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Involuntary Sterilization of the Mentally Challenged: A Legal and Ethical Dilemma

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Abstract

The mentally incompetent, including the developmentally disabled and the mentally ill, represent a vulnerable segment of our society that historically has been segregated, violated, and victimized. Since the late 1800s, we have evolved from an elitist, eugenic society to a more humane people, accepting our responsibility to provide adequate care and services to this population while protecting their constitutional rights of privacy, self-determination, and procreation. The right of procreation has mainly been denied due to nonconsensual or involuntary sterilization since the early 1900s until the past twenty-five years. Twenty-one states in America still have statutes addressing involuntary sterilization of the mentally incompetent. Largely due to public sentiment regarding moral obligations generated after World War II, appealed state court rulings, and Supreme Court declarations, most states have established guidelines and criteria which must be closely adhered to prior to any final court decision regarding involuntary sterilization.

Key words: mentally challenged, reproductive rights, involuntary sterilization, eugenics

Introduction

A twenty-seven-year-old woman is admitted to a psychiatric in-patient unit with a diagnosis of schizophrenia, suffering from an acute exacerbation of her symptoms. She is paranoid, delusional (talking to unseen others), refusing all care, and six months pregnant. Admission records indicate that she had been seen by an obstetrician (taken by her outpatient therapist) who reports the patient is in her second trimester or approximately twenty-four weeks into pregnancy. With much encouragement, the patient is coaxed into allowing a physical exam. Findings are inconclusive and do not indicate a pregnancy that far advanced. There are no audible fetal heart sounds nor does the size of her uterus indicate that gestational size. The probable diagnosis at this time is fetal demise, most likely due to a fall down a flight of stairs she suffered approximately four weeks prior to this admission. According to the patient's social worker, the boyfriend had pushed the woman down the stairs after she refused to give him her Social Security check.

The young woman has a long psychiatric history with multiple in-patient admissions for stabilization of her schizophrenia. She has also had multiple pregnancies; this was her fifth. All previous children were removed from her care at the time of birth and placed in foster homes. She steadfastly refused to use any birth control or submit to sterilization, stating that she loves children and the "operation would hurt."

A twenty-five-year-old developmentally disabled woman with a psychiatric diagnosis of schizoaffective disorder is admitted to the inpatient psychiatric unit. She is also pregnant with the delivery of her eighth child anticipated within the next several days. In addition to her limited intellectual capabilities (testable IQ of 65-70) and psychiatric symptoms, she has a long history of multiple pregnancies and substance abuse. This is her eighth pregnancy, having had each prior child removed from her care at birth and placed into foster care. She also refuses sterilization.

A third case involves a twenty-one-year-old profoundly mentally disabled woman who has been living at home with her mother. The parent finally decided to place her daughter in a supervised living situation (group home for the developmentally disabled) in addition to a sheltered workshop setting. She petitioned the court to have her daughter sterilized prior to the move.

These three scenarios represent a legal-ethical dilemma that presently does not have any clearly delineated solutions in many states. Should these three women be involuntarily sterilized? What rights and protection do they possess, or do we, as a society, have a right to make decisions regarding the fertility status and procreation rights of individuals we deem less than perfect?

Historical Discussion with a Legal and Ethical Analysis

The population that society defines as the mentally incompetent historically has been segregated, victimized, abused, and manipulated. A movement that began in the late eighteen hundreds

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in many European countries, plus the United States and Canada, gaining momentum well into the early nineteen hundreds, was one of involuntary sterilization, or eugenics (Kevles, 1999). The term was originally introduced by Francis Galton, who happened to be Charles Darwin's cousin. It was defined as a "science" with its original roots in Great Britain but with the major growth in the United States primarily between the years 1895-1945 (Reilly, 1991; Volokh, 2011). Eugenics is defined as the practice of selective breeding for the improvement of hereditary characteristics. This so-called science was derived from Darwin's Theory of Evolution (Blank, 1991; Cussins, 2013). The legal objectives of the eugenics movement in the U.S. included: "restrictive marriage laws, involuntary sterilization and limits on immigration," (Larson, 1995). Marriage restrictions forbad the union between any man or woman who was considered to have epilepsy, be an imbecile, or feebleminded. The first state to enact such a law was Connecticut, in 1896, decreeing any such union as null and void unless the woman was over 45 years old (Larson, 1995; Krase, 2014). Approximately twenty-five more states followed suit, restricting any marriage or union of a person or persons diagnosed with a mental deficit. In 1914, a man named Harry Laughlin, a proponent of eugenics, published the "Model of Eugenic Sterilization Law," a document proposing the authorization of sterilization for what he termed the "socially inadequate" (Lombardo, 2001). This encompassed the "feebleminded, insane, criminalistic, epileptic, inebriate, diseased, blind, deaf, deformed, and dependent, which included orphans, tramps, the homeless and paupers" (Lombardo, 2001). By that same year, twelve states had passed sterilization laws. Over three thousand people had been sterilized involuntarily by 1924 with California having the most cases. That same year, the state of Virginia enacted laws permitting involuntary sterilization laws based on Mr. Laughlin's model (Lombardo, 2001). Virginia legislators justified passing the statues as cost savings strategies because the care of the insane and feebleminded rested primarily on the state. The law also proclaimed heredity as the transmission mode of mental deficiency with the resulting offspring creating a "menace to society" (Lombardo, 2001). The Supreme Court ruled in 1927 that these laws were constitutional.

Other early supporters of the eugenics movement included prison wardens, superintendents of mental institutions, sociologists, and social workers (Blank, 1991). Their philosophy was one of "mental defectives begot mental defectives; prevent their breeding and eliminate the unfit" (Blank, 1991; Krase, 2014). One such early proponent was Margaret Sanger, who was influential in the women's movement for birth control. She advocated sterilization for the "unfit," arguing that the "warm heart" of society has allowed them to reproduce themselves, when in fact, they should be "obliterated from the human stock" (Blank, 1991). As the movement gained impetus within the institutional setting, nonconsensual sterilizations were performed, primarily by the castration of males. Fortunately, as surgical techniques improved, vasectomies became the procedure of choice. Currently, states having eugenics statutes forbid castration but provide for vasectomy or salpingectomy only. Anyone performing castration or any other form of sterilization not described by the law may be subject to criminal charges for assault and battery (Pozgar, 1999).

In the early 1900s, several states attempted unsuccessfully to promulgate statutes mandating involuntary sterilization. By 1910, four states did manage to pass statutes, with another four states having similar laws by the end of the 1920s (Southwick, 1988). By 1924, 3,000 people had been involuntarily sterilized with the numbers being over 20,000 by 1927 (Reilly, 1991; Cussins, 2013).

Public sentiment was largely opposed to eugenics, but the movement had support from some prohibitionists and antiwar supporters. Legal strength was gained with the court decision and proclamation by Supreme Court Justice Oliver Wendell Holmes, in 1927, in the case of Buck v. Bell. In the state of Virginia, in 1927, a seventeen-year-old institutionalized woman by the name of Carrie Buck was chosen for sterilization. She was an unmarried mother of one child living at the same institution as her mother, also a diagnosed "mental defective". Institutional directors, supported by state officials, declared that Carrie's mental deficiency represented an example of inherited feeblemindedness. For the believers of inherited mental defectiveness, Carrie, her daughter, and her mother represented proof of genetic transmission. Public sentiment against eugenics allowed Carrie legal representation to challenge the constitutionality of Virginia's sterilization statues (Lombardo, 2001; Krase, 2014). Witnesses at her trial included the superintendent of the institution, Dr. Albert Priddy, sociologist Arthur Estabrook of the Eugenics Record Office, and a Red Cross nurse. Dr. Priddy testified that Carrie and her mother had a "record of immorality, prostitution, untruthfulness and syphilis. These people belong to the shiftless, ignorant, and worthless class of anti-social whites of the South" (Lombardo, 2001). Mr. Estabrook and the nurse, following an examination of Carrie's child, declared that she too was mentally deficient. Based on these comments, the Virginia judge upheld the eugenics law and ordered Carrie's sterilization to prevent further defective children being born (Lombardo, 2001). The court decision was appealed to the United States Supreme Court in front of Justice Oliver Wendell Holmes. Being a proponent of the eugenics movement, he upheld the involuntary sterilization ruling of Carrie Buck. He reiterated the so-called facts of the case, declaring the need for sterilization based on the mother, daughter, and granddaughter's mental defectiveness. His memorable words: "It is better for all the world, if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind……three generations of imbeciles are enough" (Buck v. Bell, 1927). Strong opposition to his ruling came primarily from the medical community, arguing statistically that 80% of mentally retarded individuals are born of normal parents and that no scientific evidence supported his claim (Blank, 1991). Unfortunately, the case of Buck v. Bell set the precedent for the subsequent sterilization of approximately 8300 more institutionalized individuals in the state of Virginia (Lombardo, 2001; Krase, 2014).

Future scholarly research uncovered a conspiracy between Carrie Buck's attorney and the lawyer for Virginia to guarantee the upholding of the Virginia sterilization laws based on the eugenics philosophy. It was found that Carrie's pregnancy resulted after a rape and not from sexual promiscuity. Her child, named Vivian, had above average intelligence receiving "As" and "Bs" on her school report card (Lombardo, 2001).

In 1933, Nazi Germany passed their eugenics law based on Harry Laughlin's Model Eugenical Sterilization Law. The law empowered the government to sterilize any persons with mental retardation, mental illness, epilepsy, blindness, deafness, physical deformity,

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alcoholism, or any hereditary condition. Nearly 250,000 people had been sterilized by 1937 before the government expanded the scope of the law to include Jews (Larson, 1995). Laughlin was even awarded an honorary degree from the University of Heidelberg in 1936 for his creation of the "science of racial cleansing" (Lombardo, 2001).

Fortunately, the eugenics movement weakened and fragmented over the ensuing years. By World War II, public sentiment likened eugenics to the Nazi selective breeding programs. Regrettably, public opinion could not overturn all state statutes with twenty-one still having involuntary sterilization laws (Blank, 1991; Krase, 2014). Of these twenty-one states, only four make reference to eugenics or heredity. The states allowing eugenic sterilization have laws that provide:

- "a grant of authority to public officials supervising state institutions for the mentally ill or prisons and to certain public health officials to conduct sterilization
- a requirement of personal notice to the person subject to sterilization and if that person is unable to comprehend what is involved, notice to the person's legal representative, guardian, or nearest relative
- a hearing by the board designated in the particular statute to determine the propriety of the prospective sterilization; at the hearing, evidence may be presented, and the patient must be present or represented by counsel or the nearest relative or guardian
- an opportunity to appeal the board's ruling to a court" (Pozgar, 1999, pp.156).

The balance of the states justify their statutes proclaiming the use of such laws is in the "best interest of the person" or for the "welfare of society" (Blank, 1991). The majority of the states do require court hearings (following a petition made by a representative for the individual), while four states only require an administrative hearing.

Following the end of World War II, requests for involuntary sterilization of the mentally incompetent have come under the close scrutiny of the court system. The mentally retarded or mentally ill individual unable to give informed consent still possesses the same constitutional rights of privacy, self-determination, and procreation that are granted to a competent individual. However, the courts still tend to favor the precedent set forth by Buck v. Bell (1927), the ruling never being overturned in all these years. In states possessing laws for involuntary sterilization, specific guidelines are being federally recommended for the protection of the individual's constitutional rights (Southwick, 1989). U.S. District Court cases that have been instrumental in narrowing guidelines and encouraging states to rewrite laws for the purpose of safeguarding procedures and protecting the individual are the North Carolina Association for Retarded Children v. State of North Carolina (1976) and Lulos v. State (Indiana, 1990). The U.S. Supreme Court urged these states to revise any statutes that cited eugenics or heredity as justification for nonconsensual sterilization, and to clearly define a specific set of criteria relevant to ruling on any requests for involuntary sterilization. North Carolina and Indiana redefined their statutory guidelines; they now include reference to the "person's physical ability to reproduce, the likelihood that the individual would engage in this behavior, unacceptable alternative birth control measures and the person's ability or inability to adequately care for a child" (North Carolina Association for Retarded Children v. State of North Carolina 1976).

Several other court proceedings have involved the critical analysis of sterilization laws, especially as the scientific community has attacked these statutes and discredited the views of hereditary mental deficiency. A Minnesota Court of Appeals cited "that sterilization must not be used as a subterfuge for convenience and relief from the responsibility of supervision" (Minn. App. 1985). The ability of society to decide who will or will not become parents was challenged by the New Jersey Supreme Court:

> "It cannot be forgotten, however, that public attitudes toward mental impairment and the handicapped in general have sometimes been very different. We must always remain mindful of the atrocities that people of our own century and culture have committed upon their fellow humans. We cannot adequately express our abhorrence for the kind of ideology that assigns vastly differing value to the lives of human beings because of their innate group characteristics or personal handicaps" (In re Grady, 1981).

The Grady case involved a nineteen-year-old woman with Down's syndrome and mental impairment. Her parents petitioned the court for a reliable means of contraception prior to her moving from their home into a supervised group home setting. The petition was initiated after a local hospital refused to perform the procedure based solely on parental consent. A guardian ad litem was appointed for the young woman, who agreed with the parents that sterilization was the best alternative. Trial proceedings agreed with the guardian ad litem and parents, however, a public advocate and the attorney general appealed the decision (Southwick, 1988). The New Jersey Supreme Court noted that involuntary sterilization of the mentally incompetent had an extensive history of abuse; the court system, therefore, was attempting to provide a substitute decision for the incompetent individual while protecting his or her best interests:

> "As we stated earlier, Lee Ann Grady has the same constitutional right of privacy as anyone else to choose whether or not to undergo sterilization. Unfortunately, she lacks the ability to make that choice for herself. We do not pretend that the choice of her parents, her guardian ad litem, or a court is her own choice. But it is a genuine choice nevertheless-one designed to further the same interests she might pursue had she the ability to decide herself. We believe that having the choice made in her behalf produces a more just and compassionate result that leaving Lee Ann with no way of exercising a constitutional right. Our Court should accept the responsibility of providing her with a choice to compensate her inability to exercise personally an important constitutional right" (In re Grady, 1981).

States that have repealed or had no existing statutes regulating involuntary sterilization of incompetent persons have instituted several procedural safeguards to protect the individual's constitutional right of self-determination. These include: "the appointment of a guardian ad litem, an adversarial hearing, and limits in the court's control" (Krais, 1989; "The right to Self-determination," 2015). Two theories, the "best interest" test and the "substituted judgment" test further protect the

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mentally incompetent's constitutional rights. The first is based on the individual's needs, while the second deals with a substitute decision made by the court (hopefully the same decision that would have been made by the incompetent individual were he or she competent) (Krais, 1989; Krase, 2014).

The "substitute decision" theory has its flaws, and if evaluated rationally, who can predict the decisions of anyone, competent or incompetent, in any given time or circumstance. More comprehensive criteria resulted from a Massachusetts Supreme Court judge who refused to predict what decision a mentally challenged person would make. He cited that the feasibility of a substituted judgment should encompass the satisfaction of such factors as:

1. a finding of incompetence
2. physical ability of the disabled person to procreate
3. realistic existence of other means of birth control
4. any medical necessity for the procedure
5. extent of the individual's disability
6. the likelihood that the individual will engage in sexual relations
7. the psychological or traumatic health risks associated with such an operation (Krais, 1989).

The "best interest" aspect was tested and further defined by the New Jersey Supreme Court in the Lee Ann Grady case. The court recommended the review of nine elements in considering a "best interest" decision for a mentally incompetent person:

1. "can the incompetent person become pregnant
2. what is the possibility of trauma or psychological damage as a result of either giving birth or being sterilized
3. will the individual be in a situation where sexual intercourse, either voluntary or imposed, can occur
4. does the incompetent person understand reproduction or conception
5. are there less drastic means of contraception
6. should the sterilization procedure take place now, or would it be more appropriate to take place some time in the future
7. can the incompetent person care for a child
8. will medical technology advance to either: (a) improve the incompetent person's condition or (b) make the sterilization procedure less drastic
9. is the sterilization being sought in good faith and in the best interests of the incompetent person" (In re Grady, 1981) (Krais, 1989).

The "substituted judgment" standard and the nine-question "best interest" test enables the court systems to use guidelines to determine what is good for the individual while still protecting his or her constitutional rights.

The American Association on Mental Deficiency adopted a Code of Ethics in 1974 with updates and revisions added in 1998. Even though there has been a steady decline in the applications for sterilization of the mentally incompetent, the organization felt compelled to publish a Code of Ethics as twenty-one states have failed to repeal statues allowing this procedure. Some of the states continue to mandate sterilization of persons they deem socially irresponsible or as a requirement to receive financial and social assistance upon release from an institution (American Association on Mental Deficiency, 1998). The ethical guidelines published by the organization encompass the division of the general population into three classes: (1) "competent persons or persons who are presumed to be competent, (2) legally incompetent persons, and (3) persons of impaired capacity" (American Association on Mental Deficiency, 1998; Cussins, 2013). The legally competent person or one presumed to be competent possesses and has the ability to exercise all rights of privacy and procreation afforded by the Constitution of the United States. This organization advocates that these same rights for the mentally incompetent or impaired individual be protected through adherence to guidelines based on the "substituted judgment" and "best interest" theories, with the level of an individual's competency being determined by psychological and sociological evaluations, as well as concomitant legal analysis within a legal framework/judgment (American Association on Mental Deficiency, 1998).

Even though judicial and ethical guidelines are in place, many court systems are still reluctant to authorize sterilization, due to the irreversibility of the procedure. In 1979, federal sterilization regulations were passed into law. The essence of the law dealt with standardized consent forms in the person's native language, education as to alternative contraceptive measures available, and informing the individual of the permanency of the procedure. Medical technology has made significant advances in reliable, non-invasive means of contraception for women which now include monthly injections, injections every three months, IUDs, and several types of implants. Even though oral contraception has been available for more than twenty-five years, prevention of pregnancy depends on the incompetent person's living situation, functional level, and her ability to comply with taking a daily medication. Vasectomy still remains the most reliable means of birth control for a man (The Boston Women's Health Book Collective, 1992).

Many of our developmentally disabled and mentally ill persons living in communities across the nation are associated with various private, local, and state operated support organizations. These agencies provide a variety of services in the form of assistance with activities of daily living, transportation, job placement, money management, sex education, and family planning. For example, organizations such as the Association for Retarded Citizens offer sexual hygiene and contraception classes for their clients, tailored to the individuals' level of comprehension. These agencies are strong public advocates that enable and empower our citizens, whom society has historically deemed less than adequate, to exercise the freedom guaranteed to them by the Fourth Amendment of the Constitution of the United States.

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Summary and Recommendations

Involuntary sterilization represents an embarrassing and shameful part of our history. Even though most states do not have nonconsensual sterilization laws on record, twenty-one states still have existing statutes. Of these, four states still refer to sterilization for the purpose of eugenics. In the states without any currents laws, due process requirements of notice and the right to appeal must be met to protect the individual's civil (and human) rights (Pozar, 1999; "The right to Self-determination," 2015). Most follow the guidelines previously discussed to determine the person's level of competency and understanding. However, ethically speaking, if the court decides in favor of sterilization of the mentally incompetent person, can this be anything but thinly disguised eugenics, justified and made socially acceptable by saying it is in the best interest of the person?

Could the concept of eugenics still be with us, albeit masquerading within the guise of new scientific developments? Activists protesting genetic research, particularly the Human Genome Project, proclaim eugenics represents the driving force behind the program. Eventually, the project hopes to give us the ability to identify, test, and modify our genes and those of our future offspring. Both proponents of, and those opposed to, genotyping foresee technological advances enabling the modification of our genomes. If scientific research allows this to become commonplace, will society put pressure on parents to create genetically superior offspring? Levi Boldt's article entitled "What Now?" quoted University of California at Berkeley sociologist, Troy Duster, saying "When eugenics reincarnates this time, it will not come through the front door, as with Hilter's Lebensborn project. Instead, it will come by the back door of screens, treatments and therapies" (Boldt, 2001).

Even though the genetic engineering projects may have a vague resemblance to the practice of eugenics, are there any positive elements that may emerge without any infringement on individual human and civil rights? The gene responsible for the hereditary condition called Huntington's Disease, a fatal neurologically degenerative condition, was discovered in 1993. With its recognition, individuals who are carriers of this fatal hereditary condition are now able to prevent their future generations from suffering from this affliction (Boldt, 2001; Cussins, 2013). If an individual chooses sterilization as a means of preventing the propagation of Huntington's Disease, his or her decision is based on true scientific facts. The eugenics movement had more of an ideological and political thrust with little support from the scientific community. As a more technologically sophisticated society, we now recognize the cause of mental retardation to be multifaceted.

Some factions of society still argue that certain people should not have children, namely, those who carry genetic diseases, the mentally retarded, and the mentally ill. Who are we to say who will or will not have offspring? Involuntary sterilization represents the devaluing and dehumanizing way people with disabilities have been treated, and in some states, still are. Robert Silversteis is quoted as saying:

> "Society has historically imposed attitudinal and institutional barriers that subject persons with disabilities to lives of unjust dependency, segregation, isolation and exclusion. Sometimes these attitudinal and institutional barriers are the result of deep-seated prejudice. At times, these barriers result from decisions to follow the 'old paradigm' of considering people with disabilities as defective and in need of fixing. At other times, these barriers are the result of thoughtlessness, indifference, or lack of understanding. A 'new paradigm' of disability has emerged that considers disability as a natural and normal part of the human experience. Rather than focusing on fixing the individual, the 'new paradigm' focuses on taking effective and meaningful action to fix or modify the natural, constructed, cultural, and social environment. In other words, the focus of the 'new paradigm' is on eliminating the attitudinal and institutional barriers that preclude persons with disabilities from fully participating in society's mainstream" (Delzingaro, 2000).

Conclusion

The three women discussed at the beginning of this paper all had their fertility fates determined by the court systems. The two mentally ill women underwent court ordered tubal ligations, decided based on "best interests", while the profoundly retarded woman's reproductive ability was left intact, as the court refused her mother's petition. All three of these cases took place in New York State, one of the states still having involuntary sterilization statutes in place.

The three cases are relatively current, having taken place within the past ten years. Fortunately, cases such as these do not occur with any frequency, primarily due to changes in public sentiment for the mentally incompetent, support from strong advocacy groups that assist with protecting rights, and continuing repeals of laws in some states still having involuntary sterilization statutes. Perhaps what Margaret Sanger referred to as the "warm heart of society" continues to thrive.

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