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INFERTILITY as a DISABILITY: ETHICAL REFLECTION

BY

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ABSTRACT

INFERTILITY as a DISABILITY: ETHICAL REFLECTION

By

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During the late twentieth century, infertile women and men began to claim that they had a reproductive disability as a means to increase access to health care treatments to help them overcome their infertility. On June 25, 1998, the United States Supreme Court supported the claim that the infertile could be considered reproductively disabled under an anti-discrimination law: the Americans with Disabilities Act of 1990 (ADA). Upon review of the scholarly literature and legal cases addressing the issue of how the infertile have utilized the ADA, it is clear a great deal of confusion exists on how to interpret the ADA's language and intent with regards to issues addressing access to health insurance for the disabled, let alone the reproductively disabled. My thesis will argue that infertility should not be classified as a reproductive disability, because doing so would be unjust to the uninsured and the disabled. The ADA's primary mission is to protect the truly disabled from being discriminated against in the workplace. However, anti-disability discrimination laws can't protect the completely uninsured from being discriminated against in the provision of health care. The larger question that needs to be addressed is how does society protect individuals from being denied health care based on reasons other than disability that also might be considered ethically unacceptable.

DEDICATION

This thesis is dedicated to all infertile women and men who struggle to finance their pursuit of happiness.

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Just as importantly I would like to thank all my friends and family members for their lasting support during the last two years. As they will attest to, this was a personal journey for them as well as for me. I could call anyone of these wonderful people and bounce ideas off them day or night to help guide my thoughts with this thesis.

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PREFACE

I chose this topic because I am myself infertile. I became aware of the concept of infertility as a disability while listening to a National Public Radio (NPR) broadcast of "Morning Edition", on November 10, 1998. The topic that morning was "Insurance Coverage for Infertility". When I heard that a United States Supreme Court ruling now allowed infertility to be considered a disability as defined by the Americans with Disabilities Act of 1990 I had many thoughts. My immediate reaction was that I am infertile, but I am not disabled. Then I wondered how the United States Supreme Court came to its conclusion that infertility could be considered a disability. What became clear during NPR broadcast was that the infertile who were interviewed thought that finally, because of the United States Supreme court ruling, insurance coverage for their infertility treatments would improve. They could now claim that they were being discriminated against under the ADA if their employer denied them medical insurance for their "reproductive disability". The ADA is one of many statutory agencies that address anti-disability discrimination claims. Needless to say, during the research portion of my thesis, I struggled with the notion that infertility should be considered a disability as a means to improve insurance coverage for infertility. If I were to classify myself for purposes of this thesis, I would have to say that during the years that I was pursuing medical treatment for my infertility I was employed and medically insured. Moreover, my medical insurance provided limited coverage for infertility. Therefore, I would have been considered an privileged infertile woman who has had to make some very difficult choices regarding my infertility. Choosing to pursue medical treatment for infertility

takes courage, patience, hope and the financial resources to do so. While pursuing my dream to have a child of my own I endured many intrusive and painful medical interventions, including multiple surgeries and drug therapies. Also, I had to pay for a percentage of my infertility treatments. I do not remember exact costs, but my employer's medical insurance policy only covered a certain amount. After years of trying to conceive and due to the restrictive costs associated with the treatments I stopped pursuing medical treatment. I could not afford to pay for all the treatments associated with my infertility. In spite of all this, I question the appropriateness of calling myself disabled. I mourn the fact that I have not been able to have a child. However, unlike so many traditionally disabled, I have not struggled with achieving those things most basic in life that we all value- independence, inclusion and full integration of people with disabilities- that people with true disabilities face. Also, I had choices available to me that the uninsured infertile do not.

As I set out to write this thesis I was trying to figure out why I objected to being called disabled. I was also curious as to why other infertile men and women seemed to have no objections to being labeled "reproductively disabled". Ultimately, my reading and writing helped to deepen my conviction that the infertile should not rely on being called "reproductively disabled" to improve access to insurance coverage for their infertility. I believe it is wrong to use an anti-disability discrimination law, which was meant to help the truly disabled overcome so many barriers, as a means to improve access to insurance coverage for the infertile.

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INTRODUCTION

"As a society, we need to first prevent what infertility we can and then examine the issues of distributive justice. Genuine procreative choice simply does not exist if economic barriers effectively prohibit treatment options for the infertile of limited means." Barbara J. Berg, Listening to the Voices of the Infertile, 1995

On June 25, 1998 the United States Supreme Court ruled that infertility could be considered a disability under the Americans with Disabilities Act of 1990 (ADA). This ruling troubles me. I question what the impact of this ruling will have on the traditionally disabled as well as on the infertile. Some infertile believe that this ruling will open doors to better health insurance coverage for their "disability" and also force employers to adjust work schedules to accommodate treatments for their disability. On the other hand, some legal scholars are questioning the appropriateness of labeling the inability to procreate a disability. These scholars wonder how the Supreme Court ruling will affect future litigation regarding employer-based health insurance coverage for the infertile. They also question the nature of the legal reasoning behind labeling infertility a disability under the ADA. The purpose of this thesis is to examine the origin of this movement and explore the problems associated with it.

I oppose the notion that infertility should be labeled a disability as a means to improve health insurance coverage for infertility. I am going to argue that this movement is not ethically good for the traditionally disabled or for the infertile. The primary intent of the ADA is to improve the quality of life of the traditionally disabled by preventing discrimination against people with disabilities in employment, transportation and communication. I believe that some infertile have misappropriated the label to challenge the notion that they should have a right to employer-based health insurance coverage for their infertility.

The notion that the infertile may claim that they are "reproductively disabled" under the Americans with Disabilities Act as a means to improve access to health insurance coverage is problematic. What is evident is that calling on anti-disability discrimination laws to resolve health insurance disputes does not prevent denials of health care based on factors other than disability that also might be ethically objectionable (Mehlman, Durchslag and Neuhauser, 1997, p. 1407). Potential problems include: (1) Classifying infertility as a disability would be unfair because it would only help those who have insurance, and thus are already privileged. This unfairness would perpetuate a tendency with deep historical roots in America: the belief that those who are less well off have less of a right to have children. (2) Classifying infertility as a disability would be unfair to those who are traditionally considered disabled. The classification would take whatever power the disabled have obtained and designate it for others. (3) Classifying infertility as a disability would be to the disadvantage of some infertile: those who feel stigmatized would be reinforced in their feeling that they must keep their situation entirely private. This would perpetuate another unfortunate historical legacy: the silence of those who felt shame from their situation.

Each of the above mentioned problems will be examined in greater detail. First, the evolution of legal thought that procreation ought to be considered a disability will be examined. Second, the historical perspective that the infertile may be unworthy of parenthood and the consequences of this perspective for the infertile will be evaluated. Third, a critical analysis of the political and social ideologies that influence how the infertile act or react to their personal tragedy and an evaluation of the potential consequences of labeling oneself infertile and disabled will be conducted. This thesis will argue that dialogue attempting to classify the infertile as disabled should not be used to increase access to insurance coverage. The label should not be extended this way, even if doing so would increase insurance coverage for the infertile. Ultimately, infertility should not be classified as a disability, because doing so would be unjust to the uninsured and the disabled, and could potentially silence the infertile.

Background Information- Definition of the Infertile

Intrinsic to many women and men is the desire to pursue biological parenthood. The desire to experience the joys associated with pregnancy and childbirth and to raise children often motivates the infertile to pursue choices. Unfortunately, this desire can be thwarted by the medical condition infertility. Infertility can be defined as the failure to conceive after one year of intercourse without using contraception (House of Representatives, 101st Congress, 1st Session, Dec. 1, 1989, p. 3). The infertile often must seek medical treatment to help them conceive a biological child. Within the context of this thesis, I will be referring to the "employed insured infertile" and the "employed uninsured infertile." The "employed insured infertile" are those individuals who possess the resources necessary, albeit often limited resources, to medically diagnose and treat their infertility. Also, they may possess the financial resources necessary to challenge perceived injustices that exist regarding denial of health insurance for their condition. The "employed uninsured infertile" are those women and men who may not possess the resources necessary to either diagnose and treat their condition or pursue financial assistance. This thesis will examine critically the prospect that the infertile should rely on the ADA to help them gain access to health care resources for their infertility.

Background Information: The ADA

Upon review of the literature, I discovered that during the late twentieth century "employed insured infertile" women and men began to claim they had a "reproductive disability" to access financial and medical resources previously denied them or unavailable to them; (Millsap (1996), Mehlman et al. (1997), Gleicher (1998), RESOLVE, 1999). Within the context of the ADA, otherwise known as Public Law 101-336, which was passed on July 26, 1990, some employed infertile claimed that their "major life activity" of procreation was being discriminated against if they were denied health insurance coverage for their infertility. Claiming to be "reproductively disabled" has provided some men and women the opportunity to challenge the injustices they perceive in the workplace regarding inadequate health insurance coverage for their infertility. However, with respect to health insurance access, such claims do not help those men and women who are unemployed or are uninsured. The primary purpose of the ADA, established in 1990, was to prohibit discrimination against persons with disabilities by doing away with the barriers that prevented the disabled from participating fully in society. The intent of the ADA was to "bring individuals with disabilities into the mainstream of the economic structure of this country. In employment, in public accommodations, in transportation, in communications services..." (Senator Hatch, Congressional Record-Senate, July 13, 1990, p. 17365). The law indicates that a program or individual need only make "reasonable" accommodations or modifications in order to meet the needs of persons with disabilities (Mehlman et al., 1997, p. 1386). The employment provisions of the ADA only apply to companies with fifteen or more employees (Castellano and Chapman, 1993, p. XV). Titles I through IV of the ADA go into extensive detail regarding how the United States should comply with reasonably accommodating the disabled with regards to: (I) Employment; (II) Public Services; (III) Public Accommodations and Services Operated By Private Entities (transportation services); (IV) Telecommunications (communication services); and (V) Miscellaneous Provisions. Title V described briefly at the end of the ADA document addresses how the ADA would regulate the provision of health insurance for the disabled. However, Title V provides little guidance regarding how the anti-disability discrimination law would prevent the disabled from being discriminated against regarding the denial of health insurance by an employer and therefore allows interested parties the opportunity to challenge the intent and language of Title V of the ADA.

With regards to protection from health insurance discrimination, persons afforded anti-disability discrimination protections under the ADA are employed individuals who have some level of employer provided health insurance coverage. Employer provided health insurance policies often do not offer coverage for infertility treatments. Employers evaluate a number of factors when considering the level of health care insurance they offer their employees. Such factors include medical necessity of the procedure/service and participant/employee demographics. According to Stolman (1994) in the United States, the unemployed disabled may call on other government programs for assistance with their health care needs (pp. 85-96). However, the "employed uninsured infertile" whose company does not offer a health insurance program cannot call on anti-disability discrimination laws to resolve insurance disputes. The “employed uninsured infertile” must choose how they are going to finance this pursuit. The “employed uninsured infertile’s” only resolve is to obtain necessary financial resources through alternative avenues or choose not to pursue medical treatment because they simply cannot afford to do so. Infertility treatment can provide men and women with access to a “basic human good, the good of raising children” (Lauritzen, 1993, p. 135). Those affected by infertility often struggle with their passionate conviction that they should receive some form of financial assistance to overcome their infertility, allowing them to enjoy the basic human good of raising their own biological child. However, many infertile cannot pursue this basic human good because they do not possess medical insurance that adequately covers infertility treatments.

Anti-disability discrimination laws also only cover persons with conditions that satisfy the definition of disability. According to the ADA, an individual must have a “physical or mental impairment that substantially limits one or more major life activities” to qualify for protection from discrimination (ADA, 104 STAT.329, 42 USC 12102 Definition of Disability). Unfortunately, a great deal of confusion and controversy exists about how the ADA should be interpreted and utilized in categorizing procreation as a "major life activity".

Infertility Insurance Coverage Differs from State to State

After contacting the National Advocacy Association for the infertile, RESOLVE, I was informed that the current situation regarding provisions for health insurance for infertility treatments varies from state to state. Nearly twelve states now require employer-provided health plans to cover certain kinds of infertility treatments (Arkansas, Hawaii, Illinois, Maryland, Massachusetts, Montana, New York, Ohio, Rhode Island, and West Virginia). Each state has to offer some level of infertility treatment. Some states have meaningful mandates. But, the level of coverage mandated varies greatly among these states. For example, Illinois mandates insurance carriers to cover comprehensive diagnosis and treatment of infertility, including assisted reproductive-technology procedures, but limits first-time attempts to four complete oocyte retrievals, and two complete oocyte retrievals for a second birth. Insurance carriers are not required to provide this benefit to businesses (group policies) of 25 or fewer employees. On the other hand Montana mandates that Health Maintenance Organizations cover infertility treatment as a "preventative health care service" benefit. Other states mandate that infertility coverage must be offered, but purchasers can decide not to buy it (Resolve National Infertility Association, current as of October 1998). Some health insurance companies are being required to provide some level of health insurance coverage for infertility treatments by their state governments. However, many other states do not require that their insurance companies provide health insurance coverage for infertility.

Background: Silence and Shame

The infertile already struggle with negative images and feelings associated with their inability to conceive. Moreover, it is possible that the social isolation the infertile experience due to ignorance and being labeled disabled exacerbate shame. To prevent unnecessary suffering, infertile women and men are often silent about how their infertility affects them emotionally and financially. Being labeled disabled might provide the infertile the opportunity to overcome the social isolation they often experience. Or, being labeled infertile and disabled might create barriers to overcoming the silence that surrounds infertility.

Overcoming barriers that cause one to be silent about their personal struggles, life plans and desires is important for resolving difficult ethical dilemmas. Most ethical dilemmas involve conflicts of values. It could be argued that the "employed uninsured infertile" are morally compromised. Pursuing having a biological child is intrinsically valuable to most infertile. The "employed uninsured infertile" also have to find the financial resources to help them achieve that goal. The "employed uninsured infertile" have to choose whether or not to pursue medical treatment for their infertility and they have to choose how they are going to finance this pursuit. For many reasons, this is a life altering choice for most infertile. Silence surrounds those that choose to undergo medical treatment for their infertility because women and men often have to endure painful procedures and interventions, which directly impact upon their very private sexual lives. The uninsured infertile might also have to cope with the financial hardship that often accompanies pursuing having a child of your own. An uninsured infertile person can feel shame for their situation.

Limited Dollars for Infertility Treatments

Another reason that the movement to label the infertile disabled is controversial is that there is a limit to the amount of financial resources that can be allocated to the infertile without having a major negative impact on those with traditional disabilities and on those with traditional insurance coverage. Certainly, infertility is a great disappointment and a regrettable fact for many women and men. However, defining infertility as a disability is not in the best interests of society as a whole. Providing expensive health care services to a relatively small group without taking into account the health care needs of others would not represent a prudent use of limited resources.

A tension exists for the infertile and the disabled who demand that their particular medical needs be covered by an employer-based health insurance program. When faced with a limited source of funding for health care, the consequence is that there will be fewer medical resources for everyone, not just those with particular medical issues. Money could be directed away from vaccinations, prenatal care, and early intervention programs such as cancer screening. Even more compelling is that thousands of infertile men and women currently cover some portion of the costs associated with infertility treatments out of their own pockets with out major complaint. So, instead of demanding that employers cover all aspects of infertility treatments one has to wonder if it would be reasonable to ask the "employed insured infertile" and "employed uninsured infertile" to meet their employers half-way and "share" the costs associated with infertility treatments. Many employers do just that right now. A just and caring society should address this issue directly, rather than indirectly through the ADA. While this is a controversial issue and there are a lot of conflicting opinions as to whether infertility treatments should be covered by an employer-based health insurance policy, this is my notion of what a just and caring society should do. However, I do not intend to defend this important view in this thesis.

Overview of Literature

Numerous opinions exist regarding whether infertility should or should not be considered a disability. Others have thought and written about this topic, but no one has asked exactly the question I address. The literature falls into these major groups, the legal history of the infertile claiming to be disabled under the ADA and the outcome for the infertile of the 1998 United States Supreme Court ruling that supported the labeling of infertility as a disability. The following authors have addressed the legal history of the infertile; Mosoff (1993), Brady (1996), Millsap (1996), Tomkowicz (1996), Jacobs (1996), Gilbert (1996), Shoop (1996), Whitaker (1996), Lebowitz (1997), Mehlman et al.(1997), and Friedman (1997). They analyze how the infertile have successfully or unsuccessfully claimed to be disabled under the ADA as a means to maintain employment while undergoing medical treatments for their infertility or as a means to adjudicate entitlements to medical benefits for their infertility. Authors; Gross (1998), Fein (1998), Kilborn (1998), Kaminer (2000), Clark (2000), and Gernignani (2001) have directly commented on the outcome for the infertile of the 1998 United States Supreme Court ruling that supported the labeling of infertility as a disability. They comment on the appropriateness of the ruling with regards to infertility being labeled a disability under the ADA. Some support labeling infertility a disability because it might protect women seeking medical treatments for their infertility from being fired from their jobs. For example, some women need to request time off from their employment to receive hormone injections. Other authors question how the Supreme Court ruling will impact insurance coverage for infertility in the future. They discuss the nature of the legal reasoning and the possible future economic impact and ask whether the ruling makes legal sense. They also wonder what the future consequences will be for the traditionally disabled of extending the definition of disability to protect people without obvious physical symptoms.

The following authors; Tomkowicz (1996), Millsap (1996), and Mehlman, Durchslag, and Neuhauser (1997) have made important contributions towards understanding how anti-disability discrimination laws work. They address whom the laws might help and why they can help some people but not others. They also inform the reader as to why, in the future, it might be difficult for the infertile to challenge perceived injustices regarding denial of health insurance coverage for infertility under the ADA. Lawyers might find it difficult to argue on behalf of the "reproductively disabled" that their inability to conceive should be a covered benefit by their employer's health insurance policy when using the following terms: "sound actuarial data" and "subterfuge". These terms have proven difficult to apply and to qualify (Millsap, 1996, and Mehlman et al.1997).

Sandra M. Tomkowicz provides an extensive legal history of how the infertile have struggled with their personal goals of pregnancy, parenting and work. According to Tomkowicz (1996) "by requiring an employer to make reasonable accommodations, the ADA should now afford many couples who suffer from infertility the opportunity to pursue the goals of pregnancy and parenting without sacrificing their status in the workplace" (pp. 1052-1053). She analyzes how the Pregnancy Discrimination Act of 1978 (PDA), the ADA, the Family and Medical Leave Act of 1993 (FMCA) and the Equal Employment Opportunity Commission (EEOC) may have helped or complicated the issues surrounding how the employed infertile could maintain their employment while pursuing medical treatment for their infertility. Importantly though, she identifies a primary issue that exhausts court time and patience with regards to the ADA. The ADA states that only those persons who can demonstrate that a major life activity is substantially limited by an impairment can call on the ADA for protection. Yet, tremendous confusion exists in the courts over whether procreation or the inability to procreate should be considered a major life activity that can be substantially limited (Tomkowicz, 1996, pp. 1065-1077).

D'Andra Millsap (1996) argues from a legal perspective that while most employer-provided health insurance plans exclude infertility treatment coverage for some, if not most, the ADA provides some hope for the infertile (p. 84). The employed and insured infertile may be able to challenge infertility treatment exclusions. Millsap (1996) believes that "there is a strong likelihood that most courts will find infertility to be a disability and thus exclusion of infertility services a disability-based distinction" (p.83). By referring to case law she describes how frustrating it can be to capture how infertility may fall within the ADA's definition of what constitutes a "major life activity". Importantly she identifies another caveat for understanding the intent of the ADA with regards to the provision of health insurance for the disabled. The only protections for people with disabilities excluded from insurance coverage are the requirements that "denials be based on underwriting risks (or sound actuarial data) and not be used as a subterfuge to evade the purposes of the ADA" (Title V of the ADA, p 1040 STAT.370). Millsap (1996) addresses how difficult it is to argue on behalf of the infertile that their inability to conceive ought to be a covered benefit by their employer's health insurance policy when using such confusing terms as "sound actuarial data" and "subterfuge". With regards to insurance discrimination claims, she claims that these terms "not only cloud the issue of what constitutes a disability-based distinction for the infertile, but also for the disabled in general" (Millsap, 1996, pp. 81-84).

Mehlman, Durchslag, and Neuhauser (1997) attempt to explain how the courts are likely to interpret the ADA with regards to how this law will play a greater role in health care decision making than previously anticipated. With their analysis "they hope to provide concrete policy guidance to insurers, public programs, individual health professionals, and providers" (p. 1386). These authors describe in great detail the confusion surrounding how the ADA ought to impact disability discrimination law regarding the denial of health care to the disabled. They identify several key issues. First, the patient has to be disabled or will be disabled as a result of treatment to appeal to anti-disability discrimination laws for protection. They are acutely aware of the confusion surrounding the claim by some that infertility should be considered a disability. Second, they point out that according to Title V of the ADA, "the denial of health care is not protected, even if it is based on sound actuarial data and insurance underwriting, if it is a subterfuge to evade the purposes of the law" (Title V of the ADA, p 1040 STAT.370). According to Mehlman et al., (1997) "The meaning of this provision is currently being hotly disputed" (p. 1405). Similar to D'Andra Millsap (1996), they identify that different views exist in the courts regarding what the term "subterfuge" means with regards to the provision of health care for the disabled. Most importantly with regards to this thesis, Mehlman et al. (1997) mention what the anti-disability discrimination laws do not do "They do not prevent denials of health care based on factors other than disability that also might be ethically objectional" (p. 1407). For example, anti-disability discrimination laws do not prevent the "employed uninsured" or the "unemployed uninsured" in this country from being denied access to a minimal level of health care.

I have found only one author that directly addresses the notion that infertility should not be considered a disability under the ADA because doing so would be unjust for the traditionally disabled and just wrong. According to Kaminer (2000), "if the primary purpose of the law is to end discrimination against the disabled, expanding their employment opportunities and access to public accommodations, it is ill-served by extending its reach to people who can't reproduce without treatment" (p.1). She too questions the appropriateness of labeling infertility a disability as a means to improve insurance coverage for the infertile. However, Kaminer approaches her argument from a different perspective than mine. Her claim is that when assessing competing claims of suffering and injustice it is "troubling to see legislators responding to the needs of the middle class for infertility treatments when they have disregarded the plight of poor-fertile-women, who have been forced off welfare..." (Kaminer, 2000, p. 3).

In other words, people have explained the legal history and ambiguities of stretching the ADA in this way and Kaminer addresses briefly the moral rightness of trying to do so. However, I will be taking a broader ethical look at this issue.

Summary

There is a history in the United States of urging and encouraging reproduction in the more privileged groups and discouraging or ignoring it in the less privileged groups. I will explore this historical perspective, in this thesis, by examining each of the following problems in greater detail: (1) Classifying infertility as a disability would be unfair because it would only help those who have insurance, and thus are already privileged. (2) Classifying infertility as a disability would be unfair to those who are traditionally considered disabled. (3) Classifying infertility as a disability would be to the disadvantage of some infertile: those who feel stigmatized would be reinforced in their feeling that they must keep their situation entirely private. This thesis will argue that dialogue attempting to classify the infertile as disabled should not be used to increase access to insurance coverage. The label should not be extended this way, even if doing so would increase insurance coverage for the infertile. Ultimately, I will suggest that infertility should not be classified as a disability, because doing so would be unjust to the uninsured and the disabled, and could potentially silence the infertile.

THE EMERGENCE OF INFERTILITY AS A DISABILITY

Recently, infertile women have called upon the ADA to help them reconcile their conflicting goals of maintaining their employment while seeking medical treatment to overcome their infertility. It became apparent during my research that a critical threshold issue in attempting to classify infertility as a disability is defining the point at which a particular activity constitutes a major life activity according to the ADA.

The ADA v. Protection for the Employed Infertile

The following two cases address whether the ADA provided women protection from being fired from their jobs while seeking medical treatments for their infertility and whether infertility could be considered a protected disability within the scope of the ADA. The cases are Charline Pacourek v. Inland Steel and Lynn Gansar Zatarain v. WDSU- Television, Inc. (Pacourek, 858 F. Supp.1396, Zatarian, 881 F. Supp.242). Each woman claimed that she was discriminatorily discharged from employment as a result of taking time off from her job to receive medical treatment for infertility (hormone injections). In the hope of regaining employment both women filed anti-disability discrimination charges against their employers thru the ADA (and several other anti-discrimination statutes). They claimed that their employer's conduct violated the ADA (Pacourek, 858 F. Supp.1396, Zatarian, 881 F. Supp.242). However, the final legal opinion in these two cases contradicted each other with regard to calling infertility a disability under the ADA.

The first case examined is Charline Pacourek, Plaintiff v. Inland Steel Company, Defendant (Case No. 94 C 130, United States District Court for the Northern District of Illinois, Eastern Division, July 27, 1994). The court reasoned that it was a "matter of common sense" that Ms. Pacourek's condition "substantially limits the major life activity" of reproduction. Pacourek started working at Inland Steel in March 1975. Pacourek claimed that her employer started to unfairly scrutinize her requests for time off after she informed Inland Steel, during October 1986, that she was to begin seeking medical treatment for her infertility (Pacourek, 858 F. Supp.1396). In 1987, Pacourek began seeing a doctor regarding her infertility. That same year, Pacourek missed several days of work because of the infertility appointments. Four years later, Pacourek began to receive hormone injections for her infertility. Pacourek apparently missed work on at least some of the days on which she underwent treatment (Pacourek, 858 F. Supp.1393). On February 12, 1992, Pacourek was officially told that her attendance would be monitored closely and her employment would be terminated if her attendance did not improve. On May 21, 1993, Pacourek was told that her employment was terminated. On January 7, 1994, Pacourek filed a lawsuit claiming that she was discriminatorily discharged because she had a disability, infertility, under the ADA (Pacourek, 858 F. Supp.1396). United States District Judge James H. Alesia refused to dismiss her claim and concluded that Pacourek was disabled according to the ADA, and therefore has a claim under the ADA (Pacourek, 858 F. Supp.1404-1405). This was one of the first legal cases to recognize infertility as a disability under the ADA.

On the other hand, in Lynn Ganser Zatarian, Plaintiff v. WDSU-Television, Defendant (Case No. 94-1018, United States District Court, E.D. Louisiana, Jan. 18, 1995), Zatarian lost her case. The court did not agree that she suffered from a disability (infertility) covered by the ADA. Zatarian had a long- standing relationship with her employer as a prime-time news anchor at WDSU. In July 1992, Zatarian informed her employer that she needed to pursue infertility treatment. She needed to receive hormone injections for her infertility. Zatarian had been allowed to stagger her hours at work for months to accommodate her infertility treatments. Then, in November of 1992, WDSU-Television allowed her contract to expire and did not renew it. Zatarian claimed that she suffered from a disability covered under the ADA and thus was discriminatorily discharged by WDSU in violation of the ADA (Zatarian , 881 F. Supp. 241). District Judge, J. Vance stated that: "finding 'reproduction' to be a 'major life activity' would be inconsistent with the illustrative list of major life activities provided in the ADA regulations. The list includes, but is not limited to: walking, seeing, speaking, breathing, learning, and working" (Zatarian, 881 F. Supp.243). Judge Vance felt that it was inappropriate for his court to address the notion that infertility be considered a disability under the ADA. It was his opinion that: "Treating reproduction as a major life activity under the ADA would be a conscious expansion of the law, which is beyond the province of this court" (Zatarian, 881 F. Supp.243).

Both the Zatarian and Pacourek cases brought forth the issue of whether infertility could be considered a disability protected by the ADA. Central to both cases was whether reproduction, obviously the primary activity affected by infertility, is a major life activity.

The ADA's stance that employers must provide reasonable accommodations for individuals with disabilities has helped to protect individuals like Charline Pacourek from losing their jobs while they pursue infertility treatments. To date, however, only a fraction of those affected by infertility have benefited from legal challenges utilizing anti-disability discrimination laws to improve access to health insurance.

The Equal Employment Opportunity Commission and the ADA's Definition of "Major Life Activity"

The employed infertile seeking to improve access to health insurance are challenging the ADA's definition of what constitutes a "major life activity" in the courts. The average person in the general population can certainly procreate with little or no difficulty. Accordingly, the logical extension is made that infertile persons are disabled since they are unable to participate in the major life activity of reproduction. In March of 1995, after numerous legal cases expressed difficulty in understanding how procreation ought to be categorized within the context of "major life activity", the primary federal agency charged with enforcing the ADA, the Equal Employment Opportunity Commission (EEOC), encouraged a broad reading of what constitutes a "major life activity" (Tomkowicz, 1996, pp. 1063-1071). In the EEOC Disability Memorandum, the EEOC implicitly encouraged a broad reading of the regulatory definition of major life activities by stating that "major life activities are those basic activities that the average person in the general population can perform with little or no difficulty" (EEOC Compl. Man. (BNA) 902, at 1, Mar. 14, 1995). A consequence of the recommended broad reading is the notion that infertile individuals whose physical impairment prevents them from having children of their own should be afforded the protection of the ADA.

Some infertile have moved the dialogue regarding anti-disability discrimination into a new realm. Employed and receiving some form of health insurance coverage from their employer, infertile women (and men) have begun to claim that their employers have discriminated against them by denying them insurance coverage for their infertility treatments.

A Successful District Court Case and Health Insurance Coverage for Infertility

The following infertility case called upon the ADA to increase access to health insurance. Anita Bielicki and all others similarly situated v. the City of Chicago (Case No. 97 C 1471, United States District Court for the Northern District of Illinois, Eastern Division, May 8, 1997) received a fair amount of recognition in the medical and legal fields because of the outcome. From approximately August 1994 to October 1994, Bielicki, a Chicago Police Officer, received treatments for infertility, including tests and in-vitro fertilization. From approximately October 1994 to August 1995, Bielicki received medical treatments and tests related to her pregnancy. On June 21, 1995, the City of Chicago informed Ms. Bielicki that she was denied health care coverage for her infertility treatment and treatment related to her pregnancy. Administrators of the City of Chicago's health plan ("the Plan") determined that the medical services she received were infertility treatments and therefore not a covered benefit. On January 4, 1996, Bielicki filed a charge of discrimination in violation of the ADA (and several other anti-discrimination statutes) on behalf of herself and all others similarly situated (1997 US Dist. LEXIS 6880: 2). Bielicki filed action challenging the City of Chicago's policy of excluding medical benefits for infertility treatments. She claimed: "That her condition-infertility- substantially limits one or more of her major life activities, including procreation, reproduction, conception, pregnancy and the birth and raising of her own

children" (1997 US Dist. LEXIS 6880: 1-2). Once again, two primary issues in Bielicki's case were whether her claimed disability, infertility, constitutes a disability within the context of the ADA and whether procreation constitutes a "major life activity" within the scope of the ADA. The City of Chicago's motion to dismiss Bielicki's claim was denied by the sitting judge in Federal Court, basically validating that there may be a right to fertility services under the ADA. On January 29, 1996 United States District Judge, Suzanne B. Conlon ruled that infertility is a disability under the ADA and forced the City of Chicago to settle the class action lawsuit. Conlon ruled that infertility is a disorder of the reproductive system under the ADA (Bielicki v. City of Chicago, No. 97 C 1471, 1997 WL 260595 (N.D. Ill. May 5, 1997)). Ultimately, the City of Chicago reached a settlement with Bielicki and all others situated, and agreed to cover all medical treatments related to infertility retroactive to March 3, 1987. She fought to increase access to treatments and in doing so got access.

1998 United States Supreme Court Case that Supported Labeling Infertility a Disability within the Context of the ADA

The United States Supreme Court has indirectly supported the claim that infertility could represent a disability under the ADA. In Randon Bragdon, D.M.D. v. Sidney Abbott, a person who was human deficiency virus (HIV) positive but not yet diagnosed with acquired immune deficiency syndrome (AIDS) was considered disabled because her condition impaired her willingness to have children (118B S. Supp.2196-2218). Sidney Abbott sued dentist Randon Bragdon in 1994 because he refused to work on her teeth in his dental office in Bangor, Maine. The dentist offered to perform the needed dental services at a local hospital at no extra charge. However, the costs associated with a hospital admission would have to be covered by Abbott (118B S. Supp.2198). Abbott told Bragdon she had HIV, the virus that causes AIDS. She argued that, under the 1990 ADA, she was disabled because the HIV infection prevented her from having children without exposing the fetus and her partner to the disease. The decision by the United States Court of Appeals for the First Circuit in this case concluded that a person with asymptomatic HIV is substantially limited in the major life activity of reproduction and is thus considered disabled under the ADA (912 F. Supp. 580 [Me.1995]). The majority opinion by the United States Supreme Court in June of 1998 was that "reproduction falls within the phrase major life activity". On June 25, 1998, the United States Supreme Court concurred with an earlier Appellate Court decision that infertility could represent a disability under the Americans With Disabilities Act (ADA) because procreation falls within the category "major life activity" (118B S. Supp.2205). Justice's Kennedy, Stevens, Souter, Breyer, and Ginsburg held that "HIV infection is a "disability" under the ADA, even when the infection has not yet progressed to the so-called symptomatic phase, as a physical impairment which substantially limits the major life activity of reproduction" (118B S. Supp.2196). However, dissenting views held by Chief Justice Rehnquist, Justice's Scalia, O'Connor and Thomas were that Randon Bragdon failed to demonstrate that any of her major life activities were substantially limited by her HIV infection (118B S. Supp.2216). They also expressed the opinion that "Respondent's argument, taken to its logical extreme, would render every individual.... disabled here and now because of some possible future effects" (118B S. Supp.2216). While this was a substantial victory for people who are HIV positive, the benefits for the infertile were not immediately evident.

Conclusion

As I stated earlier, the ADA mandates that only those persons who can demonstrate that a major life activity is substantially limited by an impairment can call on the ADA for protection from discrimination in the workforce. After years of legal controversy as to whether reproduction could be considered a major life activity under the ADA and as to whether infertility could be considered an impairment under the ADA a controversial ruling came down from the United States Supreme Court in 1998. A legal case which appeared to have nothing to do with infertility and which began in district court and made it's way to the United States Supreme Court decided in favor of labeling infertility a disability under the ADA. The United States Supreme Court held that infertility could be considered an impairment and reproduction could be considered a major life activify under the ADA (118B S. Supp.2196-2218). Therefore, an "employed infertile" person could now be considered disabled under the ADA because their major life activity of procreation is impaired by their infertility. A potential consequence of this ruling is that now the "employed insured infertile" could claim discrimination under the ADA if their employer denied them health insurance coverage for their infertility treatments.

THE PERPETUATION OF UNFAIRNESS FOR THE INFERTILE AND THE EUGENICS MOVEMENT

Expanding the scope of the ADA so that infertility is a recognized disability might make infertility treatments available to the "employed insured infertile" because these individuals are employed and have some form of employer-based health insurance. In fact, some might consider the "employed insured infertile" "privileged" in the sense that they have certain benefits available to them that the "employed uninsured infertile" do not. They usually possess some form of employer provided health insurance for themselves and their family members and the ADA might provide them some protection from being denied health insurance for their infertility treatments. However, the ADA can not protect the "employed uninsured infertile" from being denied health care for their infertility because their employers do not offer any form of health insurance. Some might suggest that the "employed uninsured infertile" are "less privileged" because they might not possess the resources necessary to privately finance treatment for their infertility and/or properly care for their future children. Some might question the worthiness of women having children when they can not afford health insurance to care for themselves let alone their children. The belief that only the more "privileged" deserve to have children is found in ordinary conversation today, as well as in the history of attitudes toward infertility. The attitudes and judgments the infertile encountered were particularly heightened in the United States in the early 1900's. In the early 1990's reproductive behavior in the United States was scrutinized by a society that was concerned about the "quality and character of its future citizenry" (May, 1995; Marsh and

Ronner, 1996). Reproductive behavior during the early twenty-first century is taking place in a society struggling to meet the health care needs of all its citizens.

Brief History of the Eugenics Movement in the Early 1990's

May claims that during the early 1900's childlessness became not just a matter of personal circumstance, but also a function of public policy (1995, p. 96). To illustrate this she analyzes, in depth, the impact the eugenics movement had on different classes of women with regards to parental worthiness and public policy. The basic premise of eugenics is that the [white] human race could be improved if [white] human beings could take charge of their own evolution. Eugenics can be defined as "pertaining or adapted to the production of fine offspring, especially in the human race" (The Oxford English Dictionary, Vol. 5, 1989, p. 433). In the early 1900's this usually meant that white men and women of pure European descent were encouraged to reproduce. White men and women are defined as "a person of European extraction who lives outside Europe; hence a white person, especially in a country with a predominately non-white population" (The Oxford English Dictionary, Vol. V, 1989, p. 442). From the late 1800's through the early 1900's the white man considered himself superior to the all non-white's "A white man's country was considered a country of superior excellence. It was a country governed by those citizens who are white. 'This is a white man's country … and the white people intend to rule it now and forever'" (A Dictionary Of American English On Historical Principles, Vol. IV, 1944, p. 2478). Believers of the eugenics movement in the early 1900's strongly encouraged some white Anglo-Saxon American citizens to procreate. Anglo-American's are defined as "an American citizen of English descent" (A Dictionary

Of American English On Historical Principles, Vol. I, 1938, p. 51). Anglo-Saxon's are defined as "pertaining to English people or culture in Great Britain, its colonies and dominions and the United States" (A Dictionary Of American English On Historical Principles, Vol. I, 1938, p. 52). Some Anglo-Saxon's, during the late 1800's and early 1900's, believed that their race was superior to other non-white races. They wanted to "imbue [other races] with English character or culture" ... "this race is destined to dispossess many weaker ones, assimilate others, and mould the remainder, until ...it has Anglo-Saxonized mankind" (A Dictionary Of American English On Historical Principles, Vol. I, 1938, p. 52). Therefore, those Anglo-Saxon American women who where thought to produce genetically fine offspring were encouraged to reproduce. According to May (1995), many white Anglo-Saxon American women and men were considered "desirables", intelligent and thought to have "good character" and were encouraged to have children (pp. 61-93). Some might even refer to this population as "privileged" because they were favored for reproduction over other races in the early 1900's. Also according to May (1995), non-whites, and individuals who were mentally challenged [white and non-white] were considered to be "undesirables" or of "poor character". During the early 1900's anyone who was non-white (i.e., black, oriental and American Indian races) were often discouraged or prevented from having children (pp. 95-125). The logical extension could be made that non-white races and the "feeble-minded" may have been considered "less privileged" because they were not considered worthy of producing desirable children.

Infertile White Women and the Eugenics Movement in the Early 1900's

The eugenics movement gathered public support after the turn of the twentieth century. It appears that the primary objective for developing eugenics programs was to adopt policies that encouraged the creation of a superior white class for generations to come. Women were indispensable to the bearing of children, and they often became willing and unwilling participants in the eugenics movement. Some might argue however that during President Theodore Roosevelt's era some childless white women were unfairly pressured to procreate:

> "As part of their campaign, crusaders for eugenics launched the first major attack against the childless, who, in President Roosevelt's words, were shirking their duty to the nation through "willful sterility" (May, 1995, p. 62).

During the Roosevelt era it was hoped that the children of a particular group of white Anglo-Saxon American men and women would become the future leaders of America (May, 1995, p. 62). Those women who were not contributing to his campaign to create a superior class of future citizens were not fulfilling their obligation to their country. There was a fear that any decline in a white woman's devotion to procreate would lead to race-suicide (May, 1995, pp. 61-93). Race-suicide in the early 1900's is defined as a voluntary restriction of births, within a particular race, to such a point that the population cannot maintain its numbers" (A Dictionary Of American English On Historical Principles, Vol. III, p. 1880). The belief that Anglo-Saxon men and women were superior in intellect, social standing and accomplishment to members of non-white groups encouraged those who believed in the eugenics movement to argue against the use of birth control to prevent race-suicide amongst the white population. However, infertile

Anglo-Saxon American women were unable to comply with President Roosevelt's demand to produce children.

Political, institutional, medical and legislative measures that encouraged some Americans to become parents were particularly devastating for the infertile in the early twentieth century. Infertile white married women during President Theodore Roosevelt's era likely had to endure social isolation because they were unable to produce "naturally superior" children. During the 1900's "the political character of the United States, a nation that depended upon the biological character of its people, was dependent upon women to bear and rear the next generation of citizens" (The Readers Companion to U.S. Women's History, 1998, p.178). Therefore, women were as important to politics as men were during President Theodore Roosevelt's era. Because they were unable to contribute to the New World order, many white women, who were involuntarily childless, had to endure a great deal of public shame and humiliation. According to May (1995), they were considered by many to be "unworthy" and "un-American". They were considered unproductive, deficient and "barren" in the literal and figurative sense (pp. 26-29, 102-127, 131-134). They often found themselves condemned for selfishness if they bore no children.

Poor Women and Non-White Women and the Eugenics Movement

During my research of the early 1900's Eugenics movement it appears poor women and women of color had to endure very different levels of persecution during the first half of the twentieth century. Political and religious leaders in the early twentieth century did not want this segment of society breeding (May, 1995, pp. 95-125). They believed anyone who was not a white Anglo-Saxon American citizen was inferior in intellect and social standing. May (1995) claims that any means to prevent the uneducated non-white population from having children was to be exercised. "It is the relatively uneducated women who keep the United States population on the rise" (p.134). However, those who believed in the eugenics movement wrongly believed that the non-white population was producing more children than the white population. The highest birthrate in the early1900's was among the educated white middle-class (May, 1995, p. 134). The fertility rate among black American women however was dropping in the early 1900's. "Childlessness rose among ever-married black women from 16 percent in 1910 to 26 percent in 1940. By the mid-1940's, the infertility rate was more than twice as high for black women as for white women, owing to poverty, disease, and poor health care" (May, 1995, p. 75). Racial categorization can be very misleading. Those who believed in the eugenics movement during the early 1900's may have unfairly targeted the black population as indirectly contributing to the white population loosing its' predominance. It appears by these statistics that the white population might have been reproducing at a higher rate than the black population. To be more specific the fertility rate among one population, the black population, was actually dropping off. Therefore, the perception that the white population was voluntarily restricting births to such a point that the population could not maintain its numbers was a false perspective. In fact, poverty, the lack of education and the lack of adequate health insurance can directly contribute to the lack of fertility.

Worthiness of Who Becomes a Parent in the 21st Century

During the late twentieth century onward discussion regarding infertility and insurance coverage is often framed within the context of who is worthy to become a parent. The worthiness of who ought to become a parent is often determined based on the availability of, or access to, the financial resources needed for infertility treatments. The National Center for Health Statistics estimates that 1 in 12, or 4.9 million American couples are infertile (Lee, 1996). Many of these couples have no access or limited access to medical treatment for their infertility. Public attitudes and values often suggest that the "employed uninsured infertile" and "unemployed uninsured infertile are not worthy of becoming a parent because these women and men often do not possess health insurance. The judgment made is that if the uninsured infertile cannot afford medical coverage for their infertility, then they are unworthy of having a child because they obviously do not possess the resources necessary to properly raise a child.

Elaine Tyler May's insight is very timely. She tells us "although procreation is a profoundly private experience, reproductive behavior takes place in a society that is deeply concerned about who becomes a parent and under what circumstances. This concern is not new, but the public's stake in who has children and who does not has changed over time" (May, 1995, p. 2). As discussed in detail earlier, the eugenics movement in this country during the early 1900's was instrumental in the public's determination of worthiness to become parents in this country. One could argue that from the infertile person's perspective a fact that has not changed over time is that the

public's concern about who has children is determined by whether one has the financial resources or not to help them achieve a pregnancy. But, using the ADA to address perceived injustices in employer-based health insurance policies for the infertile only helps the privileged, employed and insured infertile. Regrettably an unfair situation continues to exist for the less privileged in the United States. Similar to the non-white populations of the early 1900's, the "employed uninsured infertile" in the early twenty first century appear to be the less-favored of society. However, their worthiness to reproduce is now judged by whether they have medical insurance instead of their ability to create genetically "superior offspring".

THE "REPRODUCTIVELY DISABLED" AS A USURPATION OF THE PROTECTIONS OF THE ADA

One objection I have to stretching the scope of the ADA is that the ADA was meant to help those who are poor because of a disability: the disability keeps them from keeping a job, and keeps them from having adequate health insurance. The privileged infertile who have been able to claim that they have a "reproductive disability" under the ADA in order to gain access to insurance coverage have overextended the original purpose of the ADA.

The Evolution of the Disability-Rights Movement

My research into the evolution of the ADA has revealed that fighting for equal rights is the founding principle of the disability-rights movement and the creation of the ADA. When the disabled testified before Congress regarding the creation of the Americans with Disabilities Act of 1990 their language and their stories were to the effect that what people with disabilities have to surmount is discrimination more than impairment (Garland-Thomson, 2001, p. B12). They were fighting as a group to become independent productive members of society. The message heard over and over again from the disabled community was:

> "We don't want any favors; all we want is for others to judge us on the basis of our abilities and not on the basis of our disabilities; to judge us on the basis of facts and not on the basis of fear, ignorance, prejudice, or patronizing attitudes. Remove artificial barriers that prevent us from fully participating in the mainstream of society. That's all we want and expect." (Senator Harkin: Congressional Record-Senate, July 13, 1990, p. 17368)

The Americans with Disabilities Act of 1990 has allowed the disabled (those who have overcome the oppressive narratives and stereotypes usually applied to disabled men and women who have been unable to work and become independent human beings) to uniquely reshape our entire culture. Anti-disability discrimination laws evolved out of the struggles of people whose limitations or sufferings are much greater because of their physical and or mental conditions. What physical and mental conditions are considered normal and what are considered abnormal is defined by the social and cultural expectations of a society. Society not only selects which characteristics are to be considered normal, but it also defines what characteristic will be considered a disability. Social, ethical and policy questions arise when assessing an individual's health and the range of opportunities available to people in the population who do not meet that standard of species-typical functioning. These individuals are estimated to make up one-sixth of the United States population (Americans with Disabilities Act (ADA), 1990, P.L. 101-336, Section 2). The Americans with Disabilities Act partly endorses the perspective that disability is a natural human experience that society should accommodate:

> "Congress finds that... individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society..."
> (Americans with Disabilities Act, 1990, P.L. 101-336, Section 2).

This perspective was developed based on the life experiences of traditionally disabled women and men who tended to be overwhelmingly poor and underemployed. The government's efforts on behalf of the traditionally disabled women and men have been aimed to improve economic productivity and self-support "the combination of segregated education and systemic discrimination in employment has a devastating effect on the income and employment prospects of women with disabilities" (Mosoff, 1993, p. 109).

The Social Construction of "Disability" and the Infertile

The idea that disability is socially constructed is critically important when assessing individual claims of "reproductive disability" under the ADA. Consideration must be given to the consequences for the disabled community in total. Mosoff (1993) states that "in the context of growing social awareness and developing jurisprudence on disability rights, individuals with fertility problems have appropriated a disability rights discourse to gain access to resources and services forged by earlier efforts at advocating very different disability issues" (p. 112). The truly disabled, as stated earlier, fought for the right to become economically self-sufficient. They also fought for respect. However, Bragdon, Pacourek and Bielicki effectively used disability rights language, which was pioneered by the disabled community, for their own personal gain. The court record documents that some employed and insured infertile adopted anti-disability discrimination language to advance their own individual needs. They used language that the disabled community historically used to lobby for a more inclusive society. The language that the infertile has adopted includes such principles as accessibility, reasonable accommodation, dignity, respect, and full participation in society (Mosoff, 1993, p. 111). Those infertile that have taken their injustice to the courts (those who have challenged their employer's health insurance plan regarding coverage for infertility) believe that their right to pursue the opportunity to conceive a child of their own has been impeded by either cost or limited resources.

Using disability rights language to advance the cause of those affected by infertility is problematic. The infertile are using disability “rights” language in a different context. The privileged infertile are fighting for their individual equal “rights” to financial resources for their infertility. The truly disabled have historically used their “rights” language to fight for their right to be equally respected and independent members of society.

Women who have claimed a "reproductive disability" have adopted the group-oriented disability discourse to gain access to resources for individuals. Some women began defining themselves as "reproductively disabled" in the 1980's and 1990's as a means of adjudicating entitlements to benefits. Women claim that insurance companies place restrictions on their reproductive choice and autonomy. Women who are having difficulty conceiving children or carrying their pregnancies to term argue for their right of access to costly reproductive technology, especially in-vitro fertilization (IVF) and gamete intrafallopian transfer (GIFT). “In IVF, an egg is fertilized in a plastic petri dish and then implanted in the womb. In GIFT, sperm and egg are transferred into the woman’s fallopian tube, where it is hoped fertilization will take place” (101st Congress, 1st Session, House of Representatives, Dec. 1, 1989, p. 3). Failure to control what happens to their bodies motivated some infertile couples to challenge whatever practice or policy was depriving them of control. Those who have embraced being labeled "reproductively disabled" feel that they have lost control over what happens to their bodies. They feel that they have been unjustly denied the opportunity to pursue certain treatment options. They want to feel less like a victim and more empowered to pursue a host of infertility treatment options that they feel they have a right to, but which are currently not offered as a covered benefit under their medical insurance plan.

"Reproductive Disability" And Understanding Disability in the Traditional Sense

It is possible that the privileged infertile have been dishonest in appropriating the label disabled. Unlike the traditionally disabled in our country, women who have recently claimed that they have a "reproductive disability" tend to be educated, employed, married and not poor. One dissenting Justice who participated in the controversial Supreme Court decision agrees with the notion that some infertile have been dishonest in appropriating the label disabled. In a split decision, Justice O'Connor (dissenting in part) states that:

> "In my view, the act of giving birth to a child, while a very important part of the lives of many women, is not generally the same as the representative major life activities of all persons- "caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working"- listed in regulations relevant to the Americans with Disabilities Act of 1990." (Supreme Court Reporter, Vol. 118B, Decided June 25, 1998, p. 2217)

It is possible that the United States Supreme Court diluted and distorted the intent of the ADA. Disability rights activists have fought to avoid the persistent stereotypes of disability and to create new ways to understand disability. Creating new ways to understand disability is a difficult process. Disabilities rights activists might contend that by calling the inability to procreate a "reproductive disability" the courts have failed to advance the idea that "disability is integral to a person's character and life experiences, rather than a defect to be eliminated" (Garland-Thomson 2001:B12). One might argue it

is possible that many of the "reproductively disabled" who have called upon the courts to increase access to health insurance coverage for their infertility do not understand what it means to be disabled in the traditional sense. Their primary objective is to overcome their infertility, not to begin to understand how disability is integral to a person's character and life experiences.

Nevertheless, the ADA route has worked to gain health insurance benefits for some infertile. Discussion regarding insurance coverage for infertility can now be framed within the context that because one has a "reproductive disability" they should have access to the health care treatments required to overcome their disability. According to Mosoff (1993) "to increase access to medical resources previously denied them, some infertile women and men 'invoke rights discourse', in part by adopting a disability label, and to use the language of equality to develop objectives of individual autonomy" (p. 122). Advocacy groups for the infertile feel that when people approach their employers and ask that they provide infertility insurance coverage for their "reproductive disability", the Supreme Court has provided them a powerful tool and boosts their chances of getting a positive result. RESOLVE, the national advocacy program for the infertile explicitly states in their FAST FACTS newsletter that employers, insurance companies, and legislators should now take steps to follow the Supreme Court's lead and recognize that reproduction is a major life activity covered under the ADA (RESOLVE, January 1999). Advocates for the infertile believe the Supreme Courts ruling is a step in the right direction to improve health care coverage for the infertile and improve workplace accommodations for employees who are undergoing infertility treatments. Past lower court rulings directly addressing issues related to infertility had mixed results regarding

insurance coverage and workplace accommodations. Now, many infertile believe that the Supreme Court ruling that reproduction is a major life activity will greatly improve the chances that future court cases will be decided in favor of those facing discrimination because of infertility (RESOLVE January 1999).

To date, however the infertile who have adopted the equal rights language of the disabled community have been informed, educated, employed and insured. The voices of one of the fastest growing populations in the United States, the employed and medically uninsured, cannot be heard in the same forum. Those that are afforded the protections of the ADA when addressing health insurance disputes are disabled and employed individuals who have some level of employer provided health insurance coverage (Tucker, 1991, p. 235). The employer is required to provide equal access for the disabled to whatever health insurance coverage is offered for other employees. The employed infertile woman or man whose company does not offer an employer health insurance program at all cannot call on the ADA to resolve insurance disputes.

"Employed Uninsured Infertile" and Representation in Health Care Policy Decision Making

I am going to suggest that it is unjust to focus on the needs of a few infertile- the privileged employed and medically insured. One could argue that the "employed uninsured infertile" should have the same opportunities to receive some form of financial assistance for their infertility treatments. To begin to improve the situation of the least favored in our society, for example the "employed uninsured infertile", it may be that ethicists need to force attention towards power and address how the disadvantaged often lack the power to overcome their oppressive situations. Rawls' theory of "justice as fairness" assumes the idea that the principles of justice are agreed to in an initial situation that is fair (Rawls, 1971, p. 12). But, an unfair and unjust situation exists in our society when a class of disadvantaged people, medically uninsured infertile, cannot access medical treatment to address their infertility. Rawls (1971) acknowledges that we are born into particular classes, races and gender: "Each person finds himself placed at birth in some particular position in some particular society, and the nature of this position materially affects his life prospects" (p. 13). He also acknowledges that for justice to exist we need equal liberty. "If some have more votes than others, political liberty is unequal; and the same is true if the votes of some are weighted much more heavily, or if a segment of society is without the franchise altogether (Rawls, 1971, p. 247). However, he does not explicitly address how difficult it is for disadvantaged members of society to gain equal liberty.

Disenfranchised and marginalized medically uninsured Americans need to focus first how to obtain the power to influence policies that would change their difficult situation. Wolf (1996) suggests that "if the account of justice begins with an understanding of oppression, it can call into question the structures in which goods are produced and assigned value, as well as how they are distributed" (p. 355). The insured and employed infertile women and men who have had the courage and resources to question why their employers limit coverage, or often do not cover infertility treatments, have gathered the strength and power of the United States Supreme Court. They can now challenge how employers and insurance companies allocate health care resources for infertility services. The uninsured employed infertile currently finds themselves powerless to change their oppressive situation. Any reform that takes place regarding the

just distribution of health care resources and which addresses the just distribution of other social goods must ensure that when beneficial care must be denied the burden does not fall unjustly on any one group of people (Wolf, 1996, p. 357). The medically uninsured have unjustly carried this burden.

Summary

My research has revealed that the ADA clearly has weaknesses regarding its vague definition of disability and its oversight of medical insurance provision for the disabled community:

> "Mr. President, the ADA leaves many such troubling questions unanswered. The bill is a legislative Rorschach test, an inkblot whose meaning and significance will be determined through years of costly litigation. While I voted for this bill because I believe that the rights of people with disabilities must be protected, I did so with the awareness that it will engender wave upon wave of court rulings that will extend the bill far beyond its intended purposes." (Senator Armstrong, Congressional Record- Senate, July 13, 1990, p. 17375)

Senator Armstrong was visionary in his prediction that the ADA would encounter problems with how it should be interpreted especially with regards to health insurance protections for the disabled. Interestingly, all anti-disability discrimination lawsuits filed to date by the infertile to protect their employment or to fight for access to medical insurance coverage for their infertility have revealed that the ADA is a legislative nightmare. However, the ADA route does not resolve difficulties in providing medical insurance for the "employed uninsured infertile" and all other medically uninsured in this country. The ADA provides limited opportunity for the traditionally disabled and the recently "reproductively disabled" communities to challenge the injustices of inadequate medical insurance coverage for their needs. But, the ADA cannot help the disenfranchised and marginalized- "employed uninsured infertile" improve access to health insurance coverage for their infertility treatments.

THE ADDITIONAL LABEL DISABLED AND THE POTENTIAL TO DISCOUARGE THE INFERTILE FROM OPENLY DISCUSSING ISSUES REGARDING INADEQUATE HEALTH INSURANCE COVERAGE

In this section I am going to question whether negative stereotypes will be perpetuated for the infertile if they are also labeled disabled. Historically, society has defined infertility in America as a pitiable personal problem relegated to the private realm of compassion and medicine or a selfish choice, but inappropriate to discuss in the public arena. Alternatively, activism associated with the disabled, who have fought for equal-rights "while eschewing stereotypical stories about courageous people who overcame their disabilities or found serenity in their suffering" may cause the infertile to become more vocal about their needs regarding financial assistance for their infertility (Garland-Thomson, 2001, p. B11)

Representation, or Lack Thereof, of Infertile Personal Narratives in Literature

Reviews of the literature concerning infertility reveals that the less privileged in the infertile community have been largely underrepresented. Authors often focus on the consequences of infertility for the educated white middle and upper class women rather than on the effects of involuntary childlessness on other races and classes. A common anecdotal story is that women who have postponed having children to further their education and careers later find out that they are unable to conceive a child of their own. Those individuals who often write about what the infertile experience in their lives are-lawyers, physicians, philosophers, psychologists, and feminists- not the infertile. What is apparent is that the voices of infertile poor and infertile women of color are often silent. Women from all races and classes find great joy and personal fulfillment in having children of their own. However, according to May (1995), "the poor and people of color are even more devastated by childlessness than the affluent white middle class, because they experience proportionately more of their total feelings of satisfaction in the family than do the affluent and they were also less likely to afford infertility treatment" (p.134).

May and Marsh and Ronner attempted to enrich their historical accounts of infertility by including the voices of the childless themselves. Marsh and Ronner combed memoirs, hospital records, women's magazines and medical journals in an attempt to capture American attitudes towards infertility from the perspective of the infertile. They illustrate that historically the pressure for women to seek medical treatment for their infertility comes not from the "medical establishment", but rather from the cultural expectation that most women will be mothers and that women tend to internalize this belief (Marsh and Ronner, 1996, p. 252). By the twentieth century a societal expectation was that a successful marriage and healthy family life demanded the presence of children. This is revealed in the statement of a twenty-year-old woman who, upon seeking advice for her possible infertility, explained that, "My only goal in life is to become a mother" (Marsh and Ronner, 1996, p. 153). May (1995) states that she wanted to include "the voices of the childless themselves". She sent an "author's query" to all the newspapers and journals in the United States which targeted about 50,000 subscribers asking the voluntarily and involuntarily childless to write to her. She received replies from "more than 500 people" (p. 4). A common theme described by each author is that married childless women often found their "condition" intolerable and aggressively sought medical intervention to help them overcome their infertility. However, what was not evident from the narratives solicited by the authors was whether or not reflections by the infertile poor were represented.

Cultural and Social Events that helped to Move a Very Private Situation, Infertility, Public

Ronner and Marsh (1996) identified some key cultural and social events that motivated women, physicians and the popular press to bring topics of sexuality and infertility before the public. During the late 1800's, discussion regarding men's responsibility for inflicting sterility on their wives as a result of acquiring gonorrhea from prostitutes took place amongst physicians. By the early 1900's, physicians publicly conveyed their concern that infertility might be caused by venereal disease. Using the popular press "an influential group of physicians and anti-vice reformers attempted to convince the public that gonorrhea was perhaps the most important cause of both absolute and "one-child" sterility in the United States " (p. 116). Physicians and the public press helped move public the very private concern regarding fertility to help stop the rise in infertility encountered. These authors also note that other changes taking place in the 1900's, such as an increased openness to birth control, divorce, and sexual intimacy, also generated a willingness among men and women to speak publicly about their personal struggles with not being able to have children of their own.

Voices Are Missing

My research has revealed that a major weakness in historical accounts of infertility is that they do not incorporate more voices of women unable to seek medical treatment for their infertility because they could not afford it. A forum should exist which provides active and informed participation by members of the infertile community and the population in general to resolve difficult issues surrounding access to health care. Marsh, and Ronner (1996) mention that some poor infertile women did indeed receive free care from certain physician groups in the past (p. 158). But they did not analyze this issue in depth. Women decide not to seek treatment for their infertility because they have a hard time coping with the overwhelming emotional and physical component of infertility treatments. However, as importantly, there are many women and men who are unable and unwilling to seek medical treatment for their infertility because they cannot afford to do so. The population of uninsured poor infertile has been and continues to be marginalized. This "unworthy" class of individuals has been relegated to a negative position within society because they are often seen as being responsible for poverty, crime, and a host of other social problems (May, 1995, p. 125).

If the number of medically uninsured continues to increase during the 21st century in the United States, the definition or perception of "parental worthiness" might change. The privileged/insured might themselves become medically uninsured with respect to infertility. An apparent trend in the United States is that more employers are assessing the broad categories of needs for their employees and the costs associated with providing for those needs. Employers are increasingly deciding not to offer health insurance for their employees.

Infertility has been and continues to be an intensely private matter for women. It often takes an extraordinary charge, claim or practice to motivate an infertile woman to take her concerns public. For example, early in the 20th century women with infertility problems began to speak out as a defense against being labeled as participants in what had come to be called "race suicide" (Marsh and Ronner, 1996, p. 113). The involuntarily childless were implicated unjustly by some in their communities as participants in the drastic decline in the birthrate among native-born white Protestants of English decent. The second half of the twentieth century witnessed a public outcry against non-consensual sterilizations. With the emergence of various civil rights movements in the United States numerous states began repealing legislation that permitted eugenic sterilization (Encyclopedia of BioEthics, Vol. 2, p. 844). During the late 1900's, a new force continued to move the intensely personal experience of the infertile from the private domain into a very public domain. Those who felt their infertility treatments should be fully or at least partially covered under their insurance plans took their concerns to the United States courts.

Incorporating Voices of the Infertile and Health Care Policy Decision Making

When considering the availability of quality health care and health insurance coverage for the infertile, for example the availability of treatments necessary to diagnose why someone cannot get pregnant, the personal narratives of the uninsured infertile should be included. People of color and the poor have the highest rates of childlessness

in the United States often due to poverty and poor health care. Yet, they are often among the least insured in the United States. According to May (1995), poor and working-class women experience a higher rate of infertility than highly educated and affluent women (p. 246). Berg (1995) claims that when addressing risk factors for infertility, epidemiologists have identified three risk factors: (1) being black; (2) being a woman with a lower educational level; and (3) being a woman of advanced age (p. 92). A prevailing thought is that the higher rates of sexually transmitted diseases in the black population place them at great risk to experience reduced fecundity (p. 92). May (1995) states that, the rates of childlessness among whites, blacks and Hispanics have fluctuated over time. However, educated, affluent women of all racial backgrounds have similar rates of infertility (p. 12).

It is unreasonable to rely on anti-disability discrimination laws to increase active and informed participation in discussion regarding access to health care for the infertile. Americans have come to ask more and more of their government regarding access to health care. However, when we rely on interest groups to make democracy work the possibility exists that we as a society will deepen the divisions separating different elements of the population (Bok, 2001, p. B9). Perhaps, by encouraging improved moral conversation that takes into account the voices and values of all those affected by infertility, the "community" of health care providers will begin to improve care for all those affected by infertility.

An increased willingness to discuss infertility issues publicly rather than privately is a step in the right direction. The infertile in the 21st century appear to be more open to discussing issues surrounding infertility. We appear to be taking our concerns more

publicly instead of agonizing privately. Women in particular appear to be more willing to question the benefits and risks of old and new medical treatment options available for infertility. They are also very vocal when it comes to questions regarding health insurance coverage for infertility. I recently had an opportunity to join an Internet "chat" room dedicated to infertility issues. Two things were readily apparent. First, the women (I am assuming the participants were women because of their code names) were extremely candid about why they felt the way they did about the lack of insurance coverage for infertility. Some of them expressed anger, outrage and frustration because they could not afford to pursue certain treatment options due too the fact that their employer did not cover certain aspects of infertility treatment (such as in-vitro fertilization). To pay for infertility treatments, working class couples often exhaust their savings, take out a second mortgage on their homes and/or call on family members to help them financially. The cost of a series of three monthly attempts at artificial insemination can average $950. The average cost of a single monthly cycle of Clomid is $2,000. Clomid is a hormone used to stimulate egg production. Gamete intrafallopian transfer can cost $12,000. If the couple decides to cyropreserve some of the embryos fertilized in the laboratory for possible future implantation, the costs rise. (Gabriel, 1996) The average cost of an in-vitro fertilization cycle is $7,800, according to the American Society for Reproductive Medicine. (Gabriel, 1996) In today's market, one round of IVF can easily cost more than $10,000. Second, it was evident that these "chat" room participants were very generous in their offers to help each other find out appropriate answers to their questions. Participants offered phone numbers, addresses, and personal contacts to fellow participants. However, none of the women had heard about the court challenges regarding infertility as a disability (I presented the issue). This was a new concept to them. In response one of the infertile participants emphatically stated: "I am not disabled!!!"

However, the ADA forum and the Internet forum do not tackle the difficult moral issue that the infertile poor and uninsured find their pursuit of happiness unjustly compromised. These men and women cannot afford to pursue their desire to have children of their own without some form of financial assistance. The ADA has played an invaluable role in ensuring that the interests of the employed traditionally disabled are represented in the policy-making process. The Internet forum has provided a much-needed public outlet for the infertile to exchange information (hopefully accurate information) and share emotions. Neither forum considers the long- term implications or consequences of how the results of the infertile being labeled disabled will impact future health care policy.

Even though I have suggested that the infertile should not embrace the label disabled as a means to adjudicate entitlements to medical benefits for infertility, it is important that these individuals have taken their cause public. It often takes a sense of injustice along with feelings of anger, outrage and at times revulsion that accompanies a person's sense of injustice to overcome shame and motivate particular individuals to take their very private concerns public. Unfortunately, my research revealed that the relative silence of the infertile persons perspective regarding all aspects of their reproductive lives, including but not limited to their concerns regarding the economic, emotional, physical, and psychological aspects of infertility, is an issue authors and politicians are just beginning to address.

CONCLUSION

I have demonstrated that the infertile in America should not rely on the Americans with Disabilities Act of 1990 to solve problems in access to health insurance coverage for their infertility. The ADA has justly helped women to maintain employment while they pursue medical treatments for their infertility. The ADA route has also helped to move a very private issue public. This is a good thing for all of us. As our country continues to address difficult issues regarding the provision of health care, those courageous enough to take their historically private condition- infertility - public have helped break down the wall of silence for other infertile. The values, wants, needs, and desires, of the infertile need to be considered by a larger audience as future health care policy is established. However, it should not be assumed that all infertile women and men believe that being labeled disabled as a means to improve access to resources for their infertility is the right path. The ADA forum does not provide a means to address how to help the poor/uninsured infertile receive medical treatments for their infertility. Also, those infertile that have appropriated the label disabled, as a means to increase access to medical resources for their infertility, fail to respect those who are disabled in the traditional senses.

It might be inappropriate to some people to argue that the infertile poor/uninsured individual ought to receive some form of financial assistance to help them conceive a child. It could be argued that if you are poor/uninsured in this country you would not be able to financially support yourself- let alone a child. Nevertheless, in the past, the infertile of limited means received financial help and political support from private physicians and their state governments. In the early 1900's indigent couples could receive medical treatment for their infertility at free clinics. "The 1930's witnessed the growth of a number of free or low-cost infertility clinics, some of which had been started a decade or so previously" (Marsh and Ronner, 1996, p. 158). But, in the early 21st century, when this country has more than 44.3 million medically uninsured men, women and children, it might not be inappropriate to advocate that the poor/uninsured infertile receive some form of financial assistance for infertility treatments (Fleck , 2000, p. 3B). It is unfair to judge the uninsured infertile persons worthiness to have children when the rate of medically uninsured is already high and all indications suggest that the rate of the medically uninsured in the United States continues to increase on a daily basis. In fact, the percentage of medically uninsured may now be greater than that of the medically insured. To not address how and why so many people go without needed health care because they cannot afford to pay for it, is immoral.

Finally, those infertile that have appropriated the label disabled, as a means to increase access to medical resources for their infertility, have failed to respect those who are disabled in the traditional senses. The primary goal of those who claim a "reproductive disability" under the ADA is to "eliminate" or overcome their infertility, not to begin to understand how disability is integral to a person's character and life experiences. Immanuel Kant believed that human beings occupy a special place in creation. "Human beings have an intrinsic worth, i.e., dignity, which makes them valuable above all price" (Rachels, 1986, p. 114). The traditionally disabled have fought for the same civil rights and opportunities that all citizens have. They have also struggled to restore dignity and respect to their lives. The ADA has helped them to achieve these most basic and valuable goals. "I have come to know the daily frustrations, and needs of those who live with disabilities. I have had to learn to talk again, to read again, and to walk again" (James Brady; Congressional Record-Senate, July 13, 1990, p. 17368). For the traditionally disabled, disability is a fundamental part of their lives, as is striving for the self-respect and self-esteem all human beings deserve. Tremendous heartache is associated with not being able to have of your own. The feelings of despair can be overwhelming for the infertile. However, most infertile men and women who claim a "reproductive disability" under the ADA have never experienced the heartache associated with being disabled in the traditional sense. The Americans with Disabilities Act of 1990 should be allowed to do what it was intended to do: help the truly disabled to be treated fairly, to be accepted, and to contribute fully to our country. There must be a better avenue for the infertile to challenge the perceived injustices they feel when they are denied health insurance coverage for their condition.

The infertile that have called on anti-disability discrimination laws to resolve insurance disputes and to maintain their employment would disagree with my argument. Diane Aronson, executive director of Resolve, a national advocacy program for the infertile, which is located in Somerville, MA, applauded the United States Supreme Court's decision. Aronson stated, "We believe this ruling will help to strengthen the claims of discrimination when those with infertility are not allowed workplace accommodations to undergo treatments or when an employer does not provide infertility insurance coverage. The Supreme Court's decision will make it more difficult to unfairly discriminate against those who experience infertility" (MSNBC, July 24, 1999). Advocates for the infertile feel that the Supreme Court has provided the employed and

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medically insured infertile community a powerful new weapon to use against their employers and insurance companies (Resolve's "FAST FACTS" newsletter, faxed on January 6, 1999). Advocates for the infertile feel that infertility is a medical aliment that warrants some form of health insurance coverage. Most insurance companies will cover medical treatments that help individuals determine the reason(s) behind their infertility. But, many health insurance companies limit access to resources that might help the infertile conceive. It is expected that the recent court decisions will increase access to health insurance for infertility services. Advocates feel that since some employer based or government subsidized health insurance covers medical treatment of many other disabilities, infertility treatments should be a covered health insurance benefit. Yet, lost in the equation is that anti-disability discrimination laws only apply to those who are employed and insured by their employer.

To comment on whether some infertile truly believe they are disabled in the traditional sense, would be speculation. However, statements made contradicting such a belief are not uncommon. Statements such as the following have been made: "Call me disabled if it will improve my opportunity to receive health insurance coverage for infertility" (infertile friend). Or, "I may appear perfectly normal—I can do mostly everything—run, jump, skip—but physically we are – we are disabled, we're diseased in a way because we can't procreate naturally" (National Public Radio, 1998). Nevertheless, the courts have validated the notion that reproduction or procreation could be considered a "major life activity" under the ADA because "reproduction and the sexual dynamics surrounding it are central to the life process itself" (Justice Kennedy; 118B S. Supp.2205). The ADA clearly has weakness in its original vague definition of

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disability and as with any policy it will evolve and change. But, any future changes that occur in ADA policy should improve upon what the traditionally disabled fought for: inclusion, understanding, respect and dignity. The "reproductively disabled" have failed to demonstrate with their actions and words that they understand how important these issues are for those who have struggled to overcome the stigma of disability.

The means society uses to improve health insurance coverage for infertility ought to be respectful to the traditionally disabled community and based on a universal premise that applies to all infertile, not just the privileged "employed insured infertile". It is not unreasonable to ask everyone to think beyond his or her aliments and think about how medical coverage for all of the uninsured, including the uninsured infertile population can be improved. The real problem to be addressed is how to provide coverage to the 40-50 million completely uninsured people in the United States and the other 50 million underinsured people (George Innis, National Public Radio, 1998). Once addressed, health care access would be improved for everyone- including the infertile and disabled communities. This will provide a more just resolution. One class of individuals will not be used to advance the causes of another class.

As a society, we need to focus on the more productive initiatives taking place regarding infertility. Researchers are addressing the effectiveness of particular treatments and the costs associated with treatments. They are looking at cost-effective, evidence-based infertility care (Gleicher, 2000 and Salim, 2000). Economic evaluation of infertility services is important especially as the demand for services increases. We also need to first prevent what infertility we can. Not only can there be economic benefits in preventing infertility, but more women and men would be able to experience one of life's

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most joyful pursuits, having their own biological child with as little medical intervention as is possible.

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