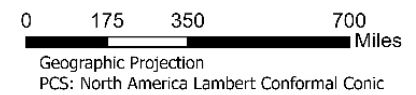
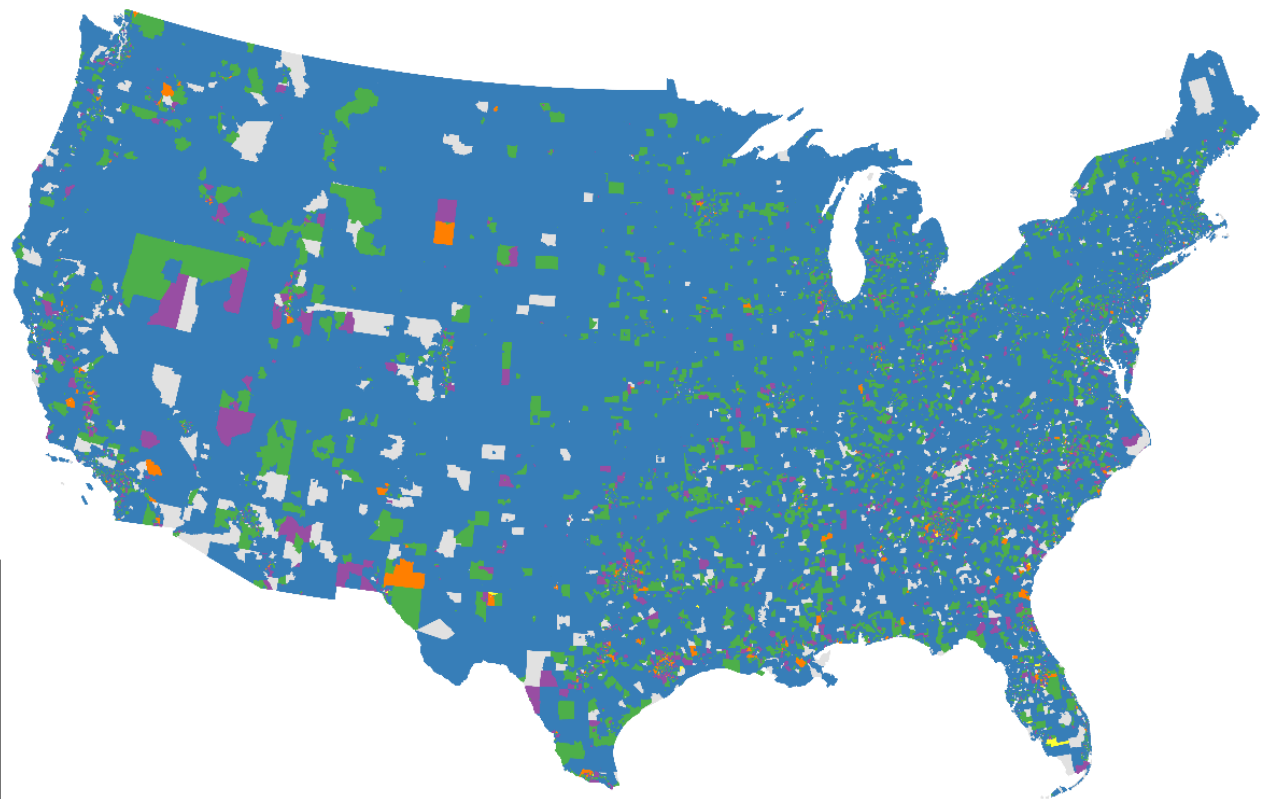
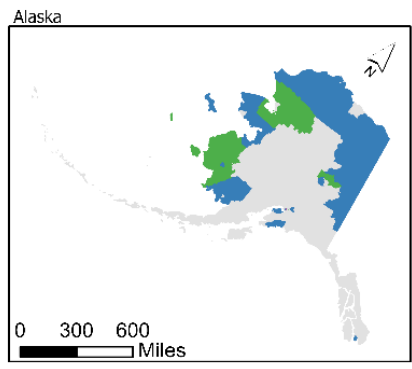
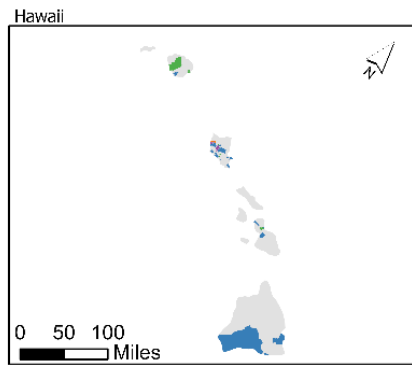


Figure 4.7. ACS 2013-2017, Fertility of women age 15-5



2013-2017 American Community Survey
Women with Births: Age 15-19 (Census tract)

- ≤4
- ≤15
- ≤28
- ≤44
- ≤74
- ≤201



2013-2017 American Community Survey: Fertility of Women Age 15-19

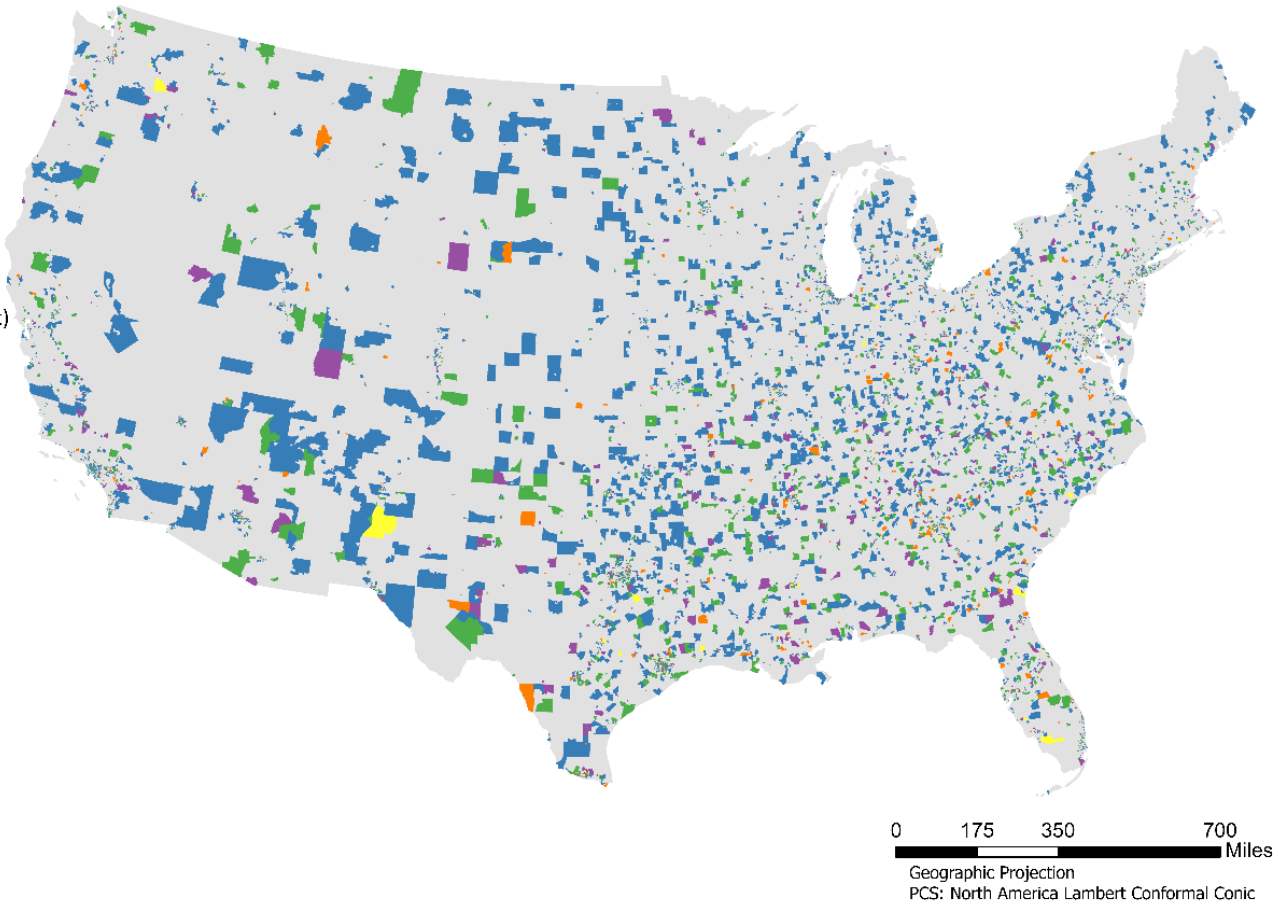
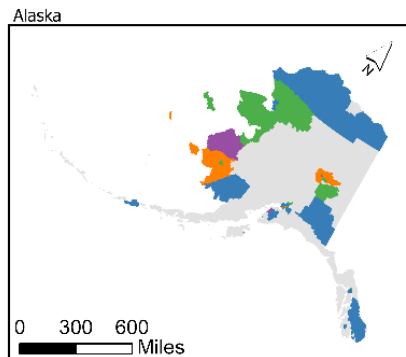
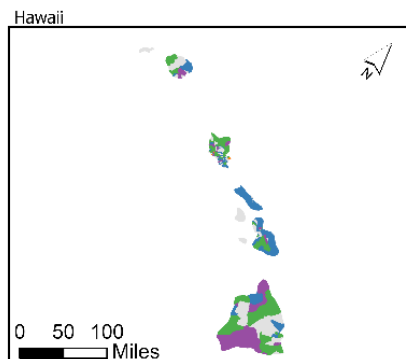


Figure 4.8. ACS 2013-2017, Fertility of women age 15-19

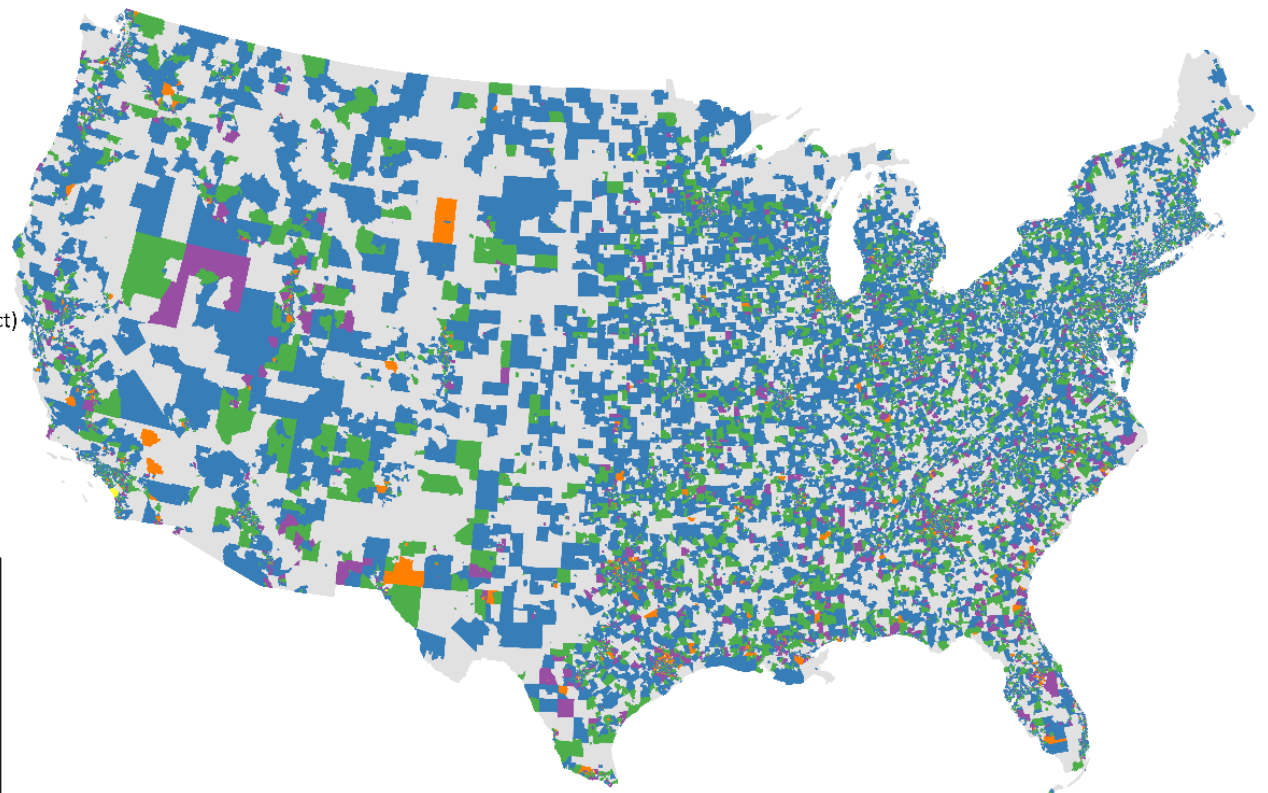


2013-2017 American Community Survey
Women with Births: Age 20-34 (Census tract)

- ≤24
- ≤58
- ≤105
- ≤185
- ≤508
- ≤1331

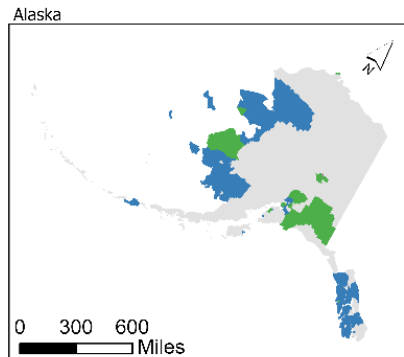


2013-2017 American Community Survey: Fertility of Women Age 20-34



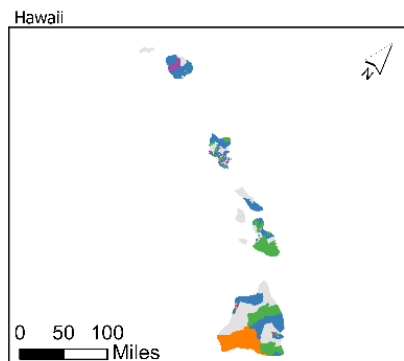
Geographic Projection
PCS: North America Lambert Conformal Conic

Figure 4.9. ACS 2013-2017, Fertility of women age 20-34

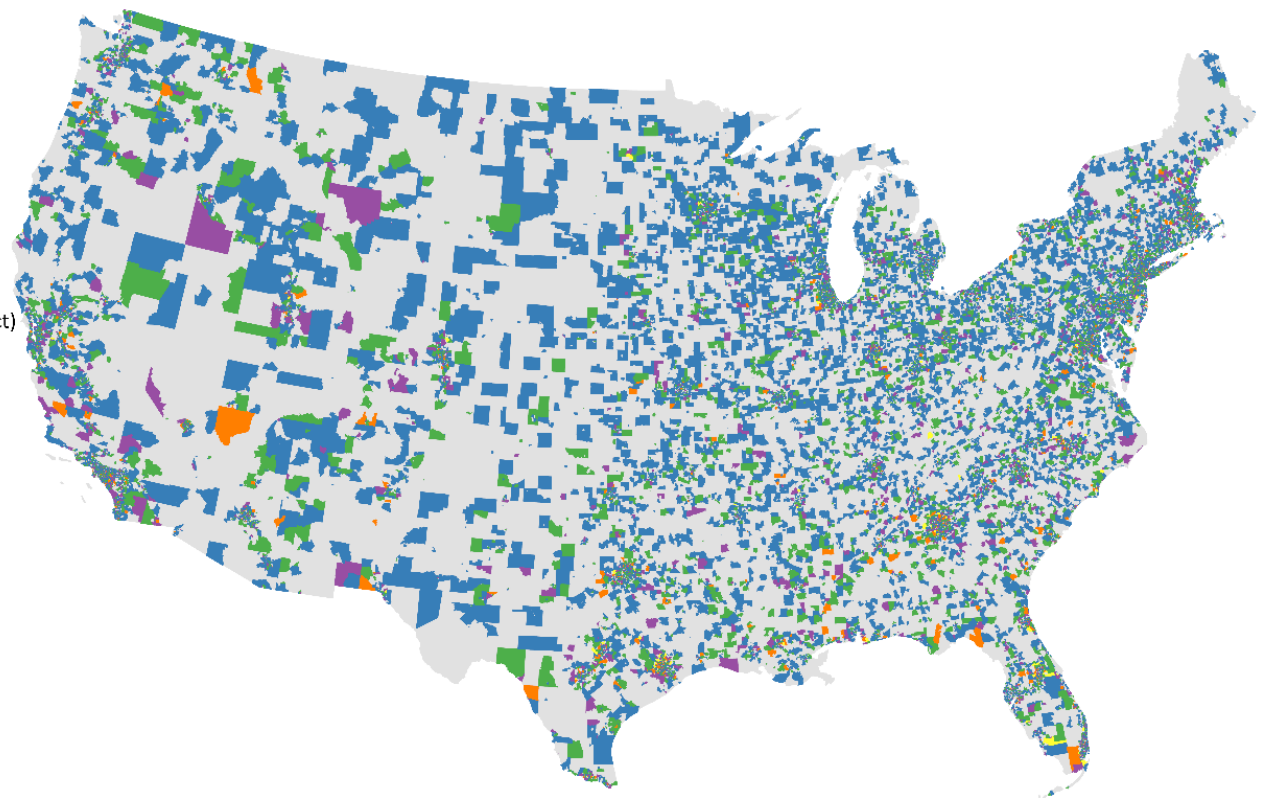


2013-2017 American Community Survey
Women with Births: Age 35-50 (Census tract)

- ≤6
- ≤20
- ≤38
- ≤65
- ≤113
- ≤310

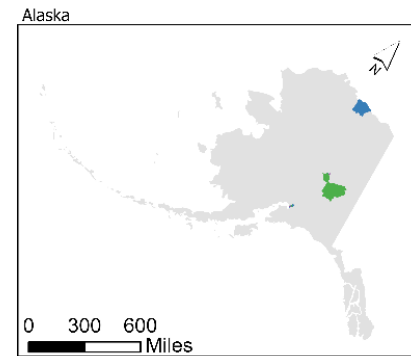


2013-2017 American Community Survey: Fertility of Women Age 35-50



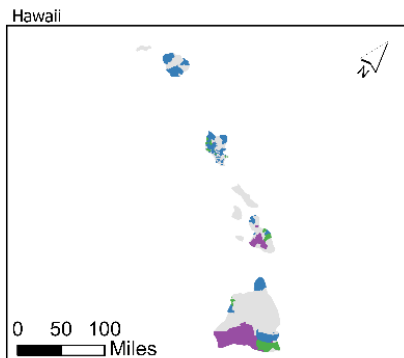
0 175 350 700 Miles
Geographic Projection
PCS: North America Lambert Conformal Conic

Figure 4.10. ACS 2013-2017, Fertility of women age 35-50



2013-2017 American Community Survey
All Women with Births: Hispanic or Latinx

- ≤10
- ≤32
- ≤64
- ≤109
- ≤189
- ≤704



2013-2017 American Community Survey: Fertility of Women:
Hispanic or Latinx (any)

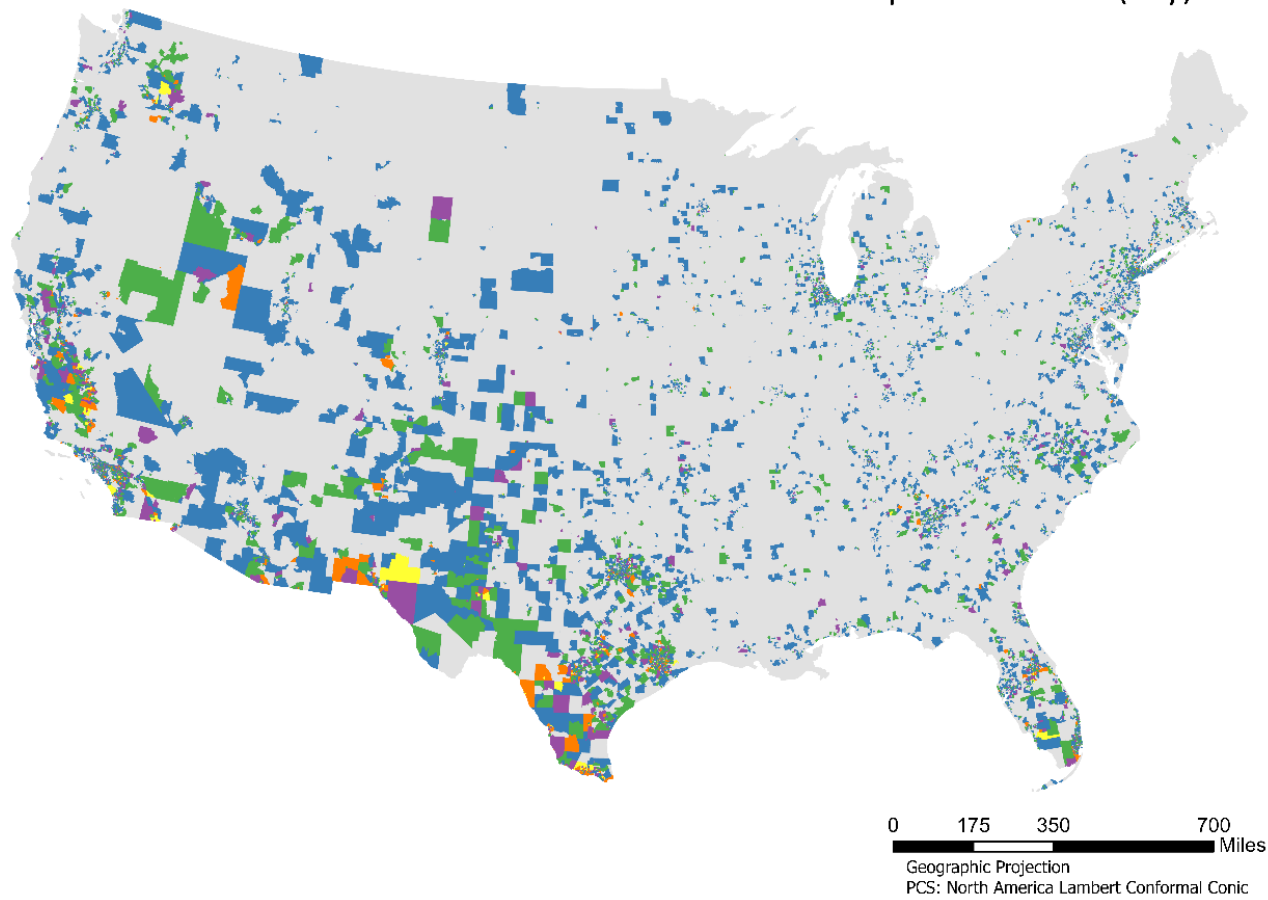
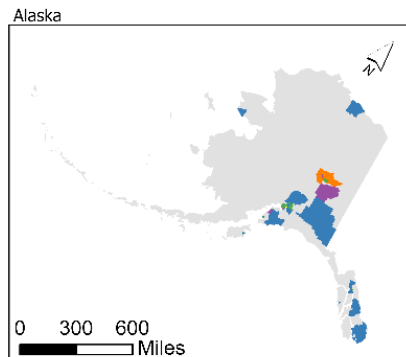
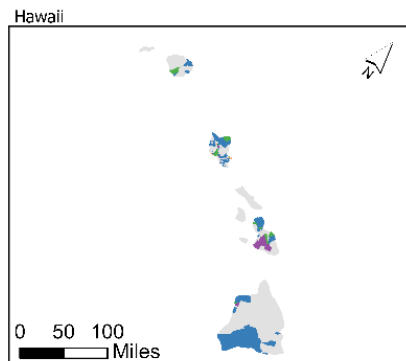


Figure 4.11. ACS 2013-2017, Fertility of women identifying with Hispanic or Latinx ethnicity

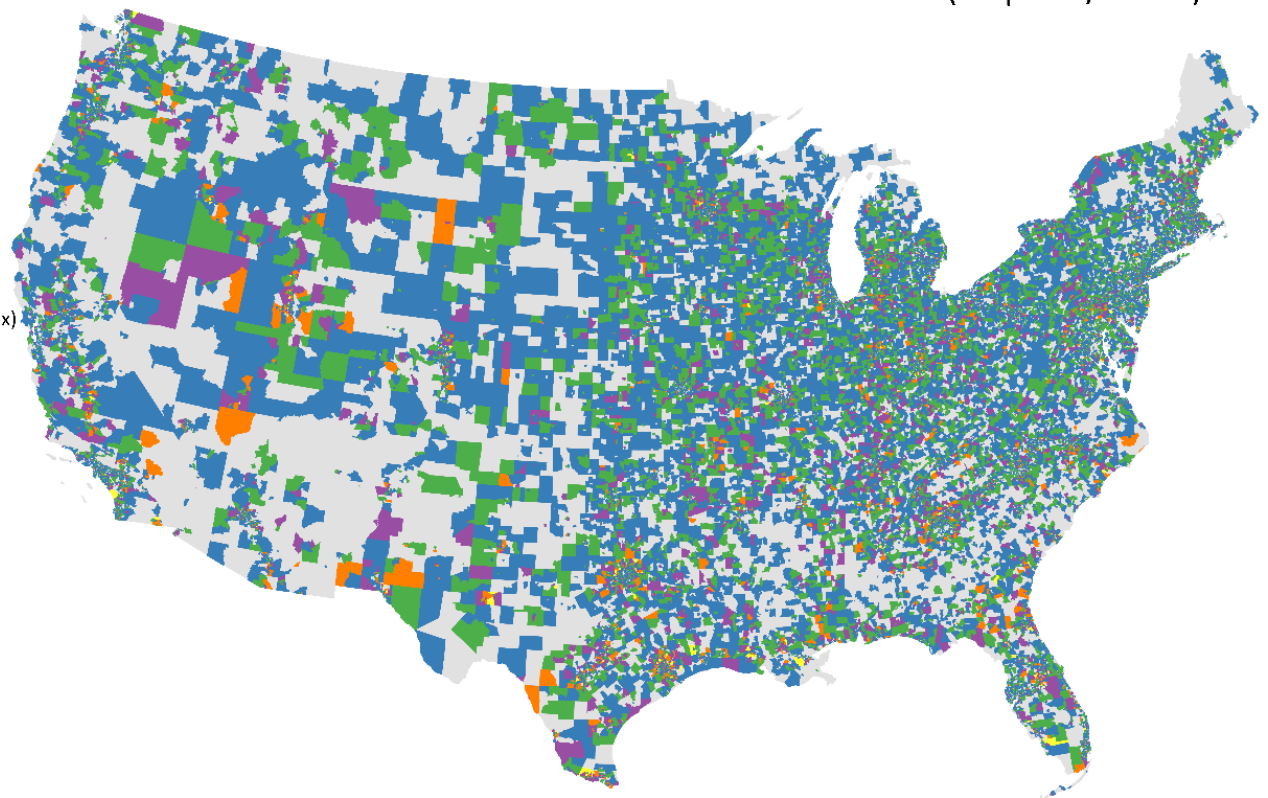


2013-2017 American Community Survey
Women with Births: Caucasian (Hispanic/Latinx)

- ≤19
- ≤48
- ≤84
- ≤139
- ≤248
- ≤1006



2013-2017 American Community Survey: Fertility of Women: Caucasian (Hispanic/Latinx)



0 175 350 700
Miles
Geographic Projection
PCS: North America Lambert Conformal Conic

Figure 4.12. ACS 2013-2017, Fertility of women identifying as White/Caucasian and Hispanic/Latinx

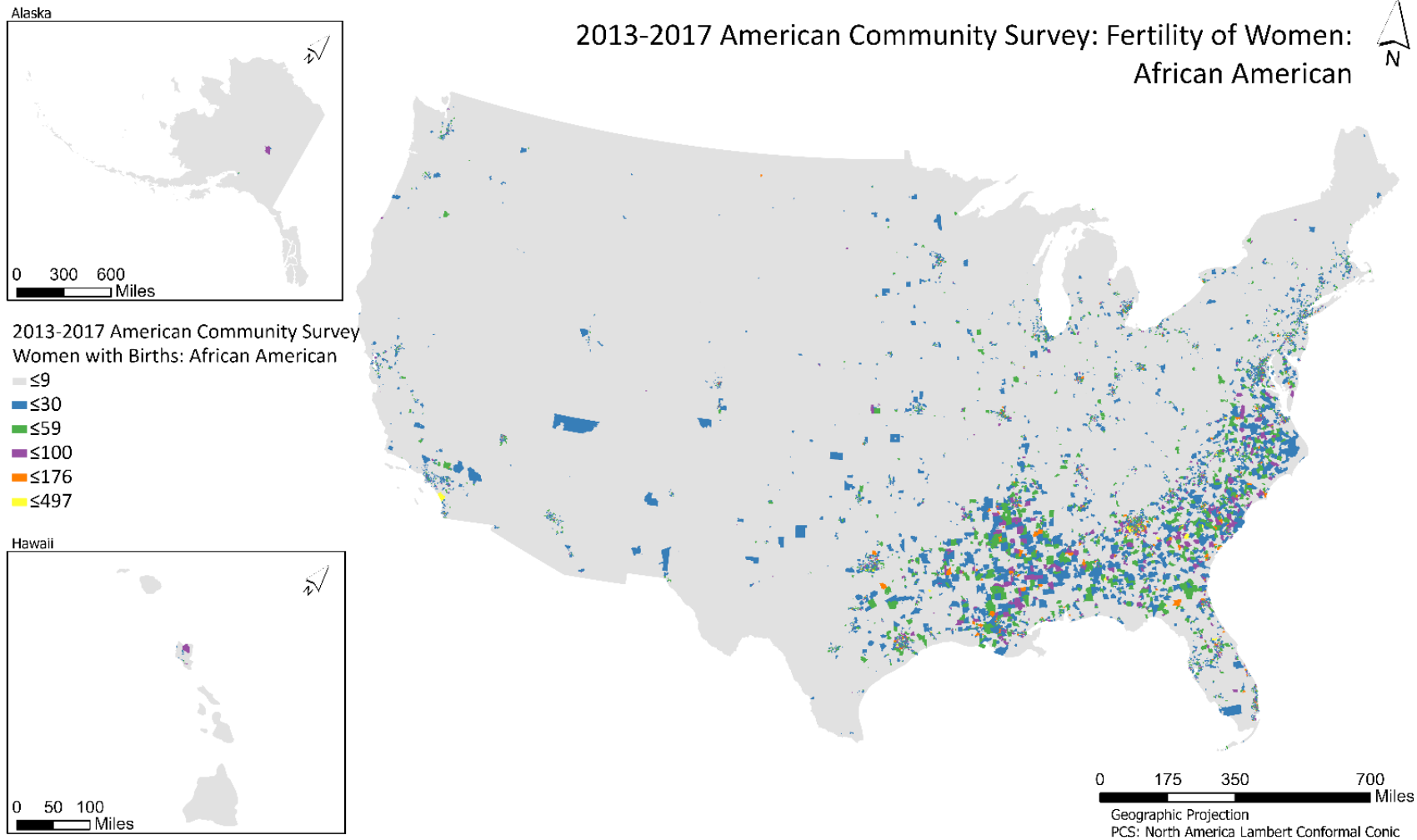


Figure 4.13. ACS 2013-2017, Fertility of women identifying as African American

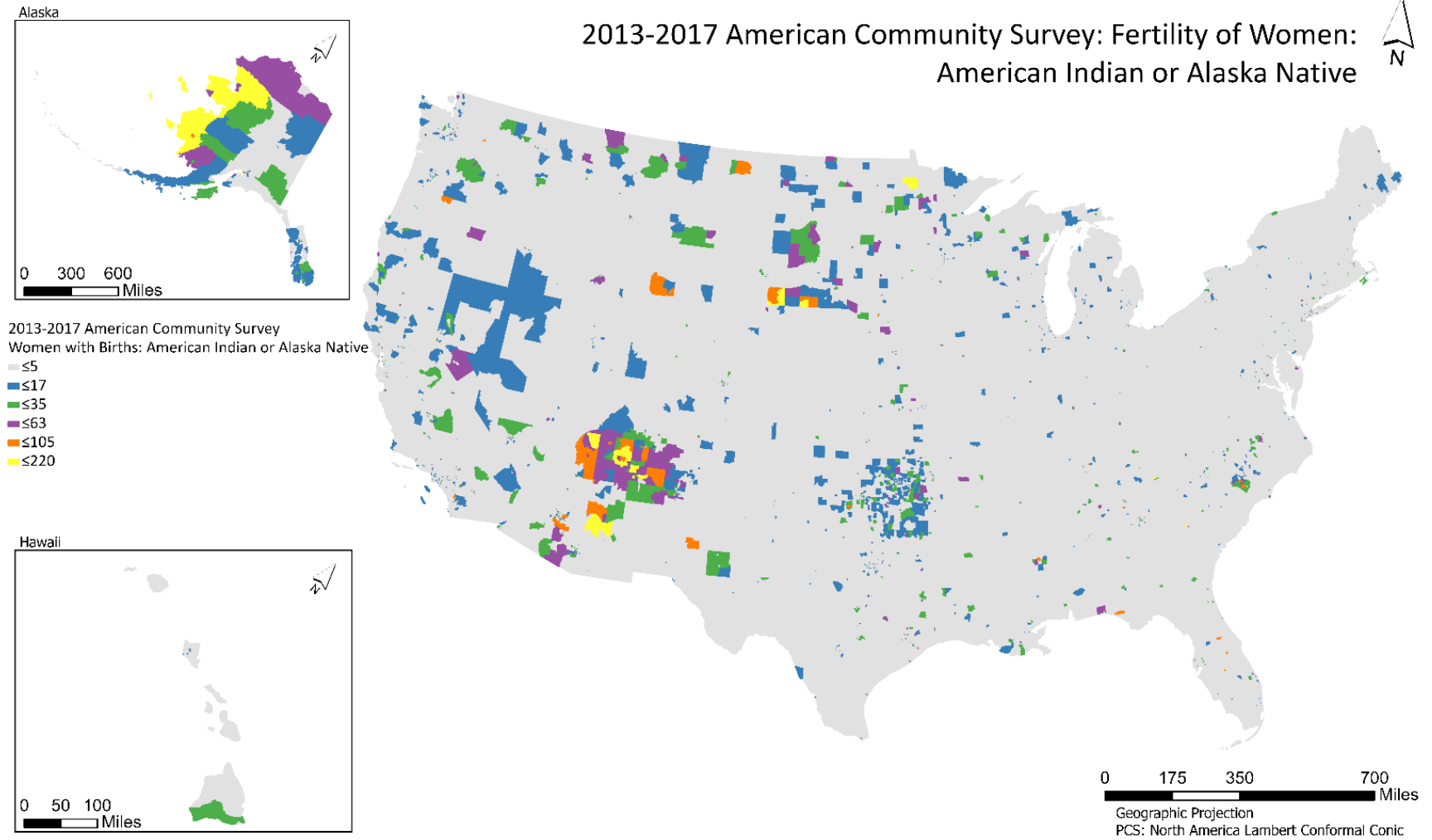
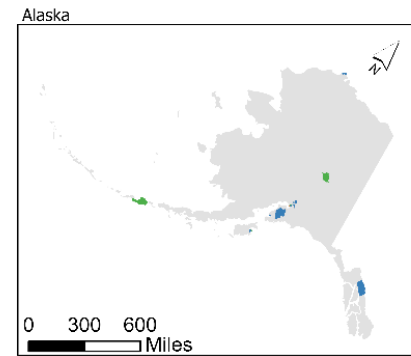
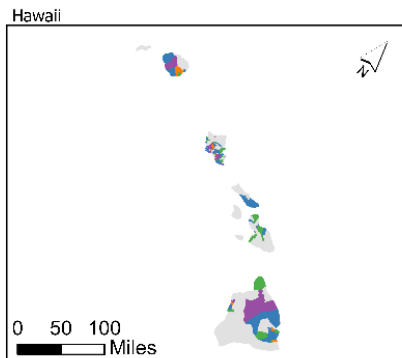


Figure 4.14. ACS 2013-2017, Fertility of women identifying as American Indian or Alaskan Native



2013-2017 American Community Survey
 Women with Births: Asian

- ≤6
- ≤21
- ≤42
- ≤74
- ≤134
- ≤363



2013-2017 American Community Survey: Fertility of Women:
 Asian

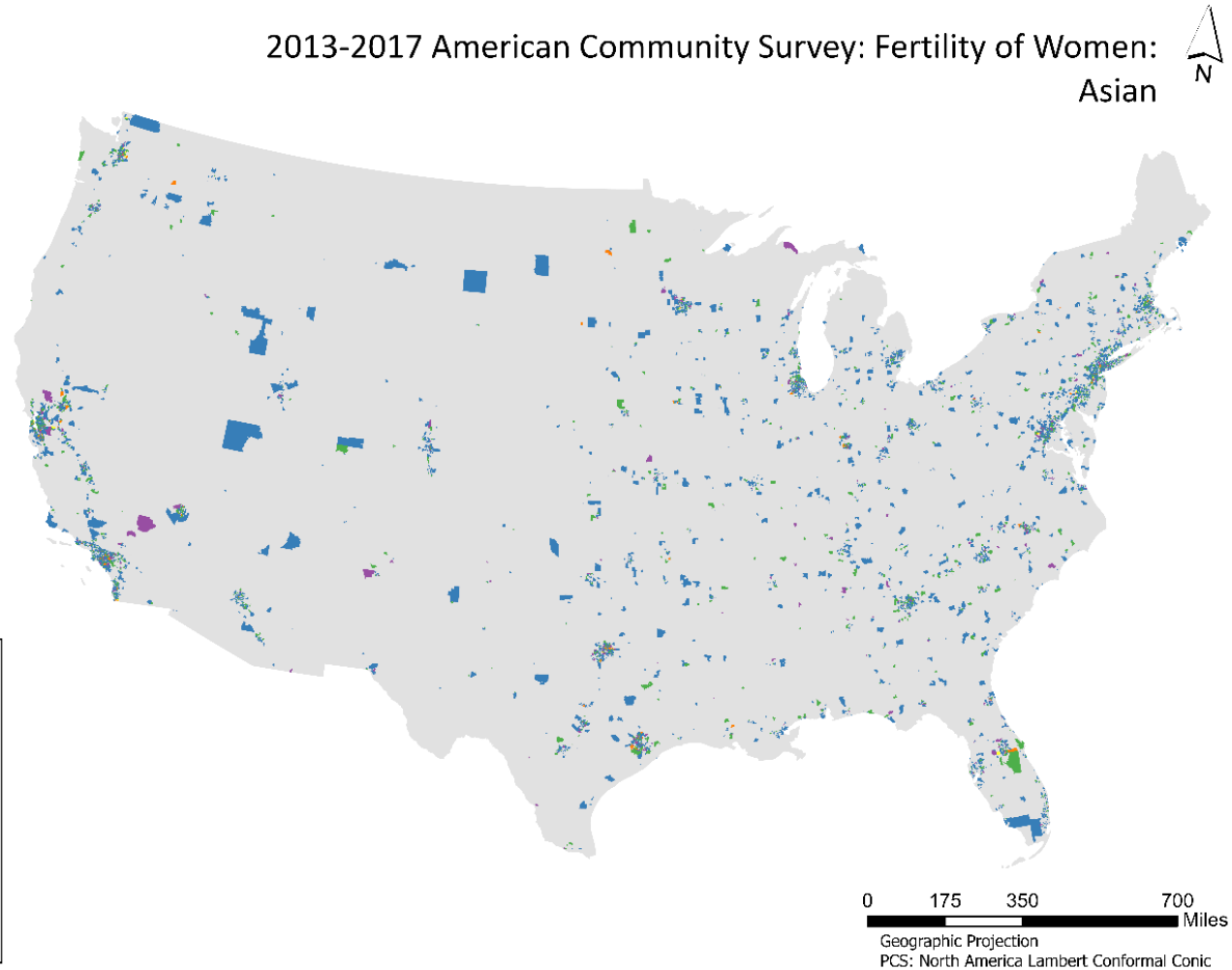


Figure 4.15. ACS 2013-2017, Fertility of women identifying as Asian

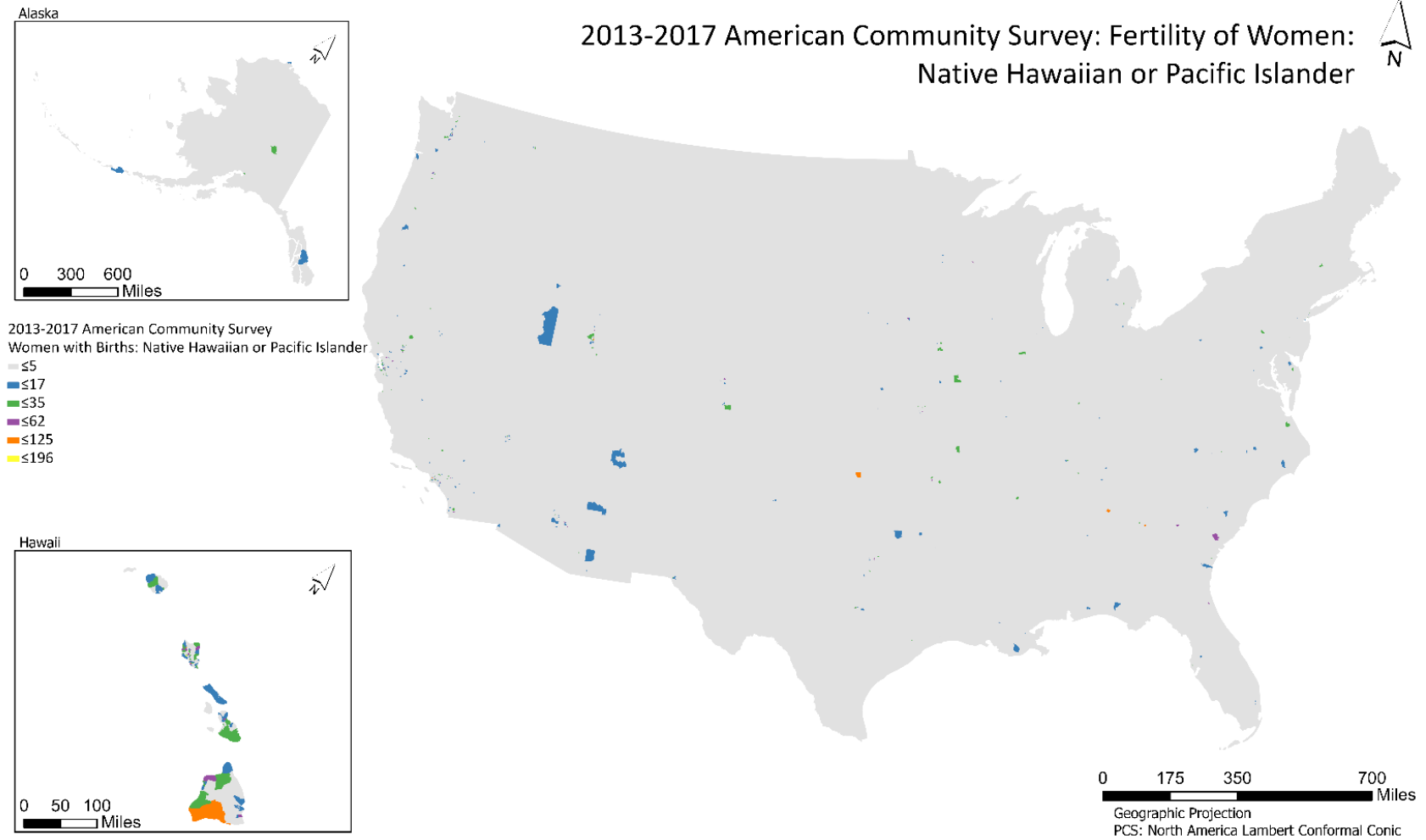
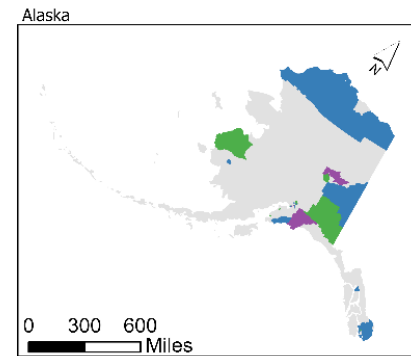
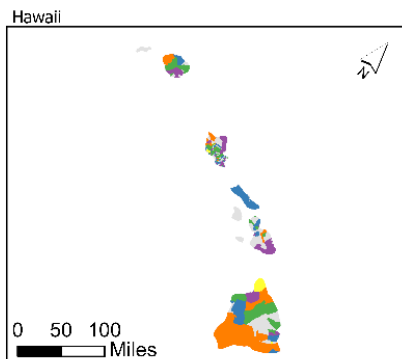


Figure 4.16. ACS 2013-2017, Fertility of women identifying as Native Hawaiian or Pacific Islander

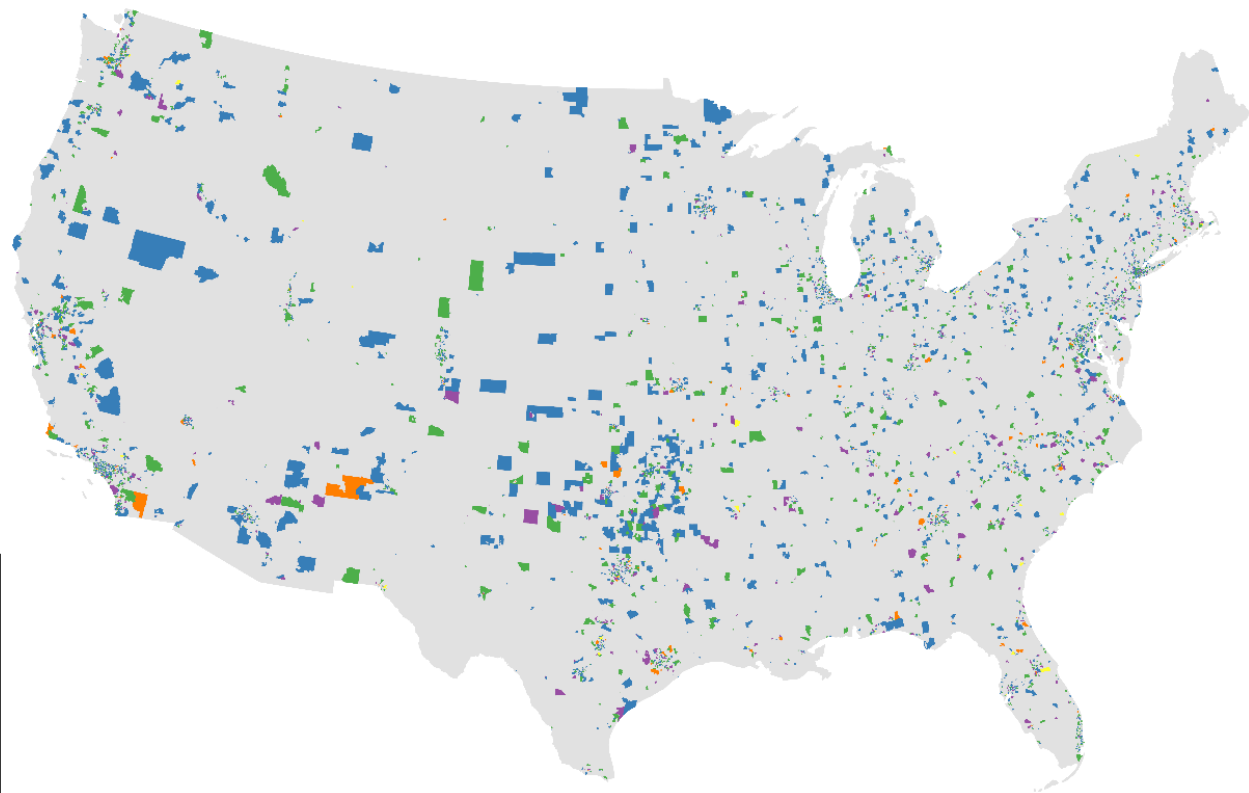


2013-2017 American Community Survey
 Women with Births: 2 or more ethnicities

- ≤4
- ≤13
- ≤25
- ≤43
- ≤73
- ≤164

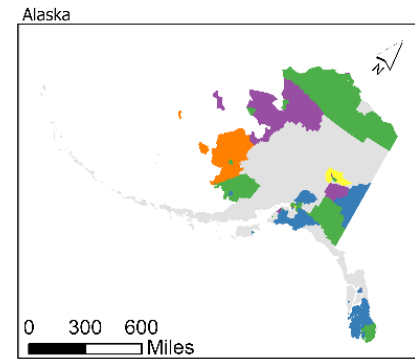


2013-2017 American Community Survey: Fertility of Women:
 2 or more ethnicities



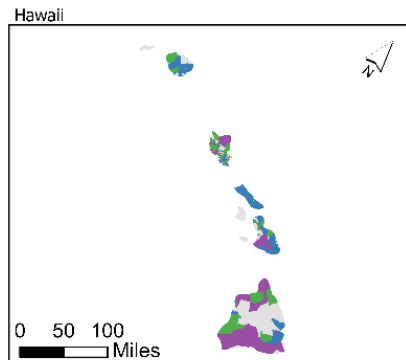
0 175 350 700 Miles
 Geographic Projection
 PCS: North America Lambert Conformal Conic

Figure 4.17. ACS 2013-2017, Fertility of women identifying with 2 or more races/ethnicities



2013-2017 American Community Survey
All Women with Births: Native (U.S.) born

- ≤24
- ≤54
- ≤93
- ≤151
- ≤265
- ≤1271



2013-2017 American Community Survey: Fertility of Women:
Native (U.S.) born

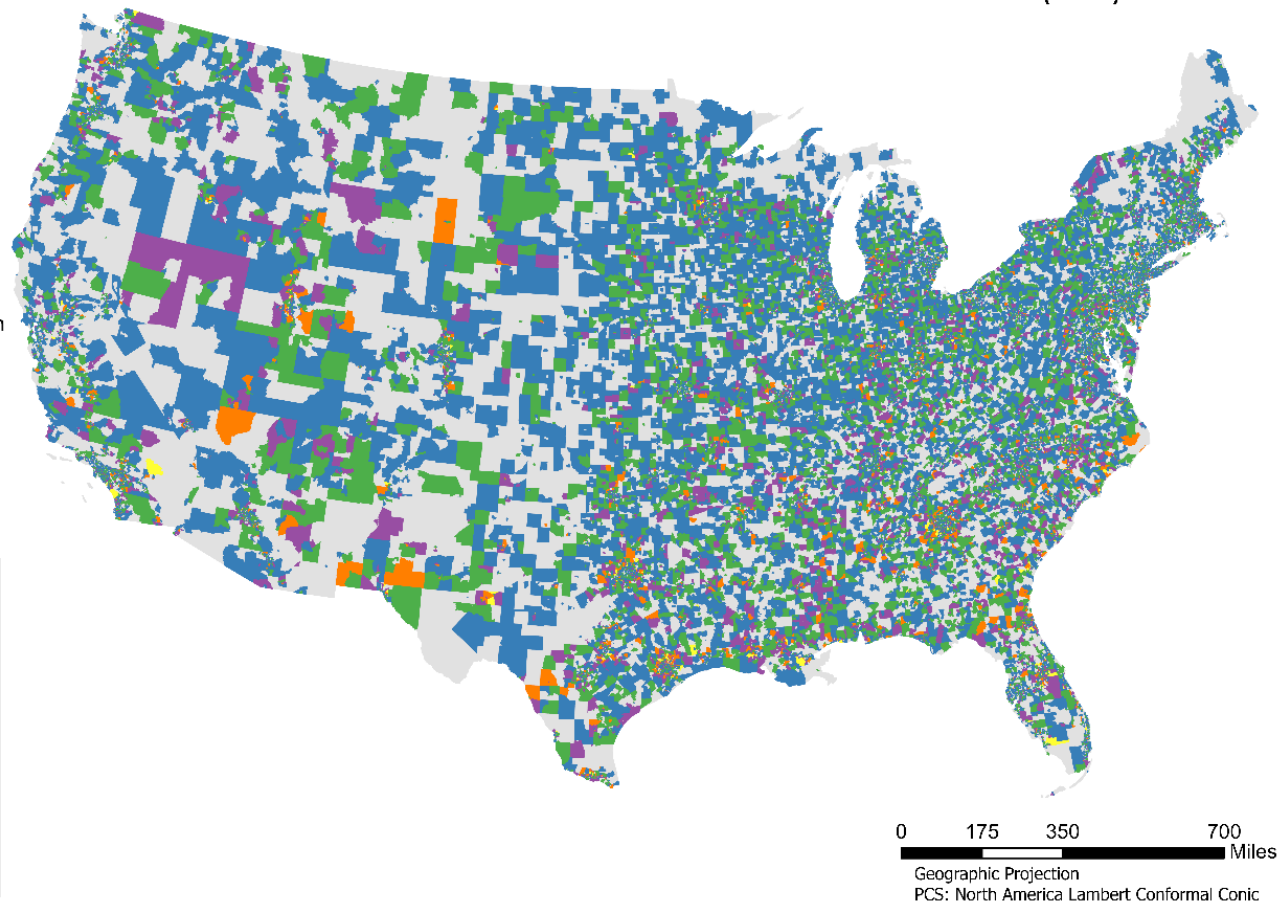
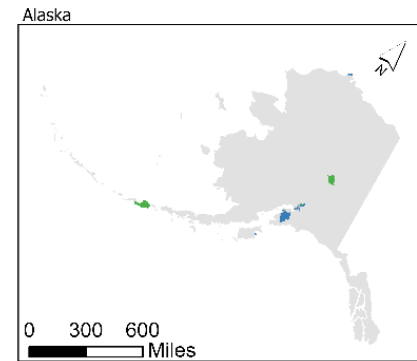
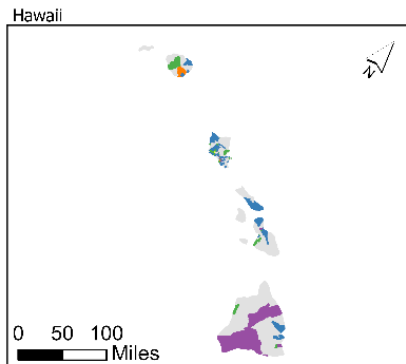


Figure 4.18. ACS 2013-2017, Fertility of US born women

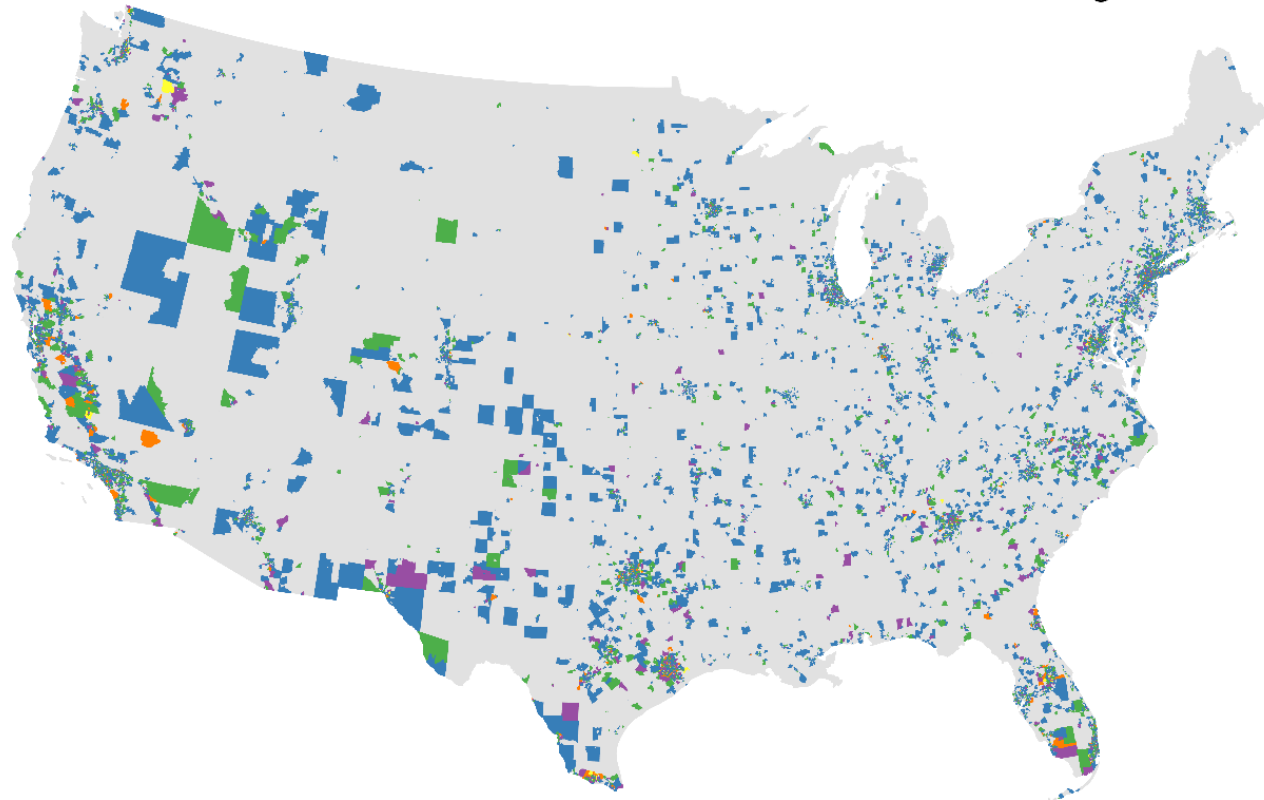


2013-2017 American Community Survey
Women with Births: Foreign* born

- ≤8
- ≤27
- ≤53
- ≤90
- ≤154
- ≤548



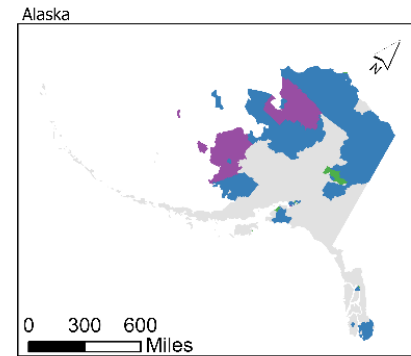
2013-2017 American Community Survey: Fertility of Women: Foreign born



*The foreign-born population is composed of anyone who is not a U.S. citizen at birth. This includes persons who have become U.S. citizens through naturalization. (United States Census Bureau)

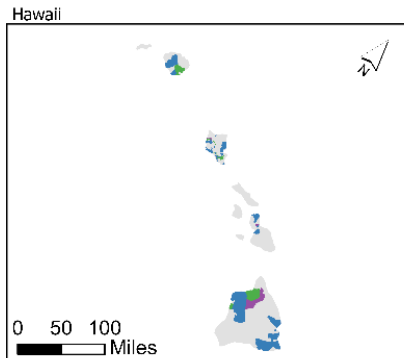
0 175 350 700
Miles
Geographic Projection
PCS: North America Lambert Conformal Conic

Figure 4.19. ACS 2013-2017, Fertility of Foreign-born women



2013-2017 American Community Survey
Women with Births: Less than High School

- ≤6
- ≤21
- ≤42
- ≤72
- ≤129
- ≤406



2013-2017 American Community Survey: Fertility of Women: Less than High School Education

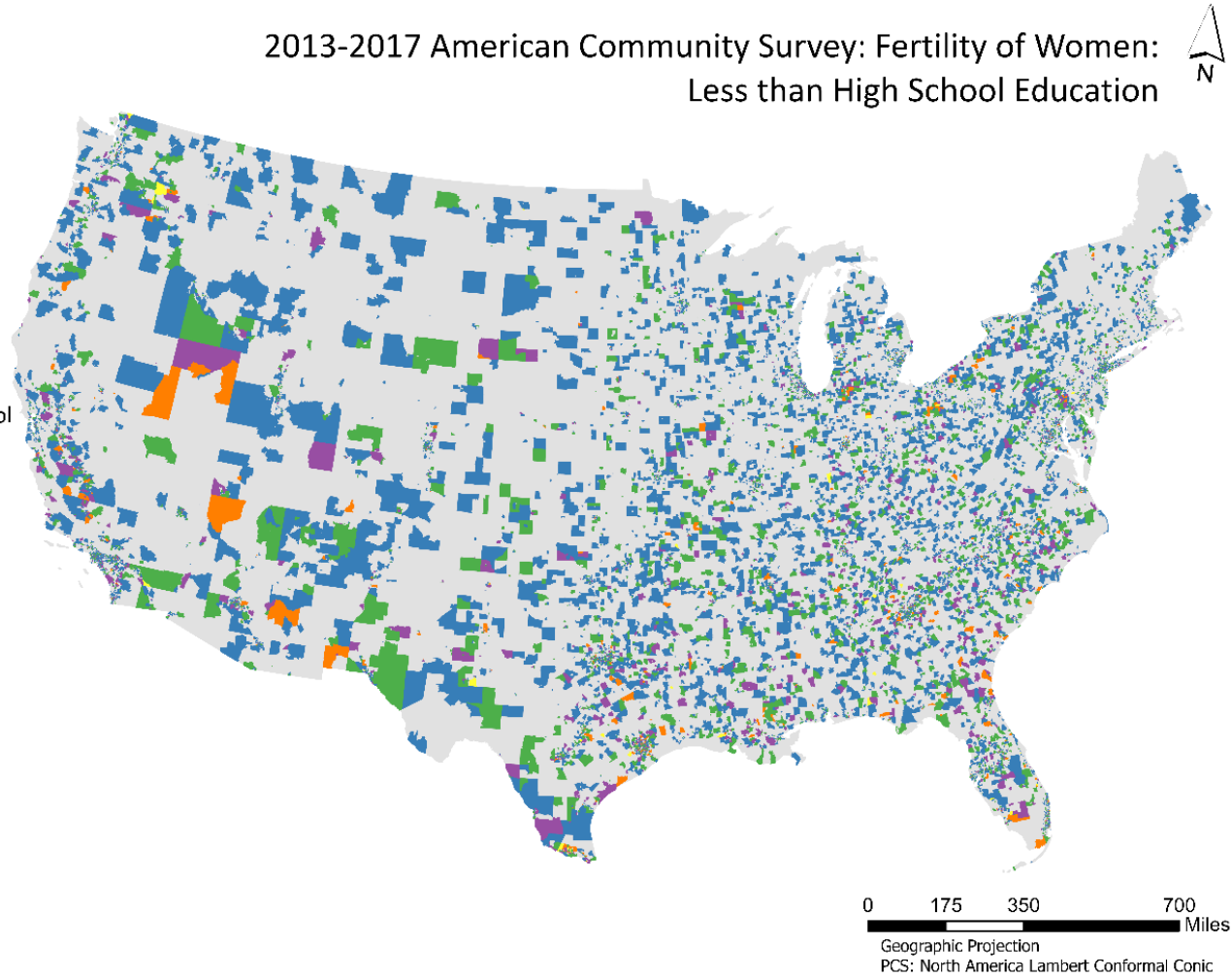


Figure 4.20. ACS 2013-2017, Fertility of women highest educational attainment: Less than High School

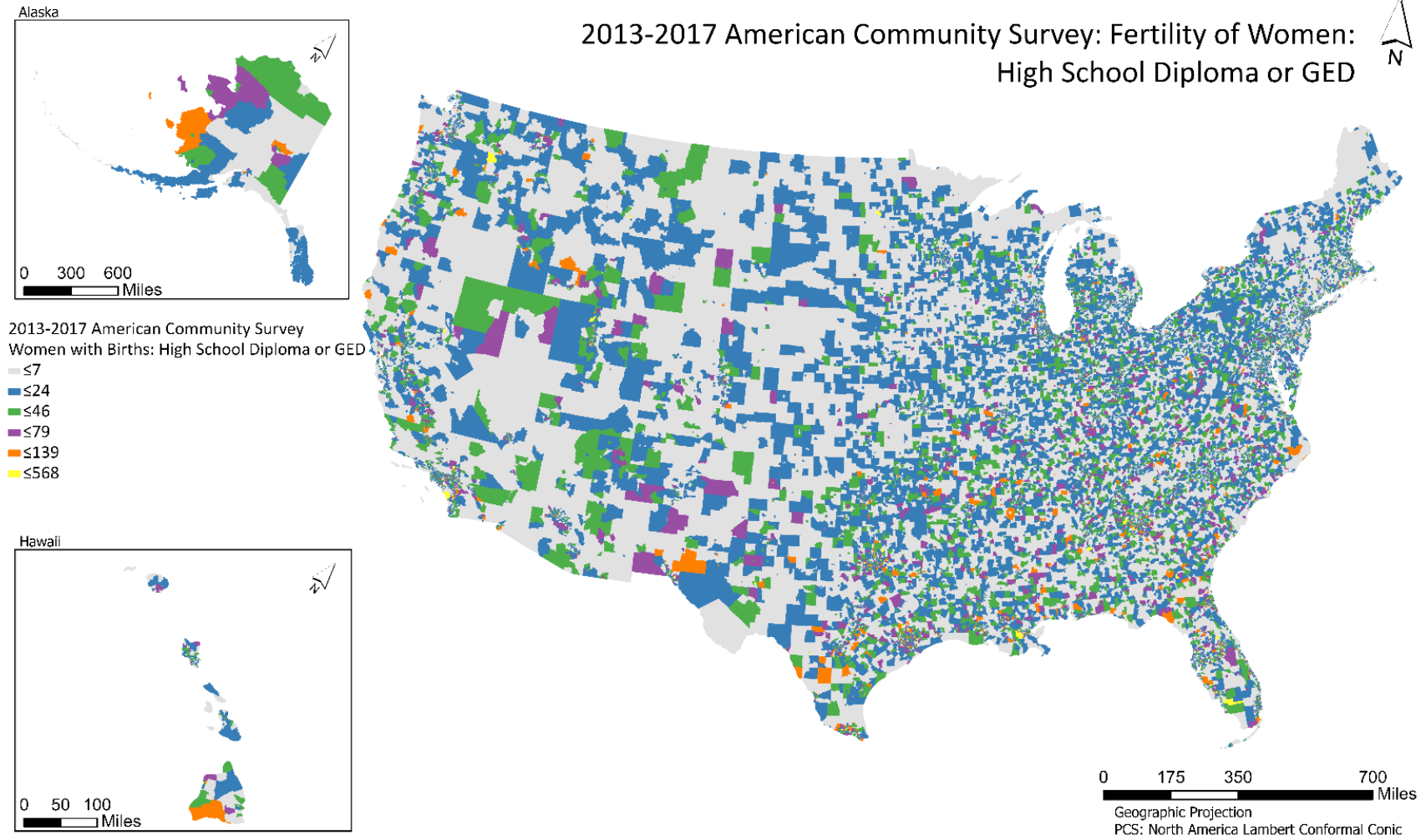
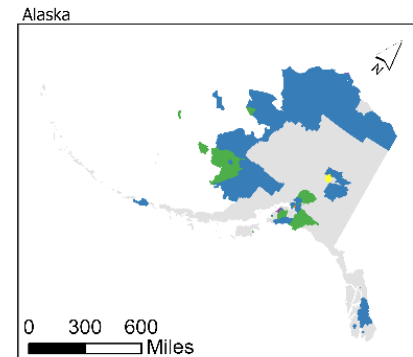
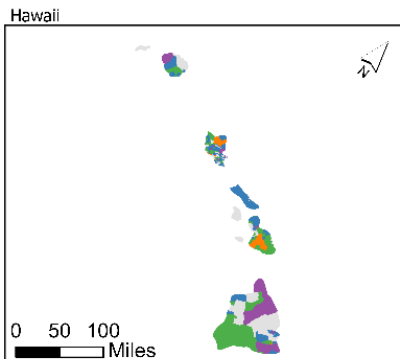


Figure 4.21. ACS 2013-2017, Fertility of women highest educational attainment: High School graduate, or GED



2013-2017 American Community Survey
Women with Births: Associates Degree

- ≤9
- ≤27
- ≤52
- ≤88
- ≤155
- ≤637



2013-2017 American Community Survey: Fertility of Women: Associates Degree

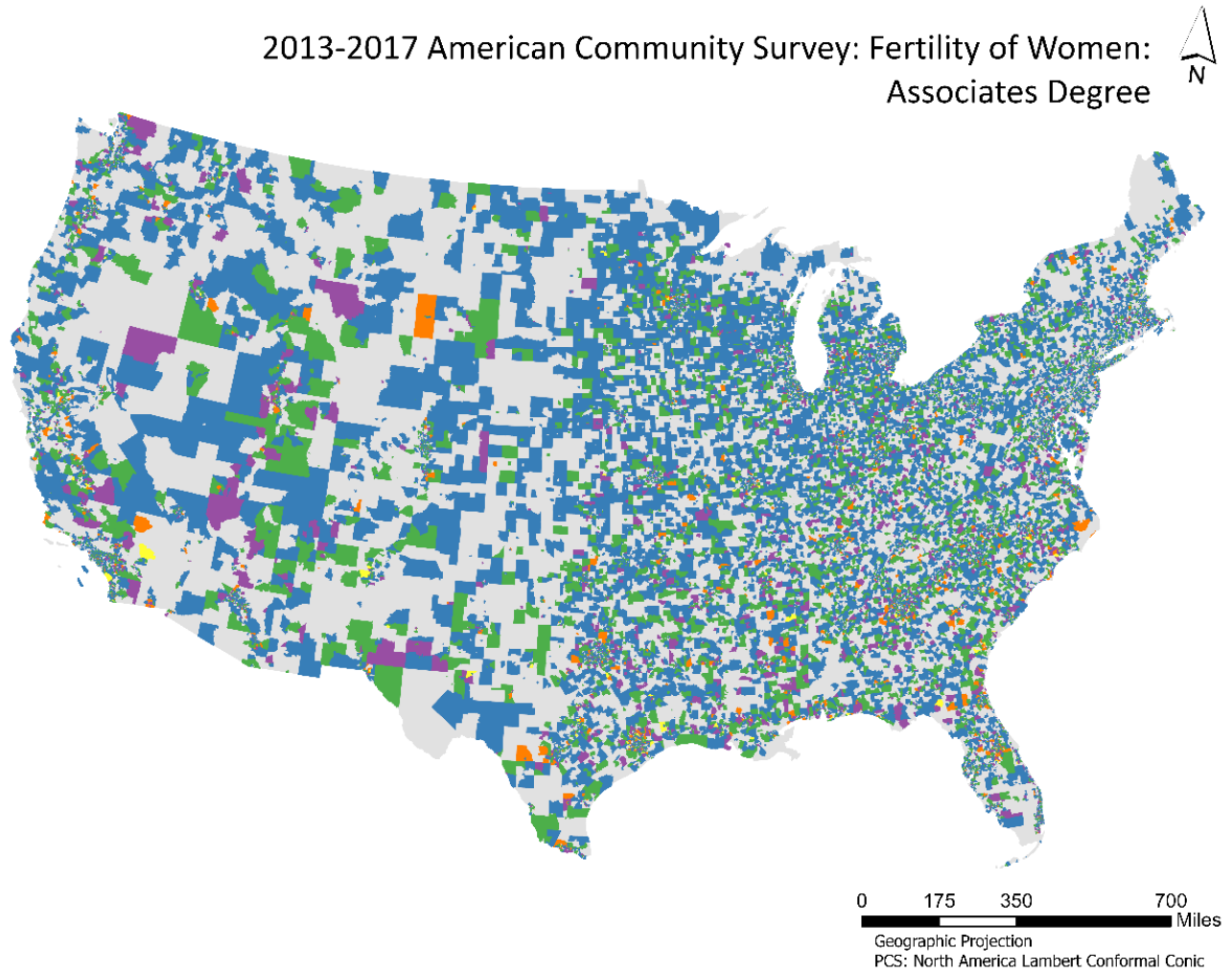
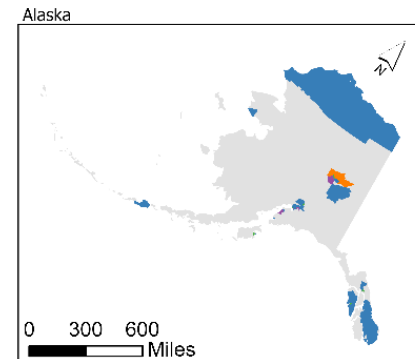
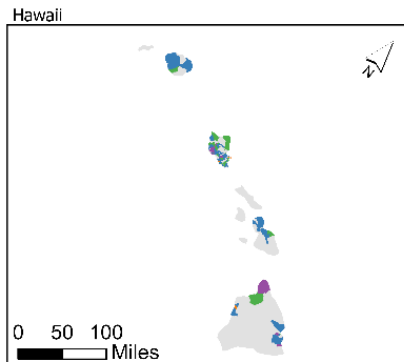


Figure 4.22. ACS 2013-2017, Fertility of women highest educational attainment: Associates Degree



2013-2017 American Community Survey
Women with Births: Bachelors Degree

- ≤6
- ≤21
- ≤42
- ≤74
- ≤143
- ≤458



2013-2017 American Community Survey: Fertility of Women: Bachelors Degree

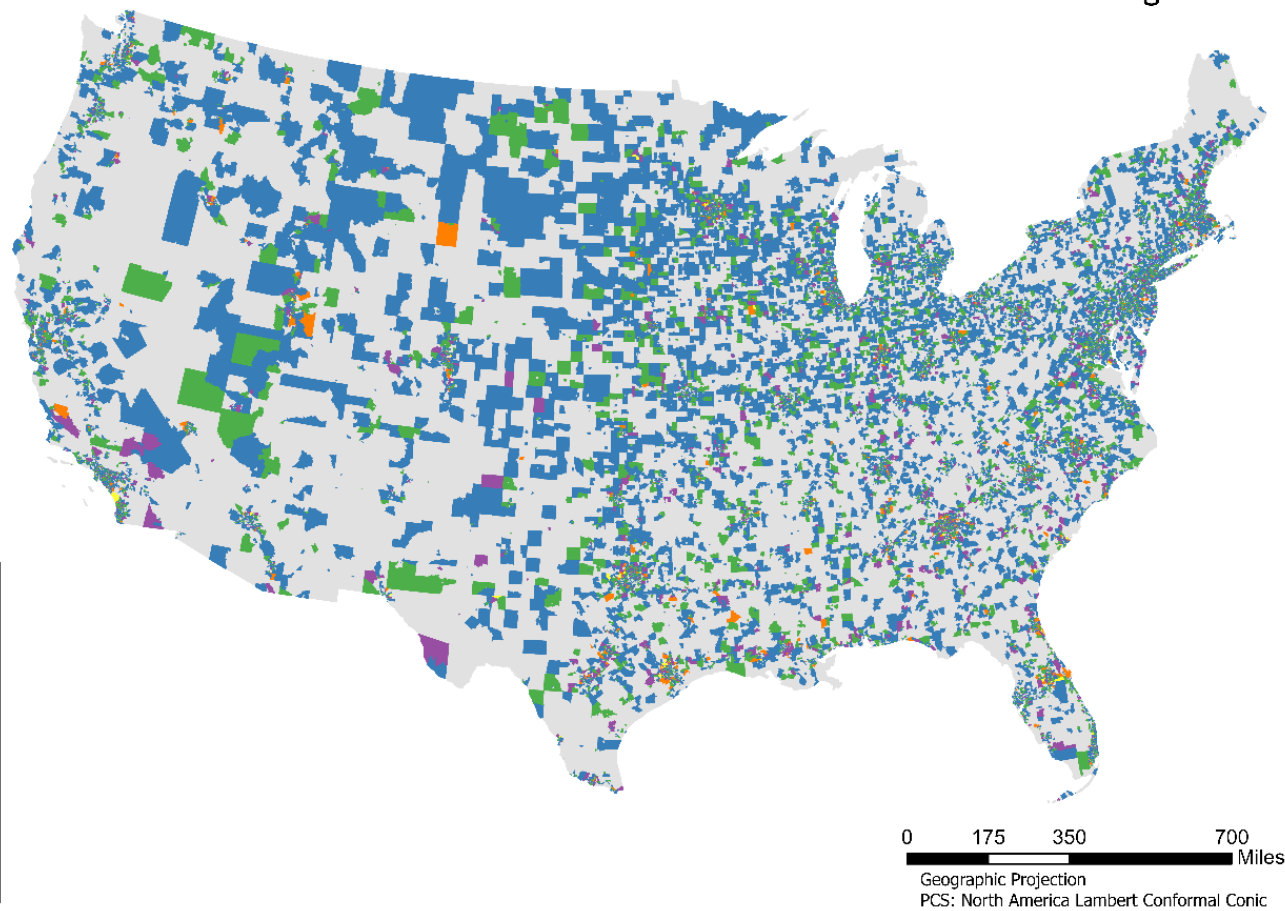
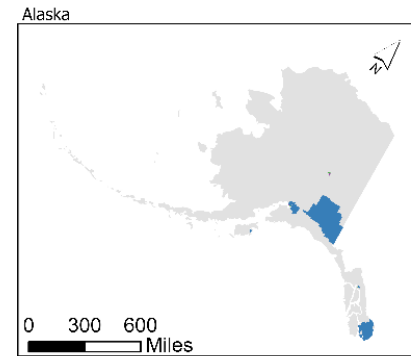
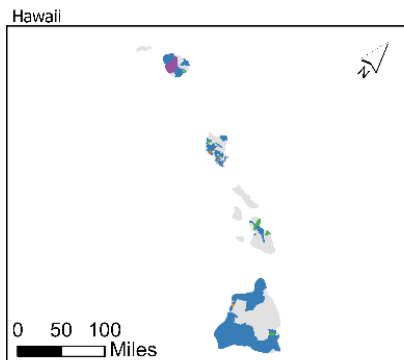


Figure 4.23: ACS 2013-2017, Fertility of women highest educational attainment: Bachelors Degree



2013-2017 American Community Survey
Women with Births: Graduate or Professional Degree

- ≤14
- ≤24
- ≤40
- ≤64
- ≤112
- ≤271



2013-2017 American Community Survey: Fertility of Women: Graduate or Professional Degree

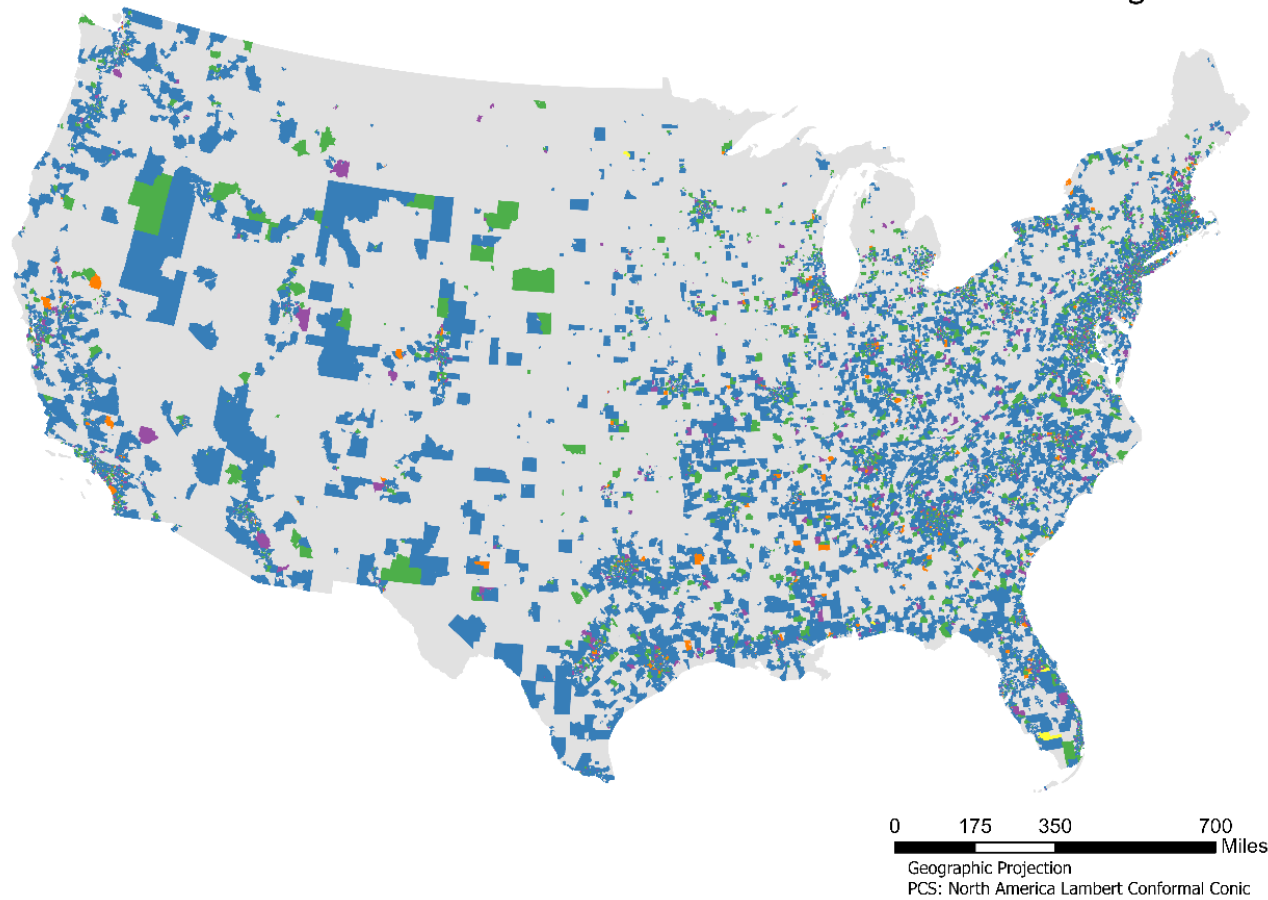
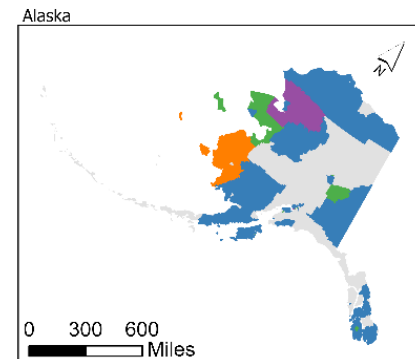
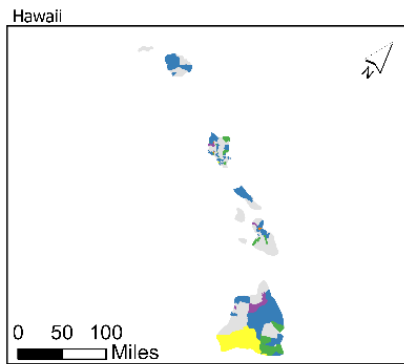


Figure 4.24: ACS 2013-2017, Fertility of women highest educational attainment: Graduate or Professional Degree



2013-2017 American Community Survey
 Women with Births: Below 100% of poverty level

- ≤8
- ≤25
- ≤48
- ≤80
- ≤134
- ≤327



2013-2017 American Community Survey: Fertility of Women:
 Below 100% of poverty level

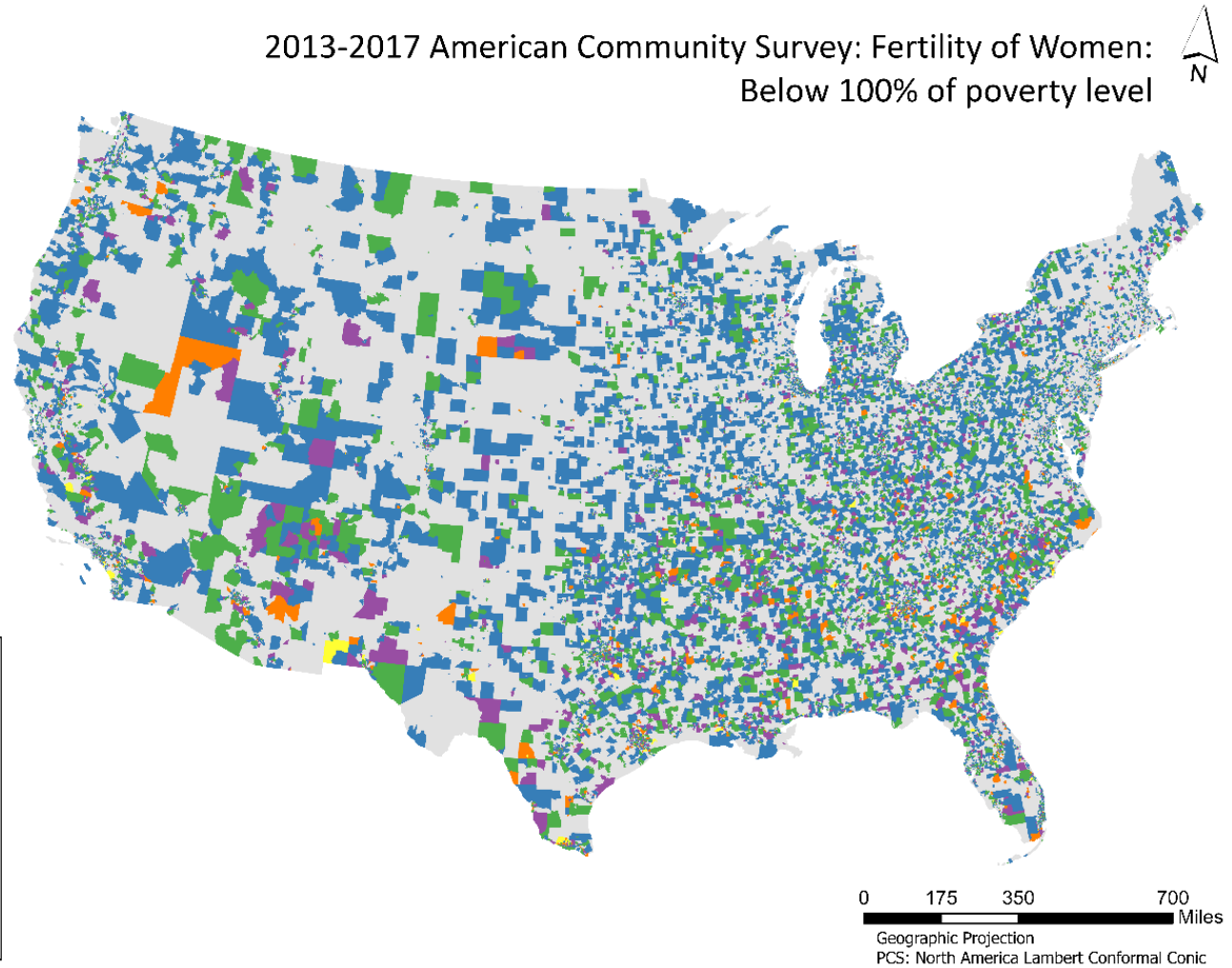
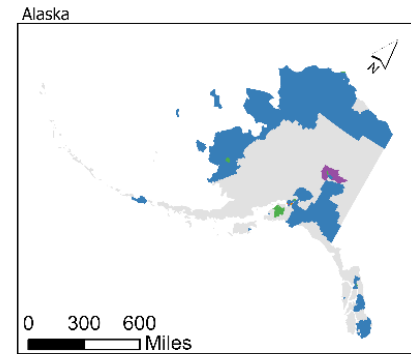


Figure 4.25. ACS 2013-2017, Fertility of women 100% below poverty level



2013-2017 American Community Survey
Women with Births: 200% or above poverty level

- ≤18
- ≤48
- ≤91
- ≤173
- ≤464
- ≤928

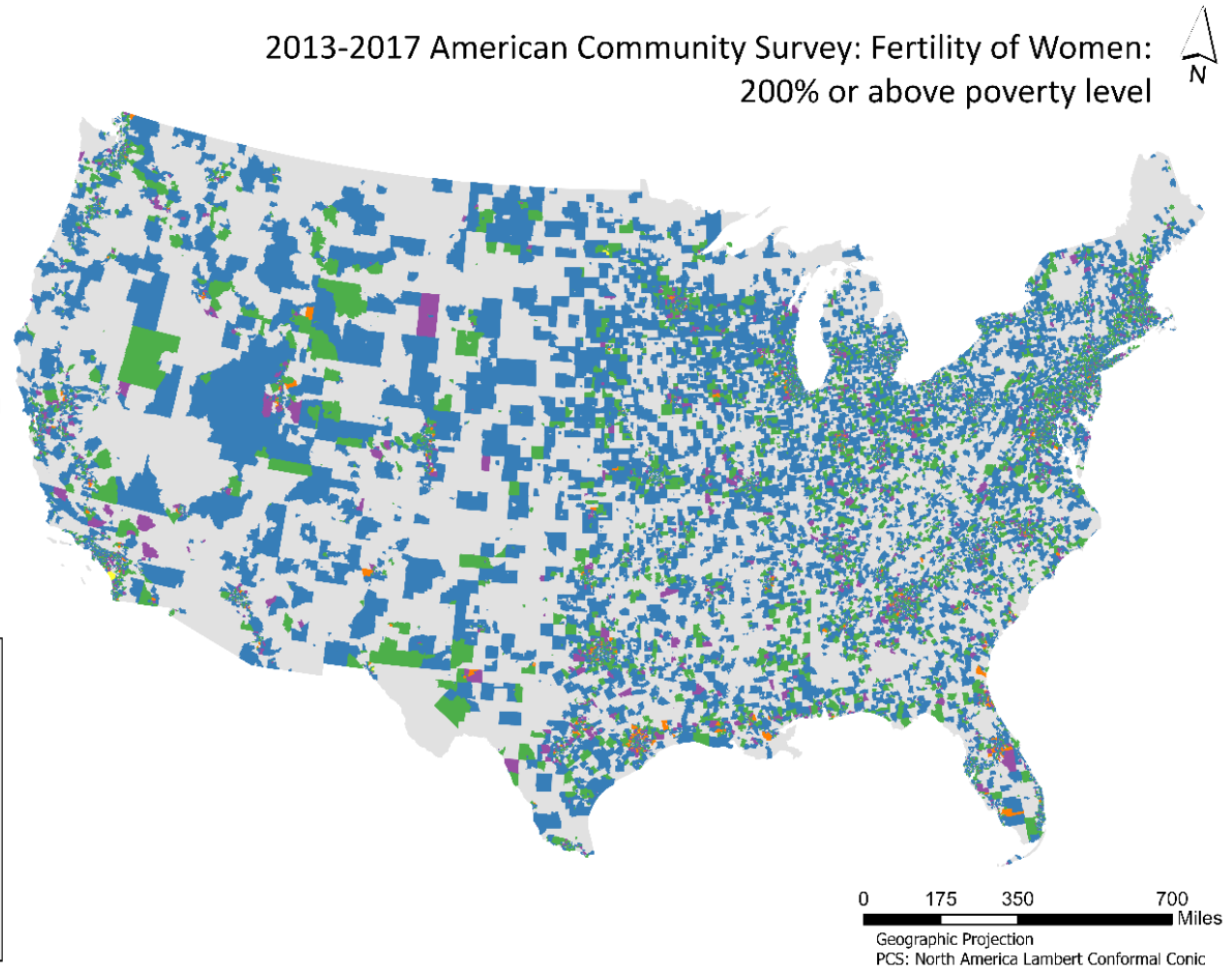
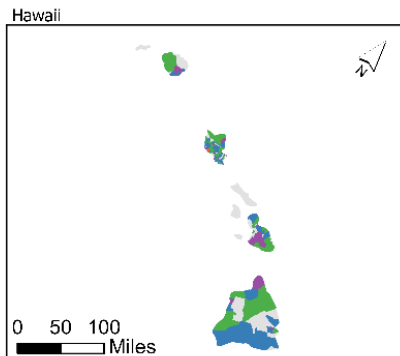
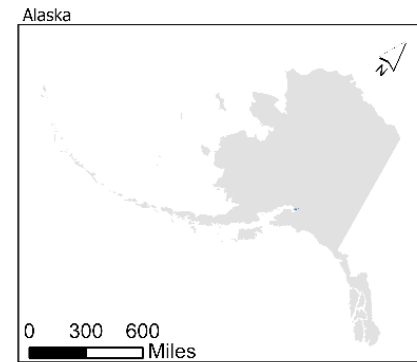
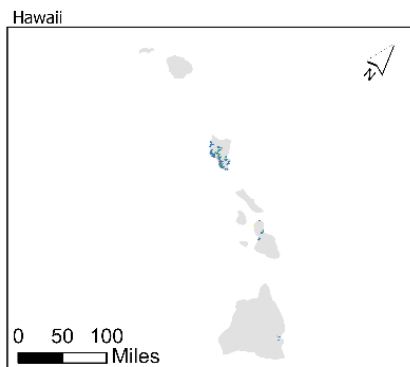


Figure 4.26. ACS 2013-2017, Fertility of women 200% above poverty level



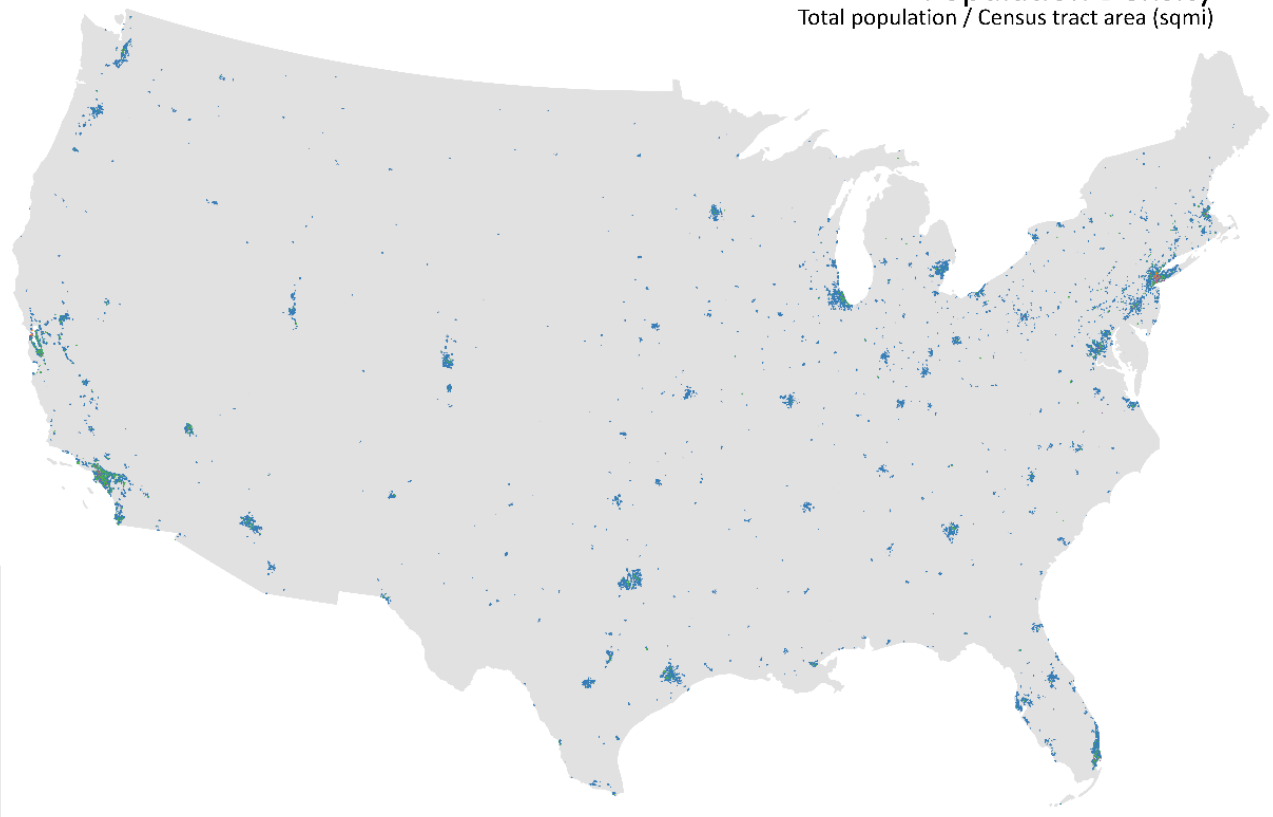
2013-2017 American Community Survey
Population Density

- ≤3078.415732
- ≤8058.046495
- ≤18858.571935
- ≤42827.230439
- ≤134662.769002
- ≤495688.125938



2013-2017 American Community Survey: Population Density

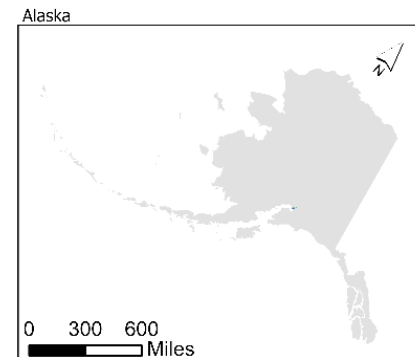
Total population / Census tract area (sqmi)



0 175 350 700
Miles

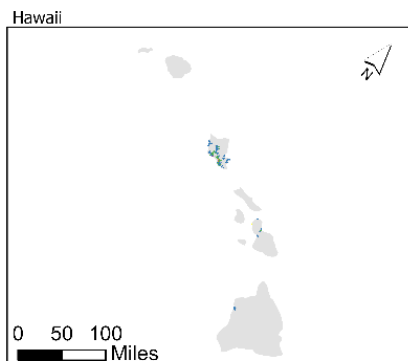
Geographic Projection
PCS: North America Lambert Conformal Conic

Figure 4.27. ACS 2013-2017, Population density by census tract



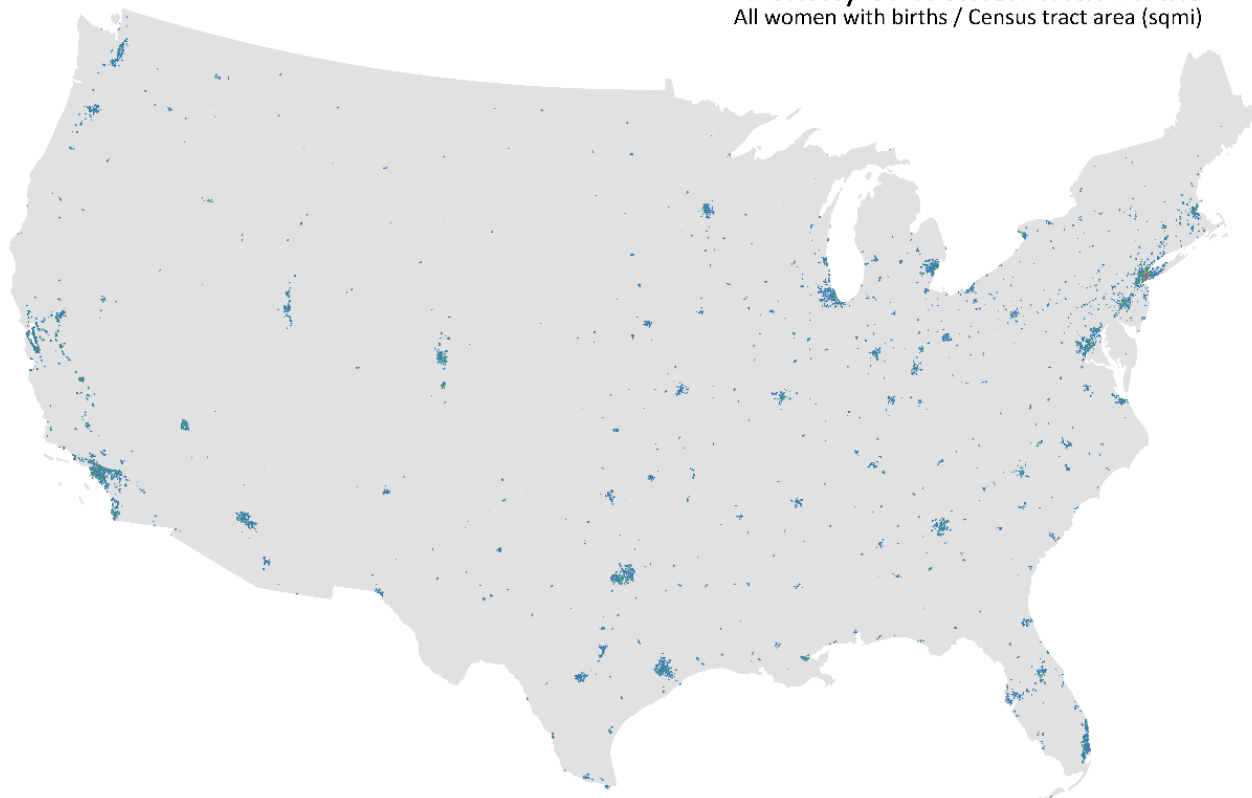
2013-2017 American Community Survey
Density of Women with Births

- ≤50.598787
- ≤151.948117
- ≤370.295178
- ≤925.521249
- ≤2806.812042
- ≤5581.196495



2013-2017 American Community Survey: Fertility of Women: Density of Women with Births

All women with births / Census tract area (sqmi)



0 175 350 700
Miles
Geographic Projection
PCS: North America Lambert Conformal Conic

Figure 4.28. ACS 2013-2017, Birth density by census tract

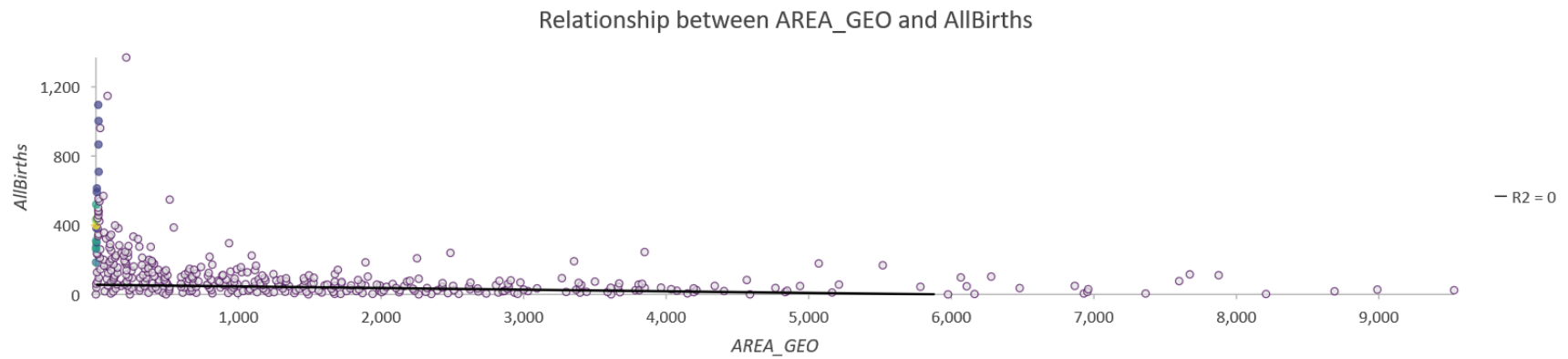
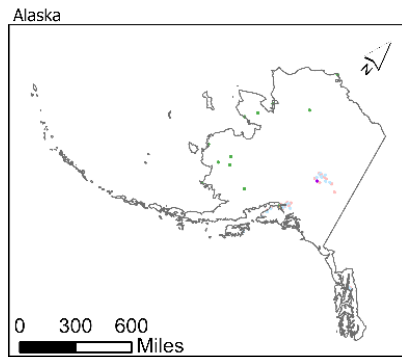
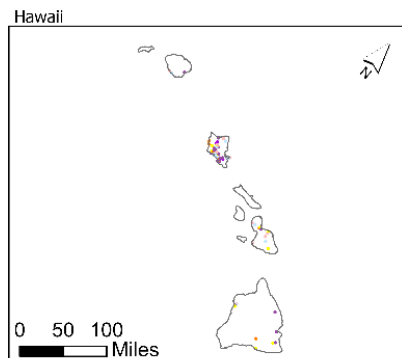


Figure 4.29. Relationship between census tract area (mi²) and all women with births



2013-2017 American Community Survey
1 Dot = 100 Women with Births

- Hispanic
- African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Caucasian (non-Hisp)
- Caucasian (Hispanic)
- United States



2013-2017 American Community Survey: Women with Births - by Ethnicity

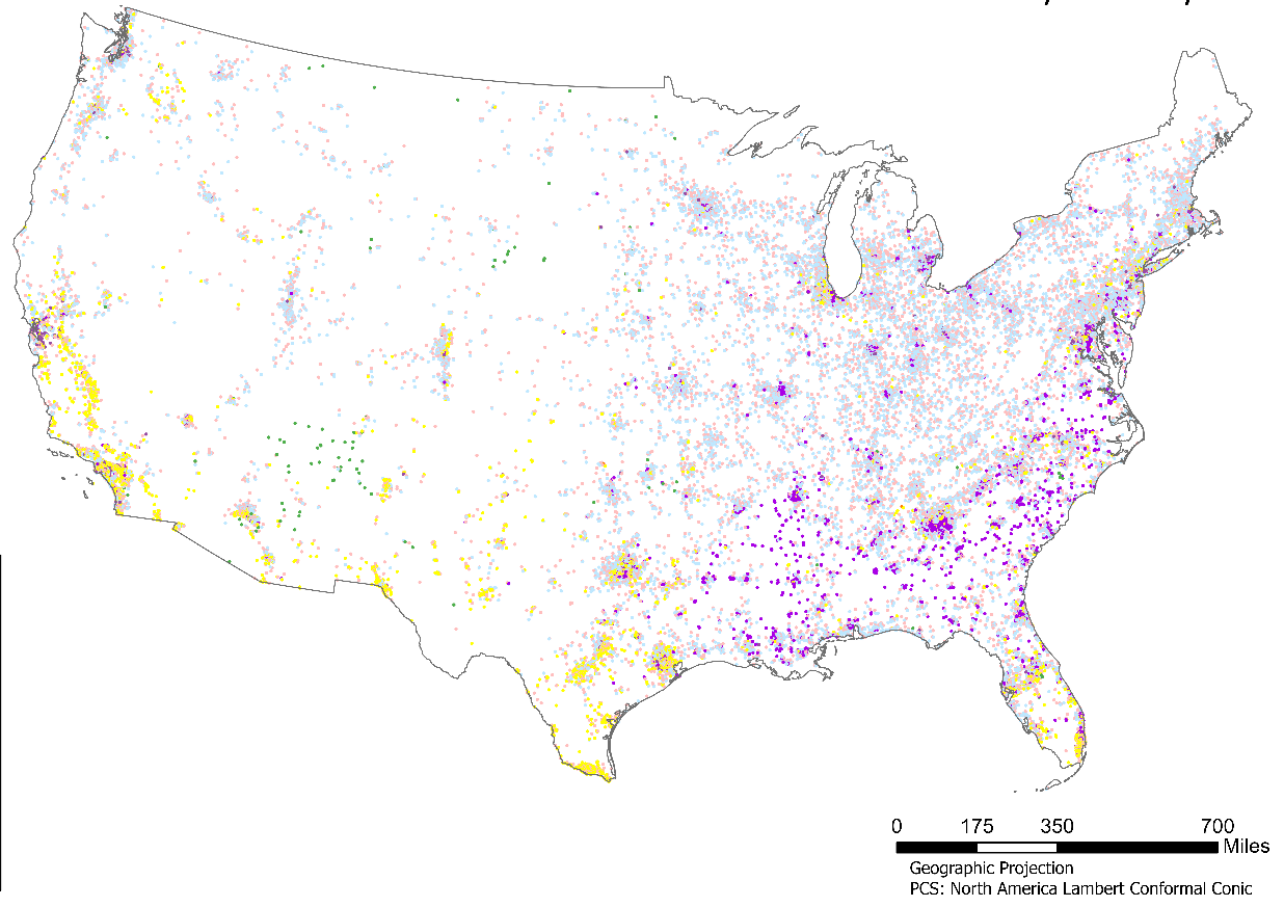


Figure 4.30. ACS 2013-2017, Dot density map of women with births based on ethnicity

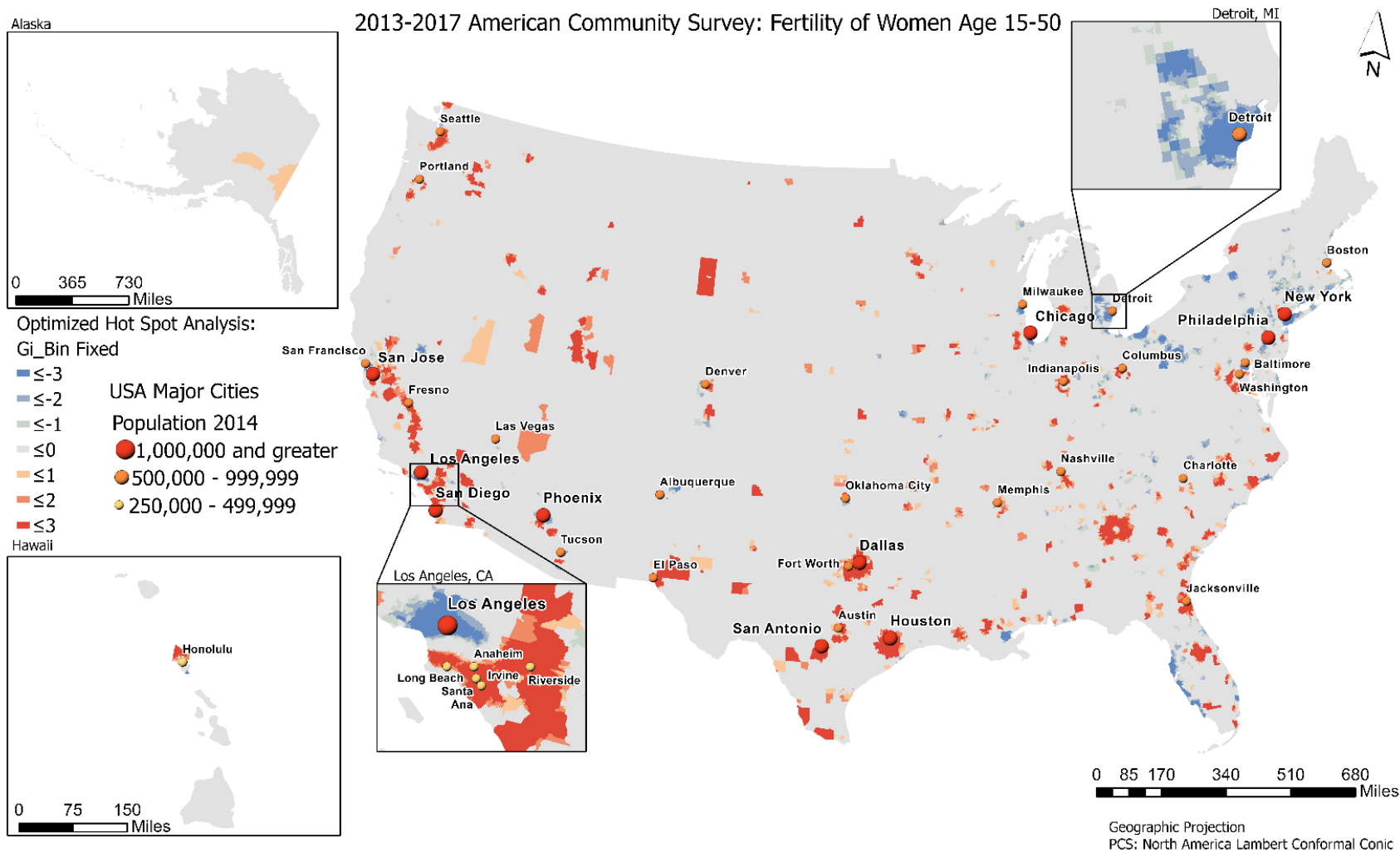


Figure 4.31. Optimized hot spot analysis: All women with births, census tract

2013-2017 American Community Survey: Directional Distributions:
All Variables, 1 Standard Deviation

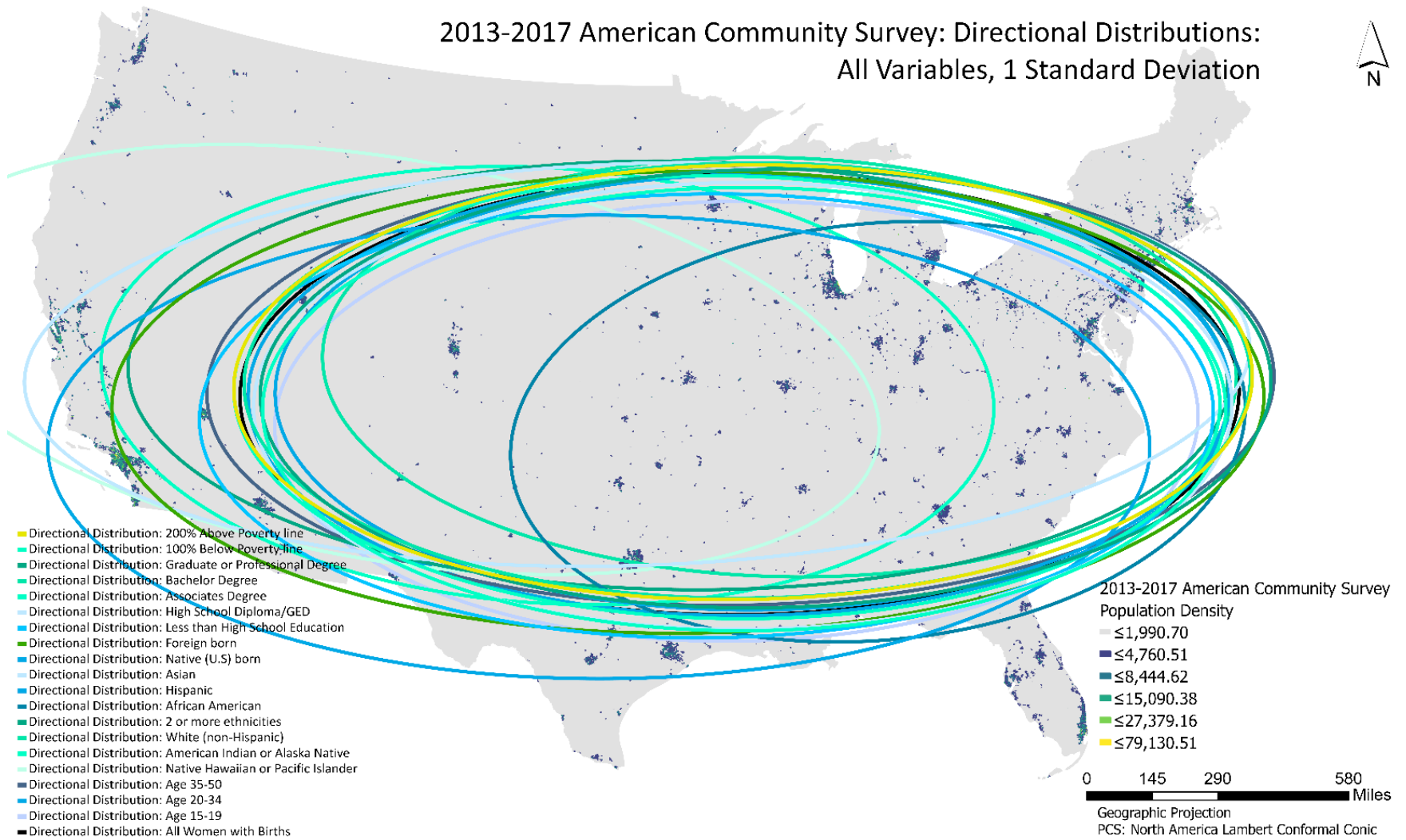


Figure 4.32. Directional distribution ellipse: All variables

2013-2017 American Community Survey: Directional Distributions:
Age, 1 Standard Deviation

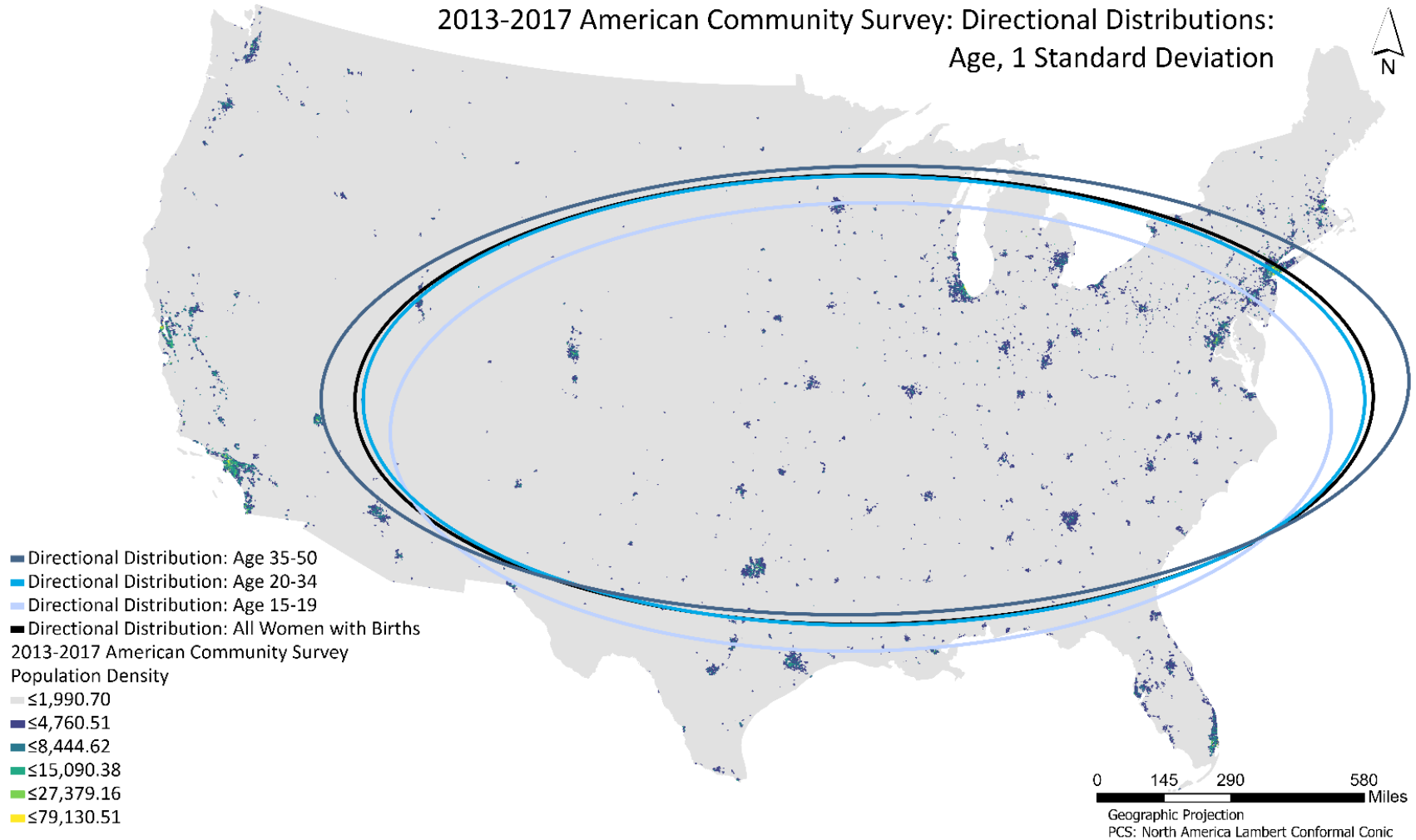


Figure 4.33. Directional distribution ellipse: Age

2013-2017 American Community Survey: Directional Distributions:
Race/Ethnicity, 1 Standard Deviation

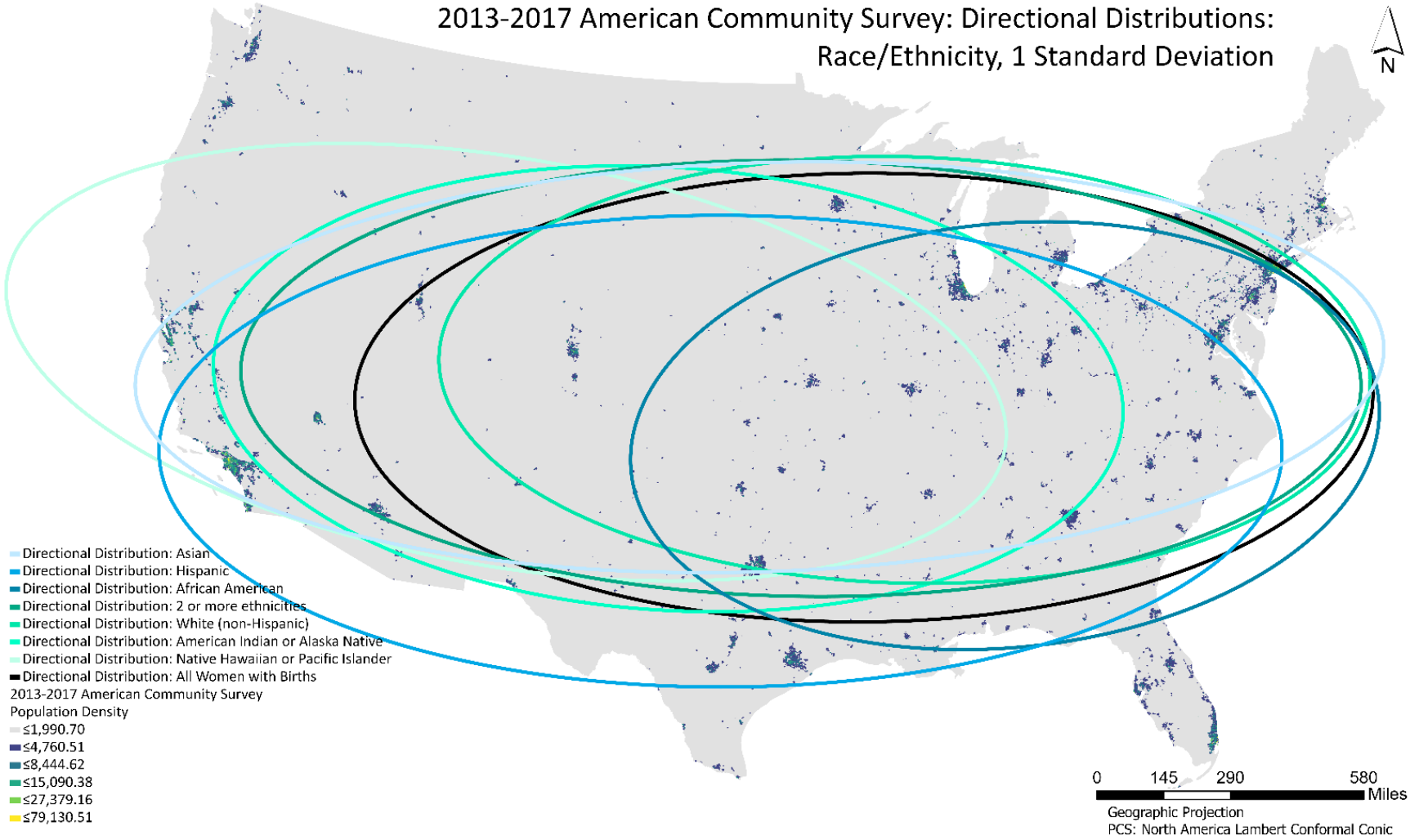


Figure 4.34. Directional distribution ellipse: Ethnicity

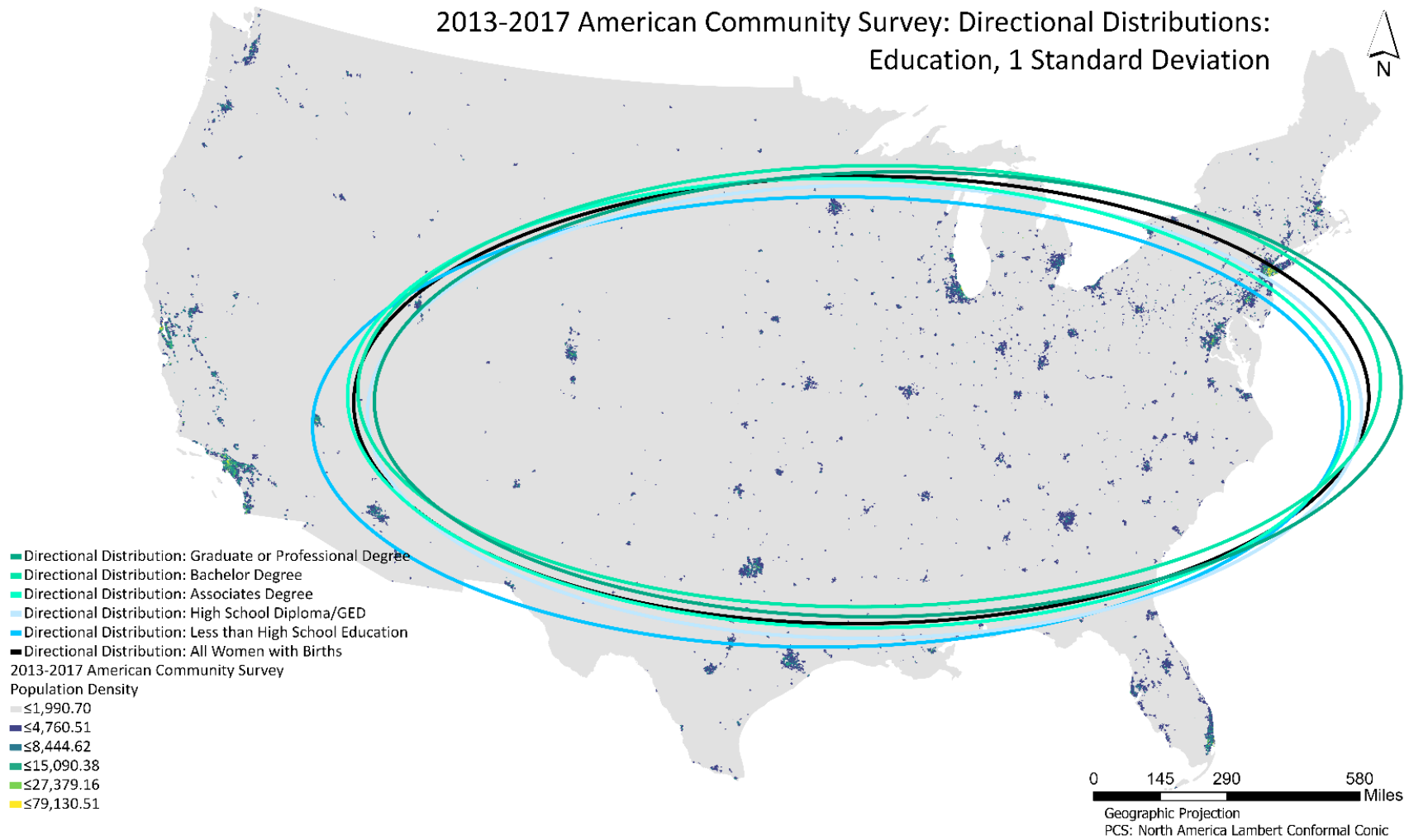


Figure 4.35. Directional distribution ellipse: Education

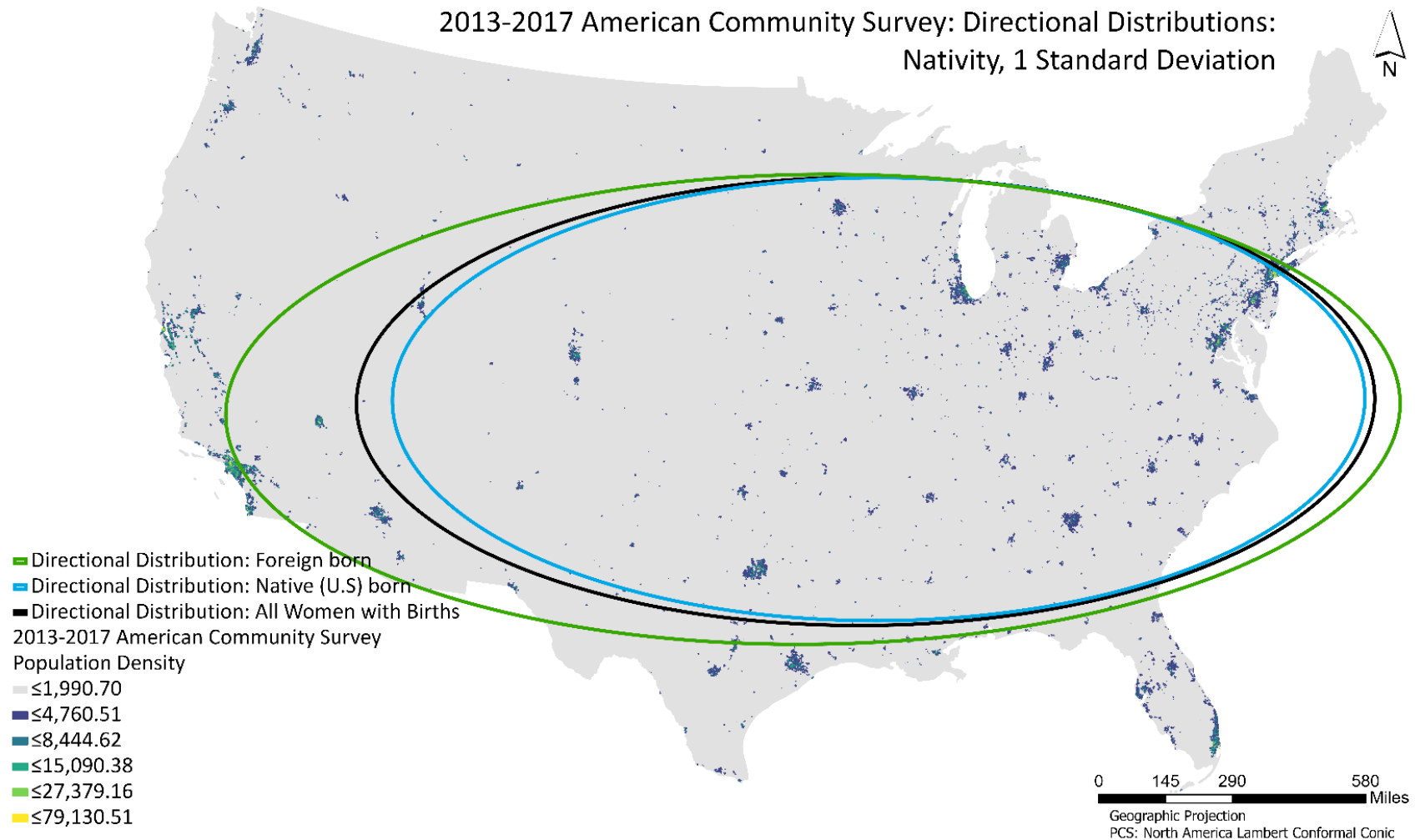


Figure 4.36. Directional distribution ellipse: Nativity

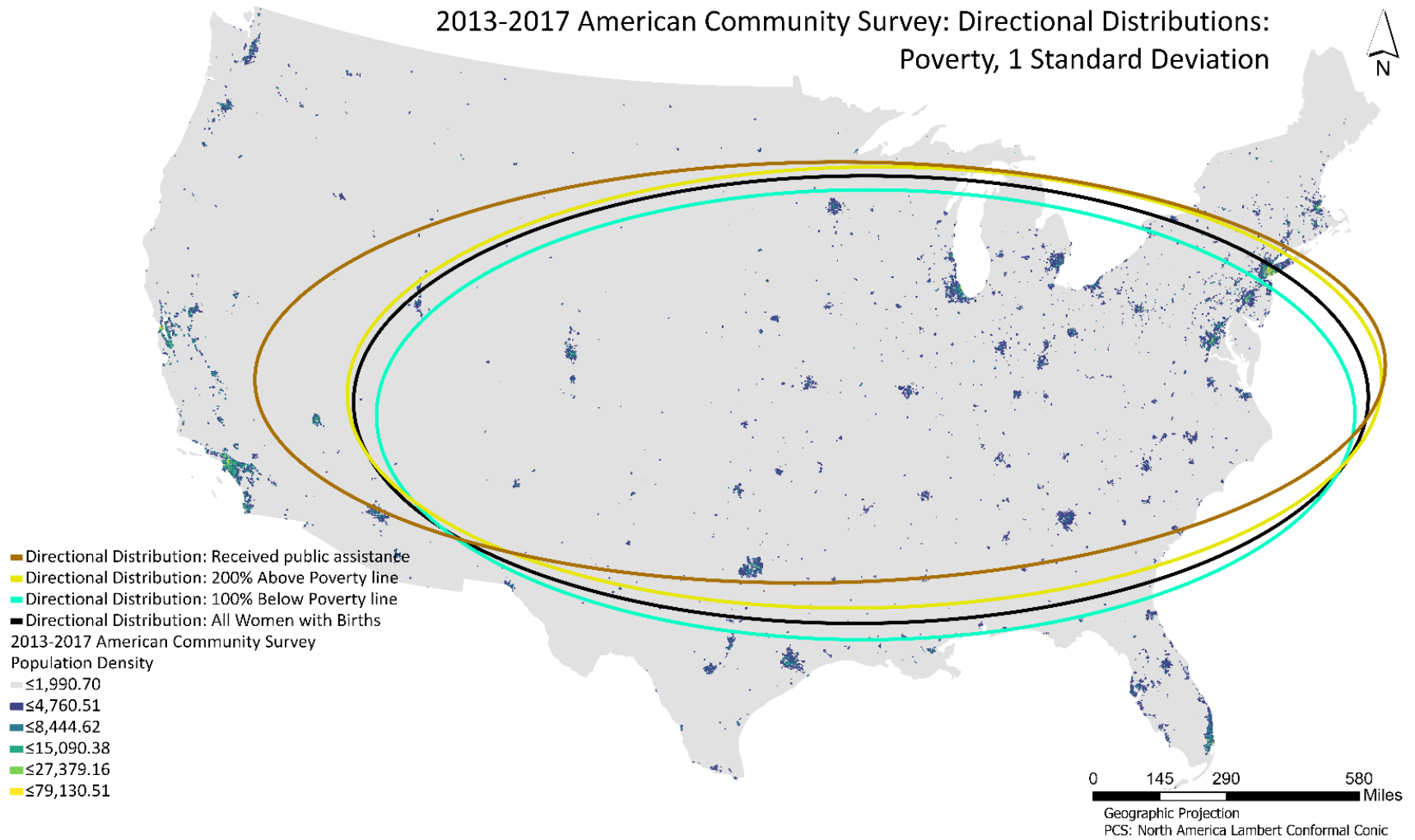


Figure 4.37. Directional distribution ellipse: Income disparity

2013-2017 American Community Survey: Directional Distributions:
Population and Birth Density, 1 Standard Deviation

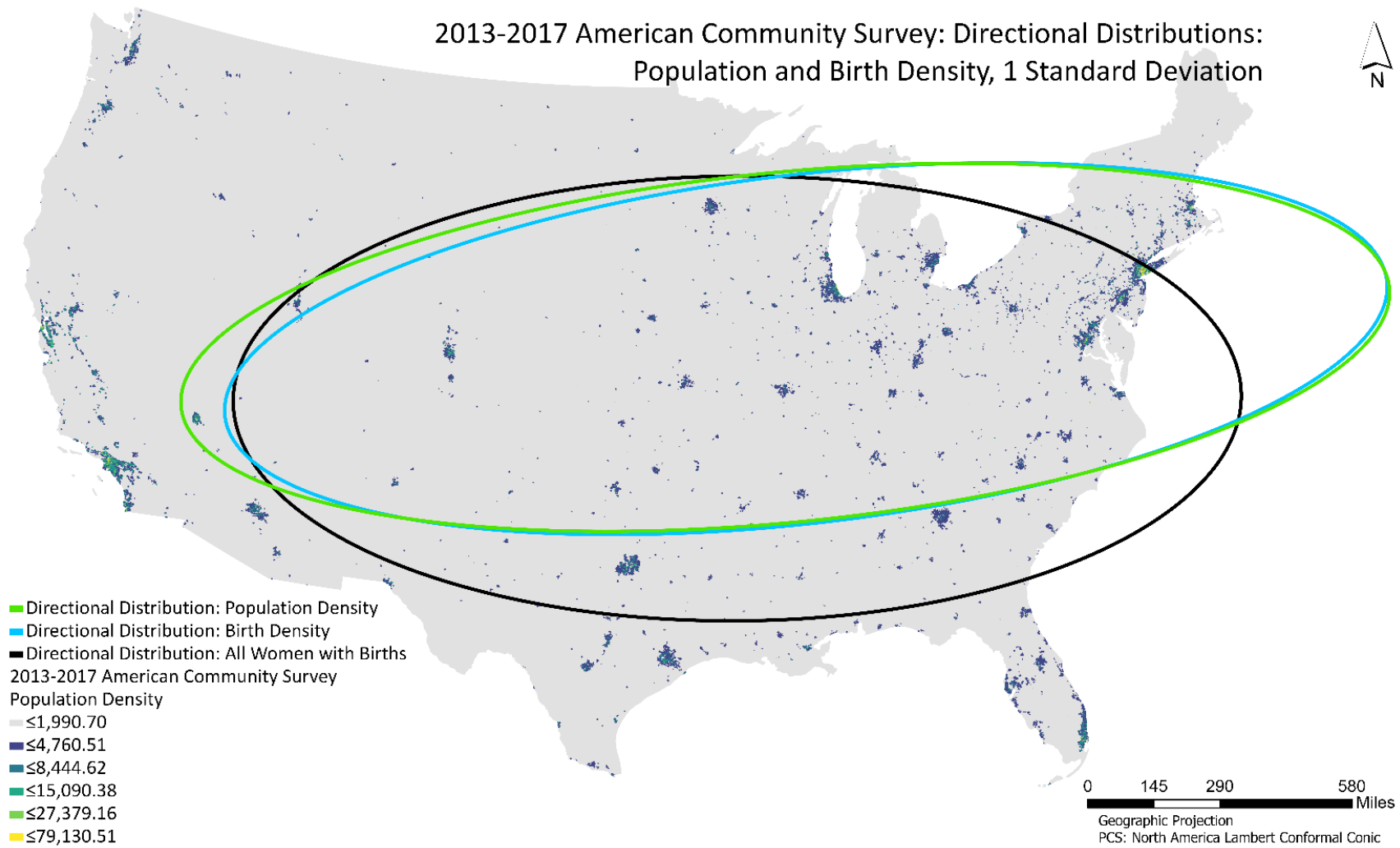


Figure 4.38. Directional distribution ellipse: Population and birth densities

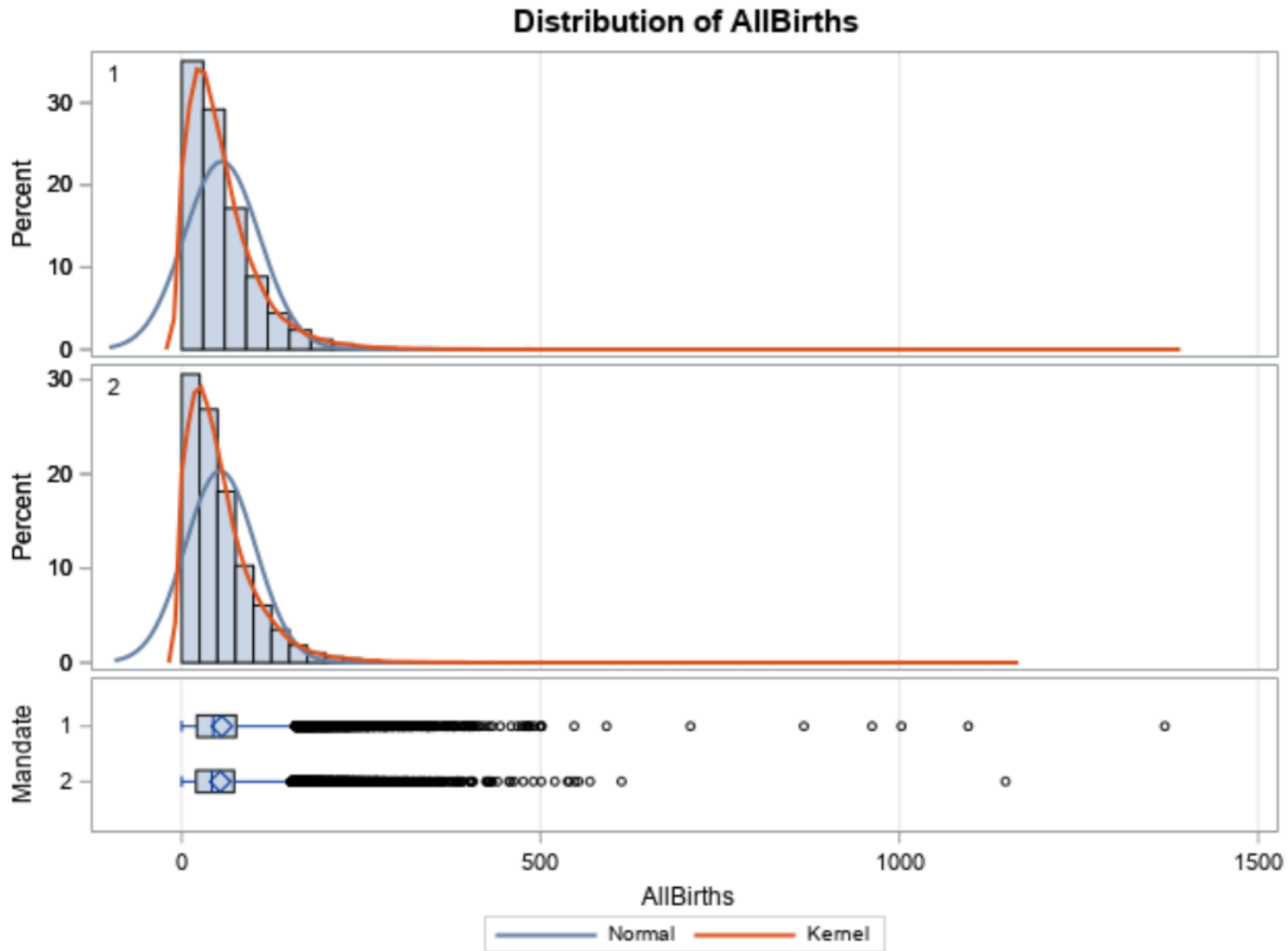
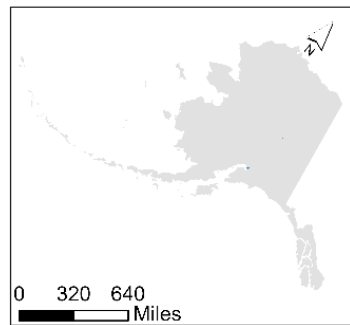


Figure 4.39. Distribution of “All Women with Births” between states with (1) and without (2) an infertility insurance mandate



Spatial Distribution of Fertility Clinics, 2017



Fertility Clinics, 2017

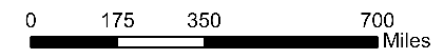
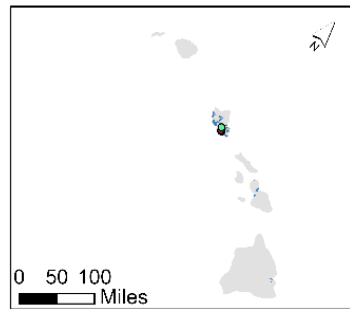
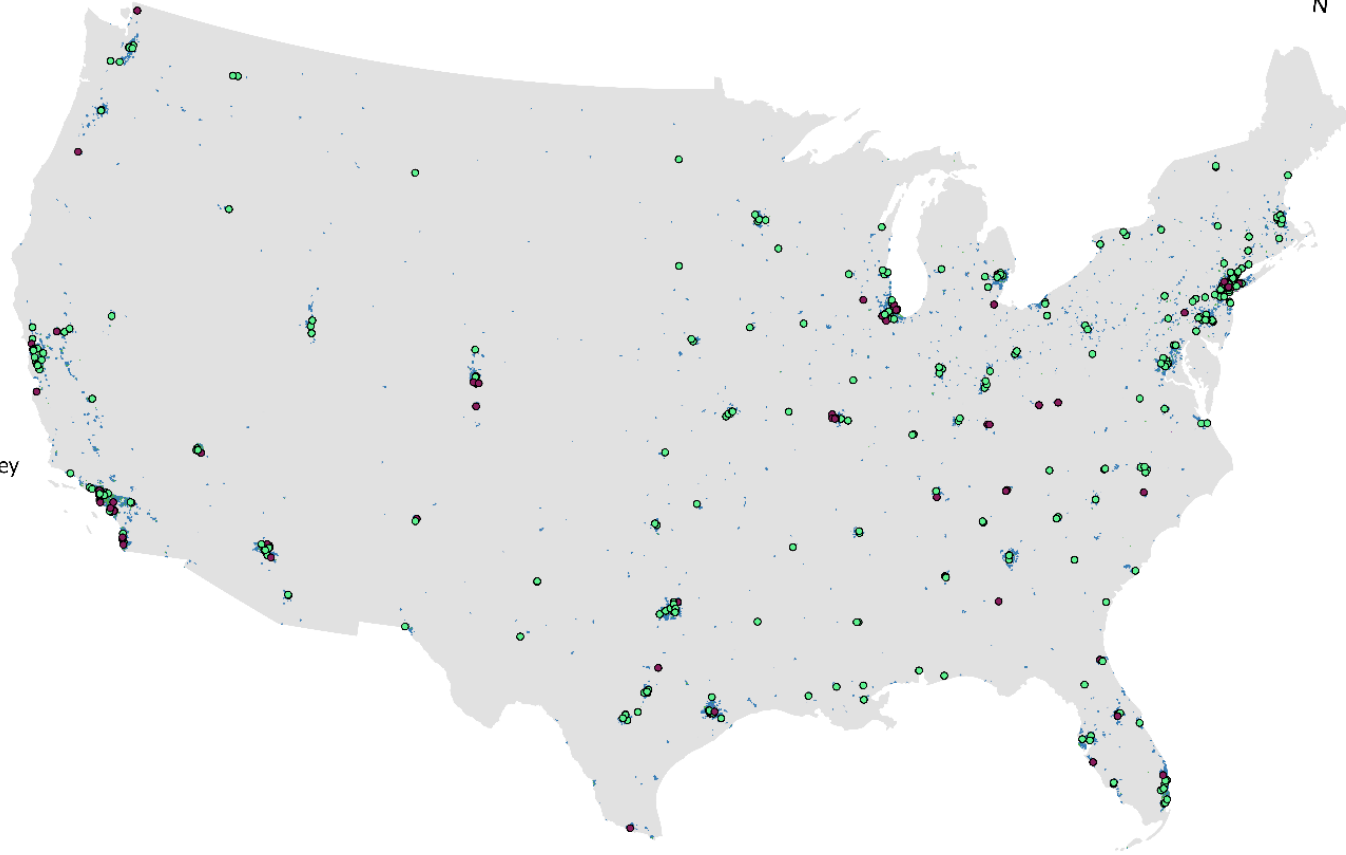
SART member

- Yes (361)
- No (79)

2013-2017 American Community Survey

Population Density

- ≤3078.415732
- ≤8058.046495
- ≤18858.571935
- ≤42827.230439
- ≤134662.769002
- ≤495688.125938



Spatial Reference
PCS: North America Lambert Conformal Conic

Figure 4.40. Spatial distribution of fertility clinics, 2017

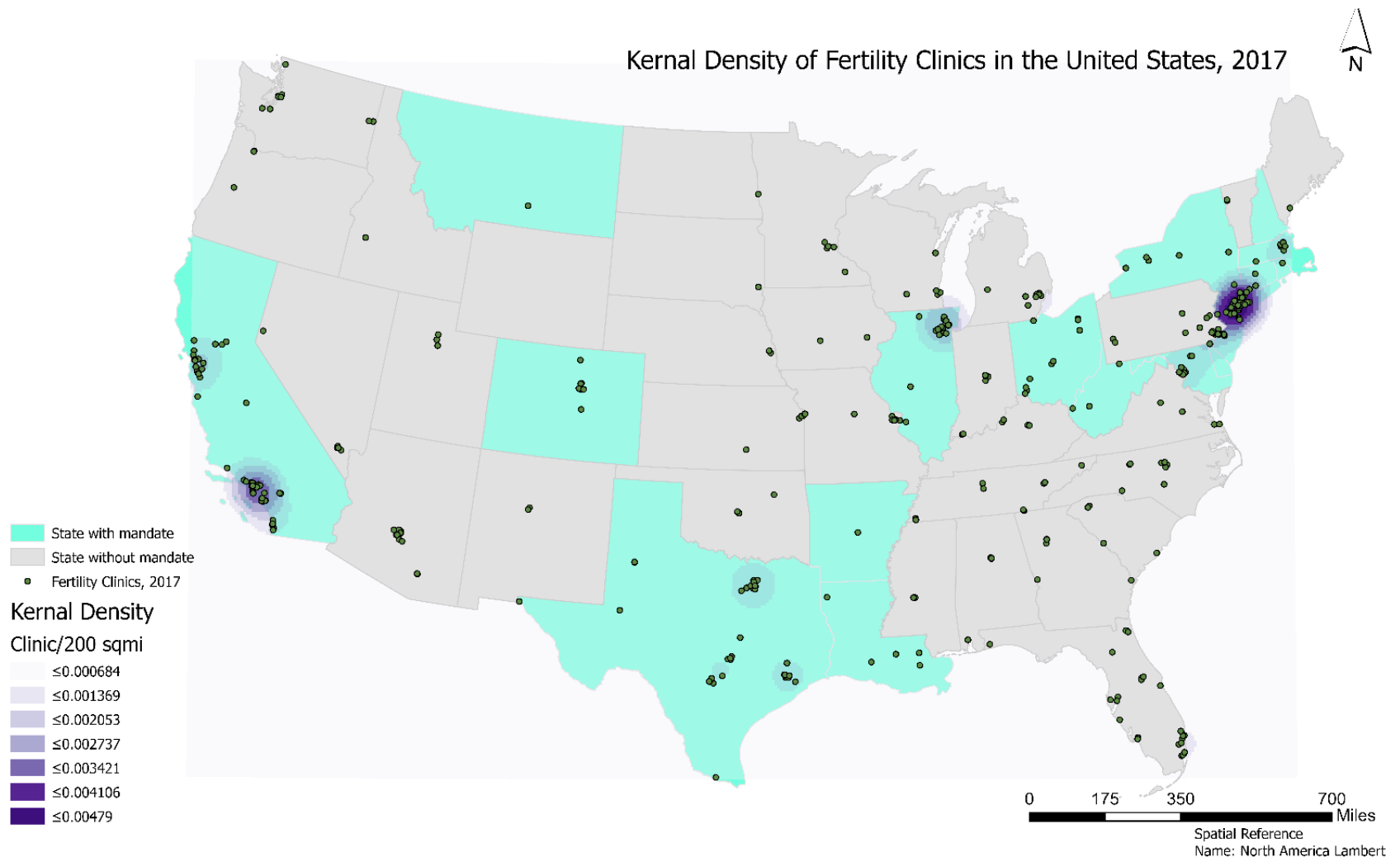


Figure 4.41. Kernel density of fertility clinics in the United States, 2017

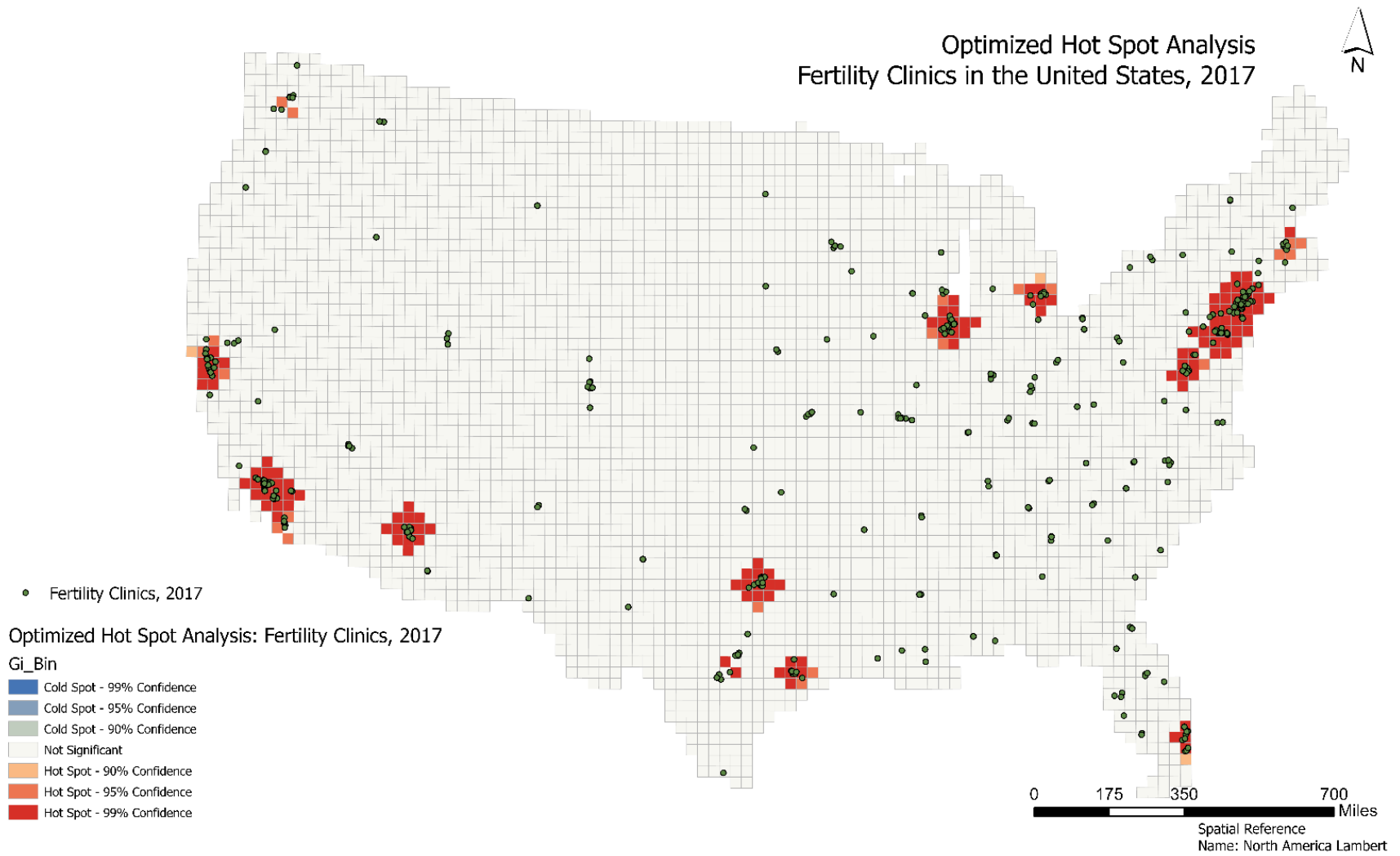


Figure 4.42. Optimized hot spot analysis: Fertility clinics in the United States, 2017

CHAPTER 5: DISCUSSION

Methodological Implications

Spatial Analysis of Fertility to Inform Spatial Analyses of Infertility

A component of this research was to observe spatial and demographic trends of fertility in the United States at the census-tract level. Results showed that the majority of women who had a birth between the years of 2013-2017 were Caucasian (68.3%), between the ages of 20-34 (74.6%), and live 200% or more above the poverty line (53.9%) (Table 3.5). A common trope in academic literature on the use of infertility services is that there is a disparity in access to those services based on the observation that there are a high number of people reportedly using these technologies who are aged <35 (Centers for Disease Control and Prevention [CDC], 2017a), Caucasian (Bitler & Schmidt, 2012; Bitler & Schmidt, 2006; Dieke et al., 2017; Kissil & Davey, 2012; Seifer et al., 2010), and have high incomes (Ho et al., 2017; Mehta et al., 2016; Seifer et al., 2010; The Ethics Committee of the ASRM, 2015). When comparing the demographics between people using infertility services and demographics of women with births overall, the two reflect similar demographic trends.

It would be interesting if the demographics of people using infertility services also followed spatial trends of fertility in the United States, especially knowing there are areas of the United States where women of certain ethnicities, such as African American, are reproducing significantly less in some areas than others (Figure 4.34). Do the spatio-demographic patterns of women who

gave birth through assisted reproduction follow similar spatial patterns as with all women with births?

This research utilized analytical methods to observe spatial trends of infertility, specifically observing these count data with a linear analyses using Poissonian and negative binomial distributions, and spatial autocorrelation that observes the Moran's I and Gary's c statistics along with directional distributions of the number of women with births based on a variety of Census derived demographics. However, there are some limitations in the applicability of the same methods for infertility related data. This research used census tract level data, which is the lowest scale available for Census based fertility data. Infertility related data may not be readily accessible at that same spatial scale and was not currently available from the Census. It is possible that the organizations providing these infertility statistics do not record them at such large scales, but it is possible to make census-tract level data available through processes of de-identification. Such processes require a research design with the appropriate statistical tests and software packages, which this research provided.

For spatial analyses, national-level observations may not be the most efficacious for infertility related data because of how low the use rates are compared to the whole population of women of reproductive age. This – could result in a zero-inflated model that cannot account for so much absence of observations. There are zero-inflated models for the Poissonian distribution that can account for a high frequency of “0” counts (Lambert, 1992; Ridout et al., 2001; Waguespack et al., 2020), so investigation of the data to determine the best model fit will be an important first step. This research does not utilize the zero-inflated model because it was important to observe the absence of women who gave a birth in the last 12 months.

Along the same lines of spatial analysis, it may be more efficacious to observe spatial trends related to infertility and use of infertility services within state or county boundaries. Results from spatial autocorrelation showed that each variable contained a p-value of $<.0001$ (Tables 34-39), indicating a rejection of the null hypothesis that there is zero spatial autocorrelation present in the values reflecting demographically categorized counts of women with births. By restricting the spatial analysis to individual states or counties, a more accurate observation of the spatial distribution of fertility of a state or county can be determined. This may be more informative for state-specific policy development related to infertility.

There is, however, a socio-cultural explanation to why such high spatial autocorrelation exists among this fertility data. This is because the data is related to an aspect of human reproduction. Would we really expect something like the spatial patterns of human fertility to be randomly distributed across our legally defined geographic boundaries? Sexual reproduction is not unique to humans, but humans made fertility into a politicized and socially structured practice (Basu, 1997). Human reproduction is also not as private or restricted to two individuals as it is often romanticized to be; in fact human reproduction is “the process in which society itself is created” (Robertson, 1991, pg 2). Knowing that data related to human fertility will likely be spatially autocorrelated due to socio-cultural factors that influence the proliferation of human society across space, future analyses should be interpreted with more attention to *where* or *in what direction* spatial autocorrelation exists. Statistically significant results should be explored further with visual and statistical methods that examine the direction of spatial autocorrelation.

Taken together, this research that showed the spatial distribution of census-tract level estimates of human fertility within a five-year span provided more than data related to the spread of human fertility. It also provides a frame of reference for future analyses related to census data

and a frame of reference for which to observe spatial distributions related to the use of infertility services.

Theoretical Implications

The Influence of Place and Policy on Access to Infertility Services

The theoretical implication of observing place and policy in relation to infertility services is that social constructionism can provide a paradigm in which to observe the complex, bi-directional influence of multi-level systems and individual decisions involved in facilitating access to infertility services. Referring to the Glass and McAtee model of risk regulators (Figure 2.2), both place and infertility instance mandates (policy) fit within some of the six types of risk regulators they identified. These are: 1) discriminatory practices, policies, and attitudes, due to the exclusionary language within the mandates referring to same sex couples, single individuals, and surrogacy, 2) conditions of work, because of the role of employers facilitating the types of health insurance plans employees have access to and the size of the company for whom someone works, and 3) laws, policies and regulations, due to the fact that the infertility insurance mandates do not cover the more costly procedures and medications. Due to the interrelated nature of place and policy in this context, both variables could be situated within these three domains.

The Glass and McAtee model of risk regulators (Figure 2.2) fits with the observation that place *and* policy are risk regulators in that people in both mandated and non-mandated states experienced denials accessing infertility services: Living in a state with an infertility insurance mandated did not mean you will have access to the coverage in that mandate, and if you do get coverage, you will likely still spend upwards of \$5,000 on out of pocket expenses. A person's residence, their employer's residence, and the state of the infertility insurance mandate are all

regulatory factors that mediate an individual's access to infertility services. However, an important prerequisite is that such a perspective requires qualitative inquiry into the individual situations when people attempt to access infertility services.

Qualitative accounts in this research proved to be invaluable sources of information that added more context on the extent that the exclusionary language within the infertility insurance mandates restricts access to infertility services. It is one thing to observe exclusionary language within health policy text, it is another to observe the extent that such exclusionary language prohibits people from accessing the health services they require. The facilitative factors increasing access to infertility services for some people are barriers to others, which would be difficult to untangle without qualitative inquiry that includes multiple perspectives of different people using the same types of services for different reasons and in different locations. By also including organizations who provide for those who fall through the cracks of insurance qualification, the researcher was able to see how personal struggle can lead to advocacy and creation of organizations that engage in a collective efficacy to change current policies. This is based on their own experience overcoming personal, social, and financial barriers accessing insurance coverage for infertility services.

The method of qualitatively inquiring into the effect of having residence in a state with an infertility insurance mandate, rather than inquiring into the language of the mandates themselves, proved to be an effective way to understand how someone can get disqualified from accessing mandated benefits even when living in a mandated state. There are documented exclusions included in the text of the mandates, such as the minimum number of employees, but in no mandate does it mention that it is the residence of the employer that dictates the applicability of the mandate before the documented disqualifications are even observed. Residence is important, but it is both

the patient's residence *and* the employer headquarter residence that are considered in the application of these mandates. This phenomenon was identified in both the informal interviews and the expert interviews. To that end, due to the nature of the state-based insurance mandates, both place and policy will continue to be intra-active risk regulators that mitigate the access of infertility services and will be differently experienced at the personal level.

Research on the construction of policy reveals the necessity of observing intra-level experiences and how they are constructed by macro-level structures, that also function and influence decisions based on their own historically contingent paradigms (Bernstein & Razon, 2019). A policy review by Keller & Sonfield (2019) theorized that individual needs regarding reproductive and sexual health cannot be ignored and must be considered within the larger healthcare economy in the United States. "Patients experience their own health needs as part of an integrated whole, and the health care system should address them as such" (pg 8). This research serves as a type of case study in how behavior specific to human reproduction that is in opposition to the form of reproduction constructed by human society to be *normal* (heterosexual intercourse) affects the nature of policies the state develops to protect the public. This research shows how damaging the assumption of normative behavior imbedded into reproductive health policy can be for those whose reality contradicts that reality.

Foucault theorizes on the relationship between sex and power, namely the act of repression on those who engage in sex through avenues the majority judge to be abnormal. This is where the social majority maintain a type of *biopower* through the legitimization, institutionalization, and reproduction of normative sexual acts to repress those whose identities do not conform along with the social majority (Foucault, 1984b). Institutionalization of normative behaviors become reinforced through the establishment of law. An example of this is the first iterations of the

infertility insurance mandates that exclude same sex couples and single individuals, as well as restrict access to infertility services by those using surrogates who will never fall under the definition of *infertile*. The institute of law and the institute of medicine (not the formal one, the all-encompassing ‘institute’ that is the practice of medicine), then, combine to create “requirements” that must be met in order for someone wanting to use alternative forms of human reproduction to receive health insurance coverage, This places the state directly in the way of reproductive autonomy.

The history of how sex is constructed in American society led to the construction of health policy that represses non-traditional family development (Carabine, 1992; Stabile, 2016). What is required are methods of “studying through” policy to understand its historic and political foundations that led to the creation of knowledge on which the policies are based (Bernstein & Razon, 2019, pg 76; Wright & Reinhold, 2011, pg 86). As stated by Wright & Reinhold (2011), methods of research must be attuned to this form of observation to conceptualize how the current form of policy will affect the future. It is important to observe through policy that one needs to have “an awareness of the wider historical and political context in which actors and events are framed, and analytical openness not only to the conditions that have produced the present but to what the present is producing” (pg 102). In this context are the lived experiences of people attempting to access insurance coverage for infertility services.

Practice-based Implications

Accessing Infertility Services: The Roles of the Employers and Clinicians

Both employers and clinicians play a role in the facilitation of insurance coverage for infertility services, and this research identified three distinct modes of influence, one for employers and two for clinicians which are 1) employers establish insurance packages for their employees and can therefore choose to include or not include infertility benefits; 2) the establishment of fertility clinics near places of employment were perceived as beneficial by patients; and 3) clinicians can choose medical billing codes that will increase the likelihood of having certain infertility services and medications covered by insurance.

Results from Mercer's 2018 National Survey of Employer-Sponsored Health Plans show that nearly 56% of U.S. based employers with at least 500+ employees do cover varying degrees of infertility services, but that only 26% of them cover the more advanced (and more expensive) procedures such as IVF (Ferreira, 2018). Employers establish insurance policies for their employees, so they can facilitate the degree of infertility insurance benefits. It was reported in the informal and expert interviews that a perceived reluctance to include infertility health insurance benefits is that it would be costly to the employer, who is often in the position to establish healthcare packages that the 'majority' of employees tend to use. One company that avoided this obstacle is Progyny, which offers infertility services through benefits packages that can be integrated into an existing insurance package as optional coverage. According to representatives from Progyny, their insurance benefits packages do not cost employers more than it would if an employee had an ACL surgery,

“...they pay their monthly premium and then they pay their financial responsibility in the same exact way they would if they were having ACL

surgery. They're paying deductible co-insurance and co-pay. But, there's no added fee for them to access Progyny" (Progyny, fertility benefits administrator)

Mercer's 2019 National Survey of Employer-Sponsored Health Plans found that health benefit packages will reach nearly \$13,000 per employee starting in 2019, which is a 3% increase from the previous year (Lee, 2019). Their data did not distinguish between those with or without infertility services benefits, but it shows that the healthcare cost to employers will continue to increase regardless of the addition of infertility services. However, their survey also found that, of the 2,000+ employers surveyed that have 500+ employees, making healthcare more affordable for low-wage employees was an important to very important strategy for them (based on a Likert-type scale) (Carsen, 2019). It seems that employers are aware of the high cost of healthcare, and many seem to be willing to invest in methods to manage those costs to facilitate affordable healthcare for employees. However, such goals may be more specific to employers with 500+ employees.

The organization RESOLVE lists resources for people to review before approaching their employer about the need to include infertility services in their health insurance plan. This also includes facts for employers who are considering including those benefits (RESOLVE: The National Infertility Association, 2020a). Although this information was not discussed in the interviews, advocacy organizations already seem to know the role that employers play in facilitating access to these services and are active in political advocacy for more inclusive mandates. Those organizations are also active in empowering individuals to initiate change within their own organization – again bringing back the idea of collective efficacy between people using infertility services and organizations that exist to facilitate increased financial accessibility to infertility services.

Besides the regulatory nature of patient residence and employer residence, another aspect of place is the location of fertility clinics. Distances to fertility clinics were not described as prohibitive, although some people reported traveling over three hours one way to get to their fertility clinic. People had desires to go to a high-quality clinic that was also close to either their home or place of work, however they were often restricted to choosing in-network clinics that were not always their preferred choice. Even in instances where clinics were close by, some people chose international travel due to the high cost of infertility services. An analysis of distance related to the use of fertility clinics might be better suited to be specific to a clinic network.

A notable facilitating factor discussed in the informal interviews that the business of infertility would find informative was the location of fertility clinics. It was reported that the ability to go to a clinic that was close to their employer – rather than residence – was perceived as beneficial. Employer proximity to fertility clinics was facilitative in that appointments are often early in the morning and scheduled at short notice. Also, depending on the type of service, missing an appointment can result in poor outcomes of the services provided. The ability to leave work and make it to a clinic in a short time was perceived as beneficial. Responses from interviewees are included here as examples because they did not exactly fit with the seven research questions.

“They [clinic] do their monitoring appointments as early as 6:30 in the morning and my husband and I both have jobs where our schedules are not always our own. So, knowing that we were going to have to do a lot of blood draws, a lot of ultrasounds, and a lot of procedures unexpectedly, this is the only one that could really accommodate two professional people’s work schedules” (Interview 060, Female, Caucasian, Nevada)

“So, it made sense to actually leave my state and search for a provider in New York State just because I’m there many hours a week... It’s just they’re just so many options in New York City versus in New Jersey that it just

made sense to find a place that was relatively convenient within the City versus having to drive somewhere kind of out of my way in New Jersey” (Interview 054, Female, Caucasian, **New Jersey**)

“I live in the Washington D.C. metro area. So, we own a home in Maryland, about a mile away of the D.C. border. So, we aren’t like Oregon Trailing it or anything. We go into D.C. every day for work, and that is also where our doctor is” (Interview 056, Female, Caucasian, **Maryland**)

“It [clinic] was right around the corner from my office, which is really helpful for being able to pop out for appointments. Sometimes they’re not always known in advance. It was really helpful that I was able to take an early lunch or something like that. I don’t know how people do it when they have to travel far and get up at 2:00 in the morning just to get out of state” (Interview 063, Female, Caucasian, **Texas**)

“I’m in the process of possibly switching clinics. That one is a little farther from my house. It’s about half an hour. But, it’s on my way to work. So, it’s not really that big of a deal” (Interview 065, Female, Caucasian, **Illinois**)

For those providing the infertility services, building clinics near places of business can increase access. For employers, it is worth listening to employees to determine their needs and perhaps change the approach to healthcare services so they are inclusive.

Limitations

This research observed lived experiences of people’s to access of infertility services, however the sample size of 66 may not completely capture the reality of how people’s accessibility to infertility services are affected by living in states with and without an infertility insurance mandates. Although both domestic and international travel are not widely reported in this research,

there were some mentions during informal interviews that extensive travel is part of the reality of many people who access infertility services. This research does, however, suggest that the decision to travel to access these services is affected by the high costs of these services, where it is still cheaper to travel internationally than to use infertility services in the United States. It would be worthwhile to obtain a greater perspective of how place acts as a regulatory factor that influences people to travel long distances or change residences to access infertility services.

Although the expert interviews represented at least four different kinds of organizations offering financial options, insurance benefits, or advocacy specifically for infertility services, inclusion of more industry perspectives would give greater context to the role of these companies. Also, and more importantly, perspectives on what other solutions might exist other than creating more state-based infertility insurance mandates would be helpful. A perspective that should also be captured are those of employers. For example, why do employers include these services? Were they influenced by their state's infertility insurance mandate, and if so, do they tend to exceed benefits or only offer the minimum? Interestingly, the majority the interviewees (Table 4.1) and survey respondents (Table 4.3) worked in healthcare, but many still did not have access to insurance coverage for infertility services.

Regarding the spatial analyses, the data did not reflect current 2020 estimations of fertility and excludes three states that now have infertility insurance mandates. It would be interesting to see what the addition of Colorado, Delaware and New Hampshire would have on the comparisons of fertility between mandated and non-mandated states. However, due to their small populations sizes the effect may be minimal. Between the years of 2019-2020, some mandates have been updated since their inception, including California (2019), Illinois (2019), Maryland (2020), New Jersey (2019), New York (2020), and Utah (2020) (RESOLVE: The National Infertility

Association, 2020b). Therefore, qualitative accounts of people using these new or updated mandates could show how much more facilitative these mandates are at the individual level.

Conclusion

Adding the missing context to the access of infertility services: It's not just about policy

The problem statement on which this research is based is that accessibility of infertility services is disproportionately experienced in the United States. In order to better understand why such a disparity exists, the purpose of this study was to add context to the use of infertility services in the United States by exploring the role of environmental context, or “place”, focusing on: 1) the applicability of state-based infertility insurance mandates through the perspectives of people using those services and organizations providing types of financial assistance for infertility services, 2) spatial analysis of CDC reporting fertility clinics in the United States, and 3) spatial analyses of census-tract level fertility counts in the United States to give context to future spatial analyses of the use of infertility services.

Based on the analyses from the qualitative interviews, survey, and spatial analyses of fertility clinics, more attention should be paid to the roles of employers and insurance agencies in making decisions for what is and is not *medically necessary*. Even in situations where policies exist and can be applicable to someone's situation, the same issues persist. These services are very expensive, health insurance rarely applies, and limit accessibility to people who do not have the income to pay for those services. The survey from this research revealed that 47% of people who accessed infertility services in a state with an infertility insurance mandate were disqualified from accessing that mandate for one reason or another. The interview responses filled the contextual

gap of *why* people were disqualified, including reasons related to employer headquarters being located in states without an infertility mandate, the language in the mandates restricted them from access based on sexual orientation, use of surrogacy, the employer had less than 500 employees, or the “coverage” was not enough to sustain them throughout all the required procedures.

Although one could argue that the majority of respondent was able to access infertility services, only 20.41% of people living in a mandated state reported having all infertility services covered by health insurance (Table 4.23). Even when living in a state with an infertility insurance mandate, out of pocket expenses had to be utilized in order to continue using high-tech options such as IVF when the covered IUI procedures did not result in a pregnancy or when the maximum amount of IUIs were exhausted. Those who had their procedures or medications somewhat covered by health insurance still sacrificed money saved to achieve other adulthood milestones, such as purchasing a house. These results suggest that the infertility insurance mandates still maintain language that do not allow the mandates to be as effective as they are assumed to be.

Health policy is not static, it is “deeply historically contingent as well as continuously ‘in the works’” (Bernstein & Razon, 2019, pg 76). Considering this, social constructionism and the Glass and McAtee model of risk regulators are uniquely suited to observe the multi-level influence that exists when someone seeks infertility services. Barriers mentioned in both informal and expert interviews included the exclusionary language embedded within the statutes. As such, there are prominent roles that both employers and insurance companies hold in facilitating the efficacy of the existing infertility insurance mandates. In fact, in collaboration with their preferred insurance provider, employers can create infertility benefit packages that exceed the minimum requirements within a mandated state.

At the same time, these insurance mandates tend to be interpreted to the benefit of the insurance agency at the expense of the individual. However, employers can make decisions that make these mandates irrelevant by offering infertility services as a de facto benefit. What is more, they can develop benefits that supersede the mandated benefits of the respective state, or they can choose to integrate infertility benefits into existing insurance plans through partnering with companies such as Progyny. The quote from the IntegraMed representative rings optimistic in that as advocacy continues and as preferences for the timing and makeup of family development continues to shift, we will see insurance policies start to change and hopefully be more inclusive.

“Years ago, not all oncology services were covered. A number of years, most bariatric coverages were not covered. Most of the time they are now. I think most employers are going to begin covering fertility treatment”
(IntegraMed, MSA crisis management company)

Academic researchers must be cognizant of the roles that physicians, insurance companies, politicians, and employers play in applying the infertility insurance mandates that exist if we are to conceptualize how to reinvent access to infertility services in law, practice, and ideology. The year is 2020. When one hears 2020, one easily thinks of having good vision, to be able to see things clearly. Many things have been made clear this year. Two of the most prominent areas are that racism is very much prominent and widespread, and that political bias can easily supersede decades of scientific research. It is the hope of this researcher that the new social and spatial contexts about the use of infertility services and distribution of fertility across the United States, will make clear the connection between the intra-active nature of politics and human reproduction so we can construct a society where our laws allow for reproductive autonomy.

The intent of this research is to expand the discourse on state-based infertility insurance mandates in the United States beyond focusing on financial models that observe expenditure on

infertility services, or the emotional toll seeking infertility services has on the individual. This research warrants expansion of the discourse to perceive these infertility insurance mandates as dynamic, implemented, and interpreted by different institutions and levels of human organization. This research is also a call to action for employers and clinicians to disseminate the knowledge and application of existing infertility insurance mandates and other options available to them to increase financial accessibility to reproductive health services. Greater attention should be paid to the types of policies employers make available, and the ways clinicians code certain procedures related to infertility services. One could argue a more effective way to increase accessibility is through a paradigm shift in the healthcare and insurance industries to perceive this type of medical intervention as medically necessary, but such a shift takes time. We must allow our policies to adapt to changes in parenting behavior in the United States and refrain from structuring them based on narrow ideals of what is considered medically necessary. To those institutions influencing the construction of health policy, perhaps a phrase from William Shakespeare's *Hamlet* is most appropriate:

“There are more things in heaven and earth [Horatio] than are dreamt of in your philosophy” *Hamlet* (Shakespear, 1806)

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APPENDICES

Appendix A. Alignment Matrix

<p>Problem Statement: Accessibility of infertility services is disproportionately experienced in the United States.</p>		
<p>Purpose Statement: The purpose of this study is to add context to the use of infertility services in the United States by exploring the role of environment as a risk regulator in accessing those services. For the purpose of this study, environment refers to any influence outside of an individual’s own behavior, but that may affect an individual’s behavior. This study uses both qualitative and quantitative methods in order to fill the contextual gaps present in the current literature on the use of infertility services. Qualitative inquiry observes “environment” as a factor in reciprocal interplay between person, behavior, and environment. Quantitative inquiry observes “environment” in terms of spatial location of variables related to human fertility and location of infertility clinics reporting data to the CDC. The overarching “environmental” factor observed in this research are the state-based infertility insurance mandates because they are meant to increase accessibility to infertility services, but there are not data to substantially support this proposition. From here on, anything related to “environment” or “environmental influence” will be referred to as “place”.</p>		
Research Questions	Data Collection Instrument/Method	Item on that Instrument/Data Source(s) used to answer the Research Question
<p>R1: Why do people access infertility services in the United States?</p>	<p>One-on-one interviews Survey instrument</p>	<p>Interview Questions:</p> <ul style="list-style-type: none"> - What prompted you to decide to use an ART? (probe: infertility m/f/b?, same-sex couple?, issue with conception in general?) <p>Survey Instrument:</p> <ul style="list-style-type: none"> - Demographics Block - Infertility Self-Efficacy Scale
<p>R2: What influence does geographic location have on access to infertility services?</p>	<p>One-on-one interviews Survey instrument</p>	<p>Interview Questions:</p> <ul style="list-style-type: none"> - Where do you access infertility services? - How much travel do you do when seeking infertility services? (probe: do you have to go out of state, do you have to go to a different city, are the clinics close to you) <p>Survey Instrument:</p> <ul style="list-style-type: none"> - Residence Block - Insurance Coverage Block - Travel for Services Block - Infertility Self-Efficacy Scale

<p>R3: What influence does living in a state with mandated insurance have on access to infertility services?</p>	<p>One-on-one interviews Survey instrument</p>	<p>Interview Questions:</p> <ul style="list-style-type: none"> - How do you [How do you intend to] pay for infertility services? (probe: what types of insurance have you been able to use? Whose insurance were you able to use?) - Do you know if your state has infertility insurance mandates? If yes, have you benefited from them? - What influence have the existing infertility insurance mandates in your state had on increasing your access to those services? - What types of legal issues, if any, have you run into regarding access to fertility services? (probe: What types of interactions have you had with your employer/HR department in applying your insurance to infertility services?) <p>Survey instrument:</p> <ul style="list-style-type: none"> - Insurance Block
<p>R4: What are the roles of specialized infertility specific insurance or other financial aid organizations in increasing access to infertility services in the United States?</p>		<p>Expert interview questions:</p> <ul style="list-style-type: none"> - How is this type of insurance applied to patients? (probe: is there an employee number minimum?) - How does this type of insurance operate in states without an infertility insurance mandate? (probe: is it more difficult to apply than states that do have an infertility insurance mandate?) - What effect does prior insurance have on access to the services you provide?

<p>R5: What is the spatial relationship between fertility of women between the years of 2013-2017 based on age, education, ethnicity, nativity, and income?</p>	<p>American Community Survey, 2013-2017 5 year</p>	<p>Fertility of women age 15-50 by State, Census Tract</p>
<p>R6: What is the spatial relationship between fertility of women between the years of 2013-2017 and states with or without infertility insurance mandates?</p>	<p>American Community Survey 2013-2017 5 year</p>	<p>Fertility of women age 15-50 by State, Census Tract + type of infertility insurance mandate, present/absent</p>
<p>R7: What is the spatial relationship between fertility of women age 15-50 and the spatial distribution of SART reporting clinics between the years of 2013-2017?</p>	<p>American Community Survey 2013-2017 5-year, public access SART clinic reports, 2013-2017</p>	<p>Fertility of women age 15-50 by State, Census Tract + geolocated SART reporting clinics</p>

Appendix B. Online Survey Instrument

Access to Infertility Services in the United States

Start of Block: Demographics

Q1.1

Thank you for participating in this research about insurance for infertility services. The information you provide will be used to inform our state legislatures about what works and does not work in terms of finding ways to pay for infertility services in the United States. At the end of the survey is an option to provide some more detail about your experience seeking or using infertility services, should your experience not be accurately reflected in the survey response options. All responses to the survey and the interview are anonymous.

Q1.2 Infertility services include medical procedures and medications used to assist in human reproduction. They can include high-tech options, such as (but not limited to) in vitro fertilization (IVF) and intracytoplasmic sperm injection (ICSI), third-party options such as surrogacy, gestational carriers, and egg/sperm/embryo donation, or medications such as (but not limited to) Clomid, Bravelle, Femara, and Dostinex.

Please select the description most applicable to you in accessing infertility services:

- I [We] have not yet used infertility services, but I am [we are] are looking into it (1)
- I [We] have only seen a physician to talk about using infertility services, but have not used any type of assisted reproductive technology (ART) or medications (2)
- I am [We are] currently using infertility services (3)
- I [We] used infertility services and am [are] currently pregnant (6)
- I [We] used infertility services and had a successful pregnancy (live birth) (4)
- I [We] used infertility services but did not have a successful pregnancy and are looking for other options (eg. adoption) (5)

Skip To: Q1.4 If Q1.2 = I [We] used infertility services and had a successful pregnancy (live birth)

Skip To: Q1.4 If Q1.2 = I [We] used infertility services but did not have a successful pregnancy and are looking for other options (eg. adoption)

Skip To: Q1.4 If Q1.2 = I [We] used infertility services and am [are] currently pregnant

Q1.3 What is the reason you are seeking infertility services?

- Male factor infertility (1)
- Female factor infertility (2)
- Dual (male and female) infertility (3)

- Same-sex couple (4)
- Single individual (5)
- Cancer-related infertility (male) (6)
- Cancer-related infertility (female) (7)
- Unexplained infertility (8)
- Advanced age (9)

Skip To: Q1.5 If Q1.3 = Male factor infertility

Skip To: Q1.5 If Q1.3 = Female factor infertility

Skip To: Q1.5 If Q1.3 = Dual (male and female) infertility

Skip To: Q1.5 If Q1.3 = Same-sex couple

Skip To: Q1.5 If Q1.3 = Single individual

Skip To: Q1.5 If Q1.3 = Cancer-related infertility (male)

Skip To: Q1.5 If Q1.3 = Cancer-related infertility (female)

Q1.4 What was the reason you sought infertility services?

- Male factor infertility (1)
- Female factor infertility (2)
- Dual (male and female) infertility (3)
- Same-sex couple (4)
- Single individual (5)
- Cancer-related infertility (male) (6)
- Cancer related infertility (female) (7)
- Unexplained infertility (11)
- Advanced age (9)

Q1.5 What is your current gender identity?

- Male (1)

- Female (2)
- Transgender (male at birth to female) (3)
- Transgender (female at birth to male) (4)
- Intersex (6)
- Other not listed (5) _____

Q1.6 Please select your age range

- 18-19 (1)
- 20-25 (2)
- 26-30 (3)
- 31-35 (4)
- 36-40 (5)
- 41-45 (6)
- 46-50 (7)
- 51-55 (8)
- 56-60 (9)
- +60 (10)

Q1.7 What is your marital status?

- Single (1)
- In a relationship, not living together (2)
- In a relationship, living together (3)
- Married (4)
- Divorced (5)
- Widowed (6)

Q1.8 Are you Hispanic or Latino/a?

- Yes (1)
- No (4)

Q1.9 Please select the ethnicity you identify with:

- African-American (1)
- Hispanic/Latino(a) (2)
- Native American, Pacific Islander (3)
- Asian (4)
- Middle Eastern (5)
- Caucasian (6)
- More than one ethnicity (7)
- Other not listed (8) _____

Q1.10 What is your highest level of schooling completed?

- Some High School (1)
- High school (diploma or GED) (2)
- Bachelor's degree (3)
- Associate/Technical degree (4)
- Master's degree (5)
- Doctorate (PhD, SciD, DrPH, EdD, DDiv, ect) (6)
- Professional (Medicine, Vet, Dentistry, Pharmacy, Physical Therapy) (7)

Q1.11 Are you currently parenting?

- Yes (1)
- No (2)

Skip To: Q1.14 If Q1.11 = No

Q1.12 How many children do you have?

- 1 (2)
- 2 (3)
- 3 (4)
- 4+ (5)

Q1.12.1 Are your children adopted?

- Yes (1)
- No (3)
- Some (5)
- Other answer (4) _____

Skip To: Q1.14 If Q1.12.1 = Yes

Skip To: Q1.13 If Q1.12.1 = No

Skip To: Q1.14 If Q1.12.1 = Other answer

Skip To: Q1.13 If Q1.12.1 = Some

Q1.13 How many of your children were conceived using an assisted reproductive technology?

- 0 (6)
- 1 (2)
- 2 (3)
- 3 (4)
- 4+ (5)

Q1.14 What sexual orientation do you identify with?

- Heterosexual (1)
- Homosexual (2)
- Bisexual (3)
- Asexual (4)
- Other not listed (5) _____

Q1.15 What is your religious identity?

- None (1)
- Christian (2)
- Muslim (3)
- Buddhist (4)
- Catholic (5)

- Jewish (6)
- Other not listed (7) _____

Q1.16 What is your level of employment?

- Full-time (1)
- Part-time (2)
- Multiple part-time jobs (3)
- Self-employed (4)
- Unemployed (5)
- Unemployed, but partner is working (6)
- Retired (7)
- Other not listed (8) _____

Skip To: Q1.18 If Q1.16 = Retired

Skip To: Q1.18 If Q1.16 = Unemployed

Skip To: Q1.18 If Q1.16 = Unemployed, but partner is working

Q1.17 What is the industry in which you work?

- Hospital, Healthcare, or Social Assistance (1)
- College, University, or Adult education (2)
- Primary/Secondary (K-12) education (3)
- Retail or Wholesale (4)
- Hotel and Food Service (5)
- Government (local, state, or federal) (6)
- Arts, Entertainment, or Recreation (7)
- Information Technology (IT) (8)
- Military (9)
- Law Enforcement (10)
- Legal Services (11)
- Religious (12)

- Non-profit (13)
- Homemaker (14)
- Other not listed: (15) _____

Q1.18 What is your estimated annual household income?

- Below \$50,000 (1)
- \$51,000 - \$65,999 (6)
- \$66,000 - \$75,999 (2)
- \$76,000 - \$85,999 (3)
- \$86,000 - \$99,999 (4)
- Above \$100,000 (7)

End of Block: Demographics

Start of Block: Health Education

Q2.1 I received information about risks of fertility decreasing with age during health education courses in: (check all that apply)

- Elementary school (1)
- Middle school (2)
- High school (3)
- College/University (4)
- I did not receive this type of information at any level of schooling (5)
- I do not remember (6)

Q2.2 In your opinion, what is the earliest grade at which to learn about the risks of infertility?

- 1st - 3rd grade (1)
- 4th - 7th grade (2)
- High School (3)
- College (4)

None (5)

End of Block: Health Education

Start of Block: Insurance Coverage

Q3.1 Does your state of residence have mandated insurance coverage for infertility services?

- Yes (1)
- No (2)
- I am not sure (3)

Skip To: Q3.3 If Q3.1 = No

Skip To: Q3.3 If Q3.1 = I am not sure

Q3.2 Were you able to apply the infertility insurance mandate to cover your expenses?

- Yes, everything was covered (2)
- Yes, but not everything was covered (5)
- No (3)

Q3.3 What is your current health insurance status?

- Currently covered by private health insurance individually or through your employer, **without** MediGap. Medigap is extra health insurance that you buy from a private company to pay health care costs not covered by Original Medicare, such as co-payments, deductibles, and health care if you travel outside the U.S. (1)
- Currently covered by private health insurance individually or through your employer, **including** MediGap. (2)
- Currently covered through the Affordable Care Act (aka. ObamaCare) (3)
- Currently covered by Medicaid or state sponsored health insurance plan. Medicaid is health insurance program that is jointly funded by the federal and state governments. Medicaid provides health insurance to millions of low-income individuals and families, pregnant women, people with certain disabilities, as well as other qualified individuals (4)
- Currently covered by Medicare. Medicare is the federally-funded health insurance program for adults over age 65, qualifying, disabled younger people, and people who have been diagnosed with End-Stage Renal Disease (ESRD) also called End-Stage Kidney Disease (5)

- Currently covered by Tricare or through Veterans Affairs (6)
- Currently covered by a single service plan. (SSP) Single Service Plans are health insurance coverage paid for by an individual or an employer that provides for only one type of service (7)
- Not covered by any health insurance (8)
- Other not listed: (9) _____

Q62 Do you have a different health insurance situation that cannot be captured in the aforementioned health insurance types?

Q3.4 Do you have private health insurance to cover any costs for medical help to become pregnant?

- Yes (1)
- No (2)
- Not Sure (3)
- No, but my partner's insurance does (4)

Q3.5 Does your employer's insurance include coverage for infertility services?

- Yes (1)
- No (3)
- Not Sure (2)
- No, but my partner's insurance does (4)

Q3.6 Do you have health insurance that specifically covers infertility services?

- Yes (1)
- No (2)

Skip To: Q3.7 If Q3.6 = Yes

Skip To: Q3.8 If Q3.6 = No

Q3.7 What is the health insurance provider (name of the organization) that specifically covers your infertility services?

Q3.8 Have you heard of grants or scholarships that provide financial assistance for infertility services?

- Yes (1)
- No (4)

Skip To: End of Block If Q3.8 = No

Q3.9 Have you applied for a grant or scholarship to assist with paying for infertility services?

- Applied for and received a grant (1)
- Applied for and received a scholarship (2)
- Applied for but did not receive a grant (3)
- Applied for but did not receive a scholarship (4)
- Did not apply for a grant or scholarship (5)

End of Block: Insurance Coverage

Start of Block: Residence

Q4.1 What is your current state or U.S. Territory of residence

▼ Alabama (1) ... I do not reside in the United States (53)

Q4.2 Is your current state of residence the same state where you accessed infertility services?

- Yes (12)
- No (13)

Skip To: End of Block If Q4.2 = Yes

Skip To: Q4.3 If Q4.2 = No

Q4.3 What was your state of U.S. Territory of residence when you accessed infertility services?

▼ Alabama (1) ... I do not reside in the United States (53)

End of Block: Residence

Start of Block: Travel for Services

Q5.1 Which of the statements below most applies to you, regarding inter-state travel for infertility services?

- I moved out of state to access infertility services (1)
- I intend to move out of state to access infertility services (2)
- I am considering moving out of state to access infertility services (3)
- I have not and do not intend to move out of state to access infertility services (4)

- I traveled out of state to access infertility services (did not change residence) (6)

Q5.2 Which of the statements below most applies to you, regarding inter-state travel for higher quality infertility services?

- I moved out of state to access a better physician or fertility clinic (1)
- I intend to move out of state to access a better physician or fertility clinic (2)
- I am considering moving out of state to access a better physician or fertility clinic (3)
- I have not and do not intend to move out of state to access a better physician or fertility clinic (4)
- I traveled out of state to access higher quality infertility services (did not change residence) (6)

Q5.3 Which of these statements below most applies to you, regarding international travel for infertility services?

- I traveled internationally to access infertility services (1)
- I intend to travel internationally to access infertility services (2)
- I am considering traveling internationally to access infertility services (3)
- I have not and do not intend to travel internationally to access infertility services (4)

Skip To: Q5.5 If Q5.3 = I am considering traveling internationally to access infertility services

Skip To: Q5.5 If Q5.3 = I intend to travel internationally to access infertility services

Skip To: Q5.4 If Q5.3 = I traveled internationally to access infertility services

Skip To: End of Block If Q5.3 = I have not and do not intend to travel internationally to access infertility services

Q5.4 What was the reason you traveled internationally to access infertility services? (choose all that apply)

- Lower cost of services (1)
- Better physician (2)
- Heard from others that they had good experiences (3)
- Was a previous country of residence (4)
- Other reason not listed (5)

Skip To: Q5.6 If Q5.4 = Lower cost of services

Skip To: Q5.6 If Q5.4 = Better physician

Skip To: Q5.6 If Q5.4 = Heard from others that they had good experiences

Skip To: Q5.6 If Q5.4 = Other reason not listed

Q5.5 What is the reason you intend, or are considering, to travel internationally to access infertility services? (choose all that apply)

- Lower cost of services (1)
- Better physician (2)
- Heard from others that they had good experiences (3)
- Is a previous country of residence (4)
- Other reason not listed (5)
-

Skip To: Q5.7 If Q5.5 = Lower cost of services

Skip To: Q5.7 If Q5.5 = Better physician

Skip To: Q5.7 If Q5.5 = Heard from others that they had good experiences

Skip To: Q5.7 If Q5.5 = Other reason not listed

Q5.6 What is the country you traveled to for accessing infertility services?

Q5.7 What is the country you intend to travel to for accessing infertility services?

End of Block: Travel for Services

Start of Block: Online Communities

Q6.1 Please select your level of agreement or disagreement with the following statement: I use online ART/infertility support forums to help me make decisions about what infertility services to use.

- Strongly Agree (1)
- Agree (2)
- Neither agree nor disagree (3)
- Disagree (4)
- Strongly disagree (5)

Q6.2 Please select your level of agreement or disagreement with the following statement: I talk about my experience with using infertility services more online than I do with people in person.

- Strongly Agree (1)
- Agree (2)
- Neither agree nor disagree (3)
- Disagree (4)
- Strongly disagree (5)

Q6.3 Please select your level of agreement or disagreement with the following statement: I prefer to access online support forums for ART/infertility before talking to a physician.

- Strongly Agree (1)
- Agree (2)
- Neither agree nor disagree (3)
- Disagree (4)
- Strongly disagree (5)

End of Block: Online Communities

Start of Block: Infertility Self-Efficacy Scale

Q7.1 Please answer the following statements as they relate to how you feel about your personal experience with using infertility services by rating them from "Not at all confident" to "Very confident":

I feel confident that I can...

	Not at all confident (1)	(2)	(3)	(4)	Neutral (5)	(6)	(7)	(8)	Extremely Confident (9)
Ignore or push away unpleasant thoughts that can upset me during medical procedures (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keep a sense of humor (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Make meaning out of my infertility experience (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Handle mood swings caused by hormonal treatments (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Keep from getting discouraged when nothing I do seems to make a difference (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accept that my best efforts may not change my/our infertility (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Control negative feelings about infertility (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cope with pregnant friends and family members (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Handle personal feelings of anger or hostility (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keep a positive attitude (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lessen feelings of self-blame, shame, or defectiveness (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stay relaxed while waiting for appointments or test results (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do something to make myself feel better if I am sad or discouraged (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Keep active with my usual life routine (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feel good about my body and myself (15)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feel like a sexual individual (16)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Infertility Self-Efficacy Scale

Start of Block: Interview Request

Q8.1 Where did you hear about this research?

- Family Equality Council (1)
- RESOLVE: Infertility Support Community (Inspire) (2)
- Friend (4)
- Physician (5)
- Craigslist (7)

Reddit (8)

Other not listed (3) _____

Q8.2 Are you interested in participating in an interview to talk about your experience in accessing infertility services?

Yes (1)

No (2)

Skip To: Q8.3 If Q8.2 = Yes

Q8.3 Fantastic! What is your preferred e-mail?

Preferred e-mail: (1) _____

Q63 Do you have any other information about your situation with health insurance and paying for infertility services you would like to explain?

End of Block: Interview Request

Appendix C. Informal Interview guide

Reason for using infertility services

1. What prompted you to decide to use an ART?
 - a. Probe: infertility male/female/both?, same-sex couple?, issue with conception in general?

Questions about traveling to access infertility services

2. Where do you access infertility services?
 - a. Probe: How much travel do you do when seeking infertility services?
 - b. Probe: Do you have to go out of state, do you have to go to a different city, are the clinics close to you?
3. What has been the biggest barrier to accessing the infertility services you need?

Questions about paying for infertility services and insurance

4. How do you [How do you intend to] pay for infertility services?
 - a. Probe: What types of insurance have you been able to use?
 - i. Whose insurance were you able to use?
5. Do you know if your state has infertility insurance mandates? If yes, have you benefited from them?
6. What influence have the existing infertility insurance mandates in your state had on increasing your access to those services?
7. What types of legal issues, if any, have you run into regarding access to fertility services?
 - a. Probe: What types of interactions have you had with your employer/HR department in applying your insurance to infertility services?

Appendix D. Informal Interview Codebook

Table A1. Code book for informal interviews

Code	Abbreviation	What it is	What it is not
Social Cognitive Theory (SCT)-based codes			
Environmental	Env	Factors influencing access to/continued use of infertility services outside of the person's actions, but that may affect the person's actions; can refer to legal or medical systems	Does not refer to the person's own behaviors related to accessing infertility services
Self-Efficacy	SelfE	The person's belief they will be able to overcome obstacles accessing/continuing to use infertility services; belief that continuing to use infertility services will result in the desired outcome; can refer to tenacity	Does not refer to one's belief in ability to access things not related to infertility services; does not refer to actual actions (code as self-control if related to a behavior)
Behavioral Capability Levels and use of knowledge	BeCap	Facilitation. The person's knowledge and ability to access/continue to use infertility services; can relate to financial capability – knowing how to navigate finances, knowing how to navigate insurance; can relate to changing, or ability to change, residence, employer, or seeking other resources to use infertility services	Does not refer to capability of using things unrelated to infertility services
Expectations	Expec	Anticipation of the outcomes of continuing to use or attempting to access infertility services; can be related to retrospective thinking about expectations Indicate if there is an outcome to the expectation (Code: Outcome)	Does not refer to expectations unrelated to using infertility services
Observational Learning	ObsL	Using advice or mimicking actions of another person/couple regarding their use of infertility services or methods of seeking infertility	Does not refer to clinic recommendations from primary physicians

Table A1 (Continued)

		services; can be related to places to move or travel to access infertility services	
Barrier	Bar	Aspects of the person's reality that inhibit the ability to access/continue to use infertility services; can be physical (place-based), emotional, mental, financial	Does not refer barriers unrelated to infertility services
Something that acted as a barrier of any type to access infertility services			
Facilitator	Facil	Aspects of the person's reality that facilitate access or increased access to infertility services;	Does not refer facilitators unrelated to infertility services
Something that increased any type of access to infertility services			

Survey based codes

Code	Code Abbr.	What it is	What it is not
Insurance	Ins	Anything related to the person's health insurance being applied or denied to infertility services; can be positive or negative outcome	Does not related to things that are only about finances. Must be specific to health insurance
Finances	Fin	Anything related to a person or couple's finances used to pay for infertility services; can be related to savings, credit cards, help from other family, or plans for financial planning	Does not related to things about health insurance, only out of pocket costs
Travel	Trvl	Travel specifically related to accessing infertility services; can be mentions of time or distance traveled to access infertility services, can be mentions of international travel; can be mentions of plans to <i>not</i> travel for infertility services or <i>not having to</i> travel very much	Does not refer to travel not associated with accessing infertility services. Does not refer to employer-related travel
Employer	Emp	Aspects about the person's employer that affect the person's ability to access health insurance for infertility services; can refer to aspects of residence and location of employer headquarters; be can be related to spouse's employer	Does not refer to things unrelated to the person's employer

Table A1 (Continued)

Health Education	HealthEd	Any mention of health education specific to infertility, sex education, or wishes to have heard about infertility at an earlier age	Does not refer to education outside of health education specific to human sexual reproduction and infertility
Legal	Legal	Instances where someone had to seek legal intervention in order to gain access to infertility services; includes legal services related to third-party reproduction	Does not refer to thinking about seeking legal services for infertility services, does not include using legal services for anything other than being able to access services related to infertility services
Emergent codes			
Code	Abbreviation	What it is	What it is not
Infertility Story	InfSt	The information regarding why the person/couple are searching for or using infertility services; unexplained or diagnosed infertility, cancer related, recessive genes, same sex couple	Does not relate to the actual process of using infertility services, only the underlying reason(s) why

Appendix E. IRB Approval Letter 1



RESEARCH INTEGRITY & COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12961 Bruce B. Downs Blvd, MDC35, Tampa, FL 33612-4799
(813) 974-5638 FAX (813) 974-7091

8/26/2019

Nathanael Stanley
Global Health
Tampa, FL 33612

RE: Exempt Certification

IRB#: Pro00041799

Title: On the Importance of Context: A Mixed Method Design to Add Context to the use of Existing Infertility Insurance Mandates

Dear Mr. Stanley:

On 8/26/2019, the Institutional Review Board (IRB) determined that your research meets criteria for exemption from the federal regulations as outlined by 45 CFR 46.104(d):

(2) Research that only includes interactions involving educational tests(cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:(i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7).

As the principal investigator for this study, it is your responsibility to ensure that this research is conducted as outlined in your application and consistent with the ethical principles outlined in the Belmont Report and with USF HRPP policies and procedures.

Please note, as per USF HRPP Policy, once the exempt determination is made, the application is closed in ARC. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant an Amendment

or new application.

We appreciate your dedication to the ethical conduct of human subjects research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,



Kristen Salomon, Ph.D., Chairperson
USF Institutional Review Board

Appendix F. IRB Approval Letter 2



EXEMPT DETERMINATION

December 10, 2019

Nathanael Stanley
5510 N. Himes Ave.
701
Tampa, FL 33614

Dear Mr. Nathanael Stanley:

On 12/5/2019, the IRB reviewed and approved the following protocol:

Application Type:	Initial Study
IRB ID:	STUDY000110
Review Type:	Exempt 2
Title:	On the Importance of Context: A Mixed Method Design to Add Context to the use of Existing Infertility Insurance Mandates
Funding:	None
Protocol:	NStanley_SocialBeh_Protocol

The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BullsIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about

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Page 1 of 2



whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

Sincerely,

Jennifer Walker
IRB Research Compliance Administrator

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Appendix G. Expert Interview Guide

Services Offered

- Where is this organization located?
 - o Are only residents of that state/those states eligible for the financial assistance?
 - o Is it national (United States only)?
- What are the type of financial assistance services your company offers?
 - o Loans? Grants? Insurance?
 - o Do people have to pay anything back to the company?
 - o If you work primarily with employers, do employers pay to have your services available to their employees?

Eligibility

- Are these services directed toward patients, employers, or actual clinics?
- How is this type of insurance applied to patients?
 - o Specific:
 - Do patients finance their infertility services through this company, or does this company navigate other potential loan/financing sources for patients?
 - Is there an employee number minimum (for employer-based insurance)?
 - Credit score minimum?
 - Age min/max?
 - Are patients at only certain physicians/clinics eligible for this type of financing?
 - Are there ethnicity specifications (must be from a specific ethnic group)?
 - Are there residency requirements?
 - For certain states?
 - Are there citizenship requirements?
 - Must be US citizen? (certain amount of time since being a US citizen [4 years+]?)
- What types of infertility services can be paid for/covered?
 - o Are there restrictions?
 - o Are there caps on certain procedures?
 - o Do you all work with patients and/or their physician to determine what can or cannot be paid for, or what procedure is necessary?
- What would disqualify someone from accessing the financing options provided by your company?
 - o Can people use the money for services outside their state of residence?
 - o Are adoption services able to be paid for through this funding?
 - o Are surrogacy services able to be paid for through this funding?
 - o Are federal employees or members of military qualified?
- Regarding the people who use services at your company, do they typically have some type of insurance already, or will having insurance disqualify a person from this financial assistance?
- How does this type of insurance operate in states without an infertility insurance mandate?
 - o Probes:

- Is it more difficult to apply this type of financing in states that do or do not have an infertility insurance mandate?
- If state mandates are inconsequential, how does the presence of any insurance (some services already covered) affect the financing options your company provides?
- Have you noticed increases or decreasing in funding requests in areas with/without infertility insurance mandates?
- How does this type of insurance compare to something like MediGap? Aflac?
- What is the cost to individuals/couples who access the financing/insurance your company provides?
- What is the cost to employers who make the financing/insurance your company provides available to their employees?

Advertisement

- How do you advertise this type of financial assistance?
 - Probe
 - How do patients find out about this type of financing/insurance?
 - How do employers find out about this type of financing/insurance?

Source of Funding

- [For companies that have scholarships or grants] How are the grants/scholarships funded?
 - Is it only through donations?

Perspective

- Based on your knowledge of how this company operates, would the development of more state-based insurance mandates increase the access to infertility services?

Appendix H. Copyright Permission 1

10/27/2020

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HEALTH INSURANCE FOR INFERTILITY SERVICES: IT'S ABOUT WHERE YOU WORK, MORE THAN WHERE YOU LIVE

Author: Nathanael B. Stanley, Tara R. Foti

Publication: Fertility and Sterility

Publisher: Elsevier

Date: September 2020

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Appendix I. Copyright Permission 2

10/28/2020

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CONSIDERING LOCATION IN ACCESS TO INFERTILITY SERVICES

Author: Nathanael B. Stanley
Publication: Fertility and Sterility
Publisher: Elsevier
Date: September 2020

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