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Public Health and Sterilization of the Mentally Disabled: Under What Circumstances Should It Be Scrutinized Versus Granted By Court Order?

By Devin Griffin

I. INTRODUCTION

On July 13, 1955, Valerie was born with Down Syndrome. Consequently, she is severely retarded, with her IQ estimated to be around 30. Given that she has many limitations stemming from her Down Syndrome, she lives with her mother and stepfather, who provide daily care for her. At the age of 29, Valerie's parents sought to have a sterilization procedure performed on their daughter.¹

Valerie's parents sought to sterilize their daughter to prevent what they saw as an imminent outcome of her becoming pregnant. They had sought comprehensive care for their daughter throughout her life. As a consequence of her mental disability, Valerie had little control over or comprehension of the sexual advances she made toward adult men. She received therapy and training for behavior modification, but neither was successful in eliminating her aggressive sexual behavior.

In addition, Valerie had tried numerous forms of birth control. In her teens, she was given birth control pills, which made her ill. Her parents attempted to have her implanted with an intrauterine device; however she was not cooperative in her pelvic exam.

¹See *Sterilization of Women and Girls with Disabilities: A Briefing Paper*, Human Rights Watch (Nov. 10, 2011), <https://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities>. Sterilization is "a process or act that renders an individual incapable of sexual reproduction." It is one of the most commonly used forms of contraception today. This voluntary procedure is not to be confused with forced or coerced sterilization, which occurs when an individual is sterilized after expressly refusing the procedure, without his or her knowledge, or without providing the individual with an opportunity to consent.

In the eyes of Valerie's parents, they would soon grow too old to care for their disabled daughter. She would be forced to move into a residential home, where they would no longer be able to monitor her behavior and prevent her frequent sexual advances. Feeling that other methods of birth control were inadequate for Valerie, her parents felt that sterilization in the form of tubal ligation was the only means of protecting their daughter from future pregnancy.² The issue Valerie's parents face is one that countless mentally disabled individuals, their families, and caretakers face. Should caretakers interfere and act in what they perceive to be the best interest of their mentally disabled daughter? Should they allow their mentally disabled daughter to exercise autonomy, regardless of her mental capacity?

Like many adults, those with mentally disabilities like Valerie have sexual interests and desires. These human desires oftentimes lead them to engage in sexual activity. Of course, sexual activity, when engaged in between members of the opposite sex without taking proper contraceptive precautions, can result in pregnancy.

Sterilization is one of the most frequently chosen forms of contraception in the world.³ Those who do not wish to have children often choose sterilization because it is a simple, safe, and effective way of avoiding unwanted pregnancy.⁴ This permanent procedure contrasts with oral contraceptives, which require an individual to take the contraceptive every day, sometimes at the same time every day. For those who do not wish to have children in the future, sterilization offers convenience and the peace of mind of infallibility.

² See Eugene Volokh, *Sterilization of the Intellectually Disabled*, Washington Post (Apr. 18, 2014), available at https://www.washingtonpost.com/news/volokh-conspiracy/wp/2014/04/18/sterilization-of-the-intellectually-disabled/?utm_term=.538460acfd16.

³ In the United States, sterilization is the most popular form of birth control for couples over thirty. See Isaacs, *Reproductive Rights—1983: An International Survey*, 14 COLUM. HUM. RTS. L. REV. 311, 328 (1983) (90 to 100 million couples worldwide choose sterilization as a method of contraception).

⁴ Many individuals who choose to undergo the procedure are attracted to the one-time nature of the procedure. Once completed, the sterilized individual will not have to worry about becoming pregnant.

Mentally disabled individuals, caregivers, healthcare professionals, and state employees often have various legitimate reasons to seek sterilization of a mentally disabled individual.⁵ Where a mentally disabled woman becomes pregnant, many problems may naturally follow. One possibility is that the mentally disabled woman may not understand that a child is a natural consequence to engaging in unprotected sex with the opposite sex. She may not want to carry or care for the child that occurs as a natural consequence of such sexual activities. Further, a mentally disabled woman may not understand her pregnancy if her disability is severe. This could have harmful affects on both the mentally disabled woman and her fetus. Additionally, a mentally disabled woman may want to carry and care for a child. This individual may already struggle to care for herself, let alone for a newborn infant. Practically speaking, a child may become an additional financial burden for the mentally disabled individual or her caretaker. These considerations are only a few of those that may arise as a result of a pregnancy.

While the reasons above may indicate that sterilization can be beneficial for mentally disabled individuals, sterilization of mentally disabled individuals has ominous associations. Due to implicit complications that arise where a mentally disabled woman becomes pregnant, society in the past sought to restrict the reproductive rights of mentally disabled adults. In the past, many state legislatures passed compulsory eugenic sterilization laws, under which mentally impaired persons were routinely sterilized without their knowledge or consent.⁵ The purpose of these laws was to protect society by preventing reproduction by those deemed socially or mentally inferior.⁶

⁵ The issue of sterilization disproportionately affects women because of their biological ability to become pregnant. However, that is not to say that sterilization is not a tool used by and on mentally disabled men. Nevertheless, this paper will primarily address issues faced by the female mentally disabled population specifically. All pronouns will accordingly be feminine.

⁶ See Eric M. Jaegers, *Modern Judicial Treatment of Procreative Rights of Developmentally Disabled Persons: Equal Rights to Procreation and Sterilization*, 31 U. Louisville J. Fam. L. 947 (1992).

Given the nature of mental disability, women with disabilities were and still are particularly vulnerable to forced sterilizations performed under the auspices of legitimate medical care or the consent of others in their name.⁷ A mentally disabled woman forced to undergo a sterilization procedure may have difficulty understanding or communicating what has been done to her.⁸ Accordingly, such an individual is more likely to fall victim to pressure to undergo the permanent procedure when she does not understand or has been domineered in the decision making process.

Presently, in the United States, sterilization is performed on young girls and women with disabilities like Valerie for various purposes. These reasons range from menstrual management and personal care, to pregnancy prevention, including pregnancies resulting from sexual abuse.⁹ While it is unquestionable that there are legitimate reasons why sterilization may be best for the health and wellbeing of the mentally disabled individual, language in court decisions implicitly indicate that the procedure is oftentimes an attempt at a “quick fix” to the larger scale issue of lack of care and protection for the mentally disabled community.¹⁰ Women with mental disabilities are oftentimes excluded from comprehensive reproductive and sexual health care and are provided with limited voluntary contraceptive choices.¹¹ Overall, an upgrade of the provision of healthcare to mentally disabled individuals can prevent mentally disabled individuals and caregivers from having to undertake such a permanent health solution where it otherwise would not be sought.

Historically, forced sterilization of mentally disabled women was part of a broader pattern of denial of constitutional rights, such as the constitutional right to reproductive autonomy, the

⁷ See *Sterilization of Women and Girls with Disabilities: A Briefing Paper*, Human Rights Watch (Nov. 10, 2011), available at <https://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities>.

⁸ *Id.*

⁹ *Id.*

¹⁰ For example, prevention of pregnancy resulting from sexual assault or abuse is considered by various courts as a legitimate reason to grant the procedure request. This ignores the greater problem of the prevalence of sexual abuse of mentally disabled individuals and cloaks the issue by preventing evidence of the abuse (pregnancy) from surfacing.

¹¹ See *surpa* note 7.

right to marry, and the right to family privacy protected by the Due Process Clause of the Fourteenth Amendment.¹² Because both the court system and the health care system have failed the mentally disabled population in the past with regards to protecting and respecting their sexual and reproductive health, states must take affirmative steps for robust action to ensure that the legal and health system do not fail the mentally disabled population in the present and future.

To ensure the greatest health and autonomy interests are recognized, every state should enact comprehensive legislation to ensure that past eugenic reasoning and abuses do not make their way into the framework of any sterilization consideration. By enacting an enabling statute, each state will be providing considerations and criteria for courts to consider in sterilization requests. In regards to scope of these statutes, each state's legislation should cover sterilization decisions of all mentally disabled individuals suspected to be unable to give meaningful consent.¹³ These safeguards will ensure that the health and wellbeing of each mentally disabled individual are being met.

In addition to these safeguards, judicial analysis should look at the sterilization decision as a part of the individual's overarching procreative rights. Today, modern judicial reasoning dictates that both the right to procreate and the right not to procreate (i.e. to obtain sterilization) are fundamental rights which courts must seek to equally protect.¹⁴ However, issue arises when these two fundamental rights are placed at odds with one another. This is typically the case when parents

¹² *Id.*

¹³ Where the ability to consent is in question, a hearing should be held to determine the mentally disabled individual's ability to consent, and her understanding of the consequences of the procedure. If deemed able to meaningfully consent, the hearing will conclude and the individual may proceed with the procedure by her own will. If she is deemed as unable to consent, the court must determine whether the procedure is in the individual's best interest. This process will ensure that abusive tactics such as coercion are not taking place prior to the permanent procedure.

¹⁴ See *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942) (declaring the right to procreate to be fundamental); but see *In re Moe*, 432 N.E.2d 712, 719 (Mass. 1982) (stating that the Supreme Court has only implicitly recognized the right to obtain sterilization as a fundamental right).

petition a court to authorize sterilization of their mentally disabled child.¹⁵ This collision of rights presents a unique problem in that the court must decide which of two fundamental rights should prevail.¹⁶ If the court decides that the right to bear children is to be valued at a higher level than the right to obtain sterilization, this effectively denies the mentally disabled individual her fundamental right not to have children.¹⁷ In the current framework, the court is forced to choose to protect one fundamental value, which in turn denies the individual of the other.

To properly adjudicate this issue, these two important considerations must instead be viewed as equal components of a larger overarching right to procreate.¹⁸ The court must respect and protect each mentally disabled woman's inherent rights to either procreate or to take measures to discontinue having children. This will ensure that mentally disabled women receive the same protection as their competent counterparts.¹⁹

This comment will examine substantive and procedural legal protections afforded to mentally disabled women in the context of sterilization. Specifically, it will examine sexual and reproductive healthcare services available to mentally disabled women and sterilization as a means of contraception. Part II of this comment explains the historical framework and constitutional precedent of sterilization of the mentally disabled in the United States. Part III takes a look at sterilization of mentally disabled women from a Public Health law perspective. This section delves into sterilization as a useful tool of public health. It further sets forth and considers various judicial standards used in sterilization proceedings today. Next, in Part IV, I will propose a judicial approach for all states to follow as a model. I will then set forth a comprehensive approach to

¹⁵ *See supra* note 6.

¹⁶ *Id.*

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ *Id.*

addressing public health issues experienced by the mentally disabled population. In total, this comment will argue for improved sexual and reproductive healthcare to be made available to the mentally disabled population, as well as for the incorporation of the proposed judicial standard in sterilization proceedings, in order to benefit the public health of all.

II. HISTORICAL BACKGROUND OF STERILIZATION OF MENTALLY DISABLED INDIVIDUALS

The long and hideous history of involuntary sterilization in the United States found its origin in the eugenics movement of the late Nineteenth and early Twentieth Centuries.²⁰ Eugenics, coming from the Greek roots of “good” and “birth”, is a movement that involved the application of principles of genetics and heredity for the purpose of promoting selective breeding to “improve” the human race.²¹ Scholars of eugenics were particularly interested in eliminating “undesirable” traits such as mental disability, promiscuity, and physical disability.²² In an attempt to prevent “undesirable” traits from propagating, proponents for eugenics pushed for the sterilization of individuals with such traits.²³

During the early part of the Twentieth Century, most individuals with a form of mental disability were institutionalized.²⁴ Because these institutions often did not have the capability to handle pregnancies and infant-care, and because contraceptives were limited at the time, they often sterilized their patients.²⁵ In 1907, the state of Indiana became the first state to enact compulsory

²⁰ See Joel Alan Fischman, *In re Trusedell: North Carolina Adopts Two New and Conflicting Standards for Sterilization of Mentally Retarded Persons*, 64 N.C. L. Rev. 1196, 1201 (1986).

²¹ See Laura Rivard, *America's Hidden History: The Eugenics Movement* (Sept. 18, 2014), available at <http://www.nature.com/scitable/forums/genetics-generation/america-s-hidden-history-the-eugenics-movement-123919444>.

²² *Id.*

²³ *Id.*

²⁴ See Tammy Reynolds, *Reproductive Rights for People with Intellectual Disabilities* (May 21, 2013), available at <https://www.mentalhelp.net/articles/reproductive-rights-for-people-with-intellectual-disabilities/>.

²⁵ *Id.*

sterilization legislation.²⁶ Sterilization rates remained relatively low until the 1927 case of *Buck v. Bell*, in which the Supreme Court legitimized the forced sterilization of patients of a home for the mentally disabled in Virginia.²⁷

While the eugenics movement was entirely discredited following the revelation of Nazi Germany's horrific eugenic practices, sterilization of the mentally disabled is still legal in the United States. The Supreme Court case of *Buck v. Bell*, which legitimized involuntary sterilization, has yet to be overturned. At present, there are eighteen states that allow sterilization of persons with mental or developmental disabilities.²⁸ Even in states where involuntary sterilization is expressly prohibited by law, there have been frequent reports of medical professionals and welfare workers pressuring disabled women to undergo sterilization as a condition of keeping benefits or their current children.²⁹

Buck v. Bell was improperly decided based on hateful eugenic ideology and much must be done to ensure that states have advanced and outgrown eugenic notions that have guided decisions in the past. In order to adequately advance past the deficient *Buck v. Bell* decision, its shortcomings must be fully addressed and analyzed. The sections below will first state the facts that formed the basis for the monumental decision and then discuss inadequacies in the Court's analysis.

a. Facts of *Buck v. Bell*

In the case of *Buck v. Bell*, the United States Supreme Court set precedent that states may sterilize inmates of public institutions.³⁰ In this decision, the Court essentially embraced eugenic ideology to disenfranchise the mentally disabled, as well as dismissed the notion that mentally

²⁶ *Eugenics In the United States*, available at https://en.wikipedia.org/wiki/Eugenics_in_the_United_States.

²⁷ *Id.*

²⁸ See Keith Rosenthal, *Legally Sterilizing the Vulnerable* (Jul. 11, 2013), available at <https://socialistworker.org/2013/07/11/legally-sterilizing-the-vulnerable>.

²⁹ *Id.*

³⁰ See *Buck v. Bell*, 274 U.S. 200, 208 (1927).

disabled individuals were entitled to Equal Protection and Due Process rights.³¹ The Court argued that imbecility, feeble-mindedness, and epilepsy are hereditary, and that those with such “undesirable” traits should accordingly be prevented from passing on these defects to another generation.³² The Court’s decision in *Buck v. Bell*, which serves as the basis for state laws allowing sterilization of the mentally disabled, is unconstitutional and must be reexamined.

The facts of the case are as follows. In 1924, Dr. Priddy, the superintendent of a Virginia institution for the mentally disabled (hereinafter “State Colony”) filed a petition to the Board of Directors (“the Board”) to sterilize Carrie Buck, an 18-year old patient at his institution claim to have a mental age of 9.³³ According to Priddy, Carrie’s mother possessed a mental age of 8 and had a record of “immorality” and prostitution.³⁴ Carrie had been adopted, and attended school until sixth grade. However, Carrie became pregnant and gave birth to an illegitimate child. Her adopted family committed Carrie to State Colony as “feeble-minded,” no longer desiring to care for her or her illegitimate child.³⁵ The Board ordered for Carrie’s sterilization and her guardian appealed. Ultimately, the issue made it to the Supreme Court.³⁶

In her appeal to the Supreme Court, Buck contended that her Due Process guarantee, namely her right to procreate, was being violated.³⁷ Further, she claimed that a ruling for her sterilization would be a violation of the Equal Protection that she was afforded under the Fourteenth Amendment.³⁸

³¹ See Nathalie Antonios & Christina Rap, *Buck v. Bell (1927)*, available at <https://embryo.asu.edu/pages/buck-v-bell-1927>.

³² See *supra* note 30, at 206.

³³ *Id.*

³⁴ See *Buck v. Bell*, 143 Va. 310, 315 (1925), *aff'd*, 274 U.S. 200 (1927).

³⁵ See *supra* note 30, at 205.

³⁶ *Id.* at 206.

³⁷ *Id.* at 207.

³⁸ See *supra* note 30, at 205.

On May 2nd, 1927, the Court unceremoniously dismissed Carrie’s valid constitutional claims, finding that the state had a legitimate interest to have her sterilized because she was “feeble-minded” and “promiscuous.”³⁹ Justice Oliver Wendell Holmes famously concluded his decision, thus approving Virginia’s sterilization statute, by stating that “[t]hree generations of imbeciles are enough.”⁴⁰

b. Analysis of the Holding

The *Buck v. Bell* decision is unconstitutional because: (1) it is based on hateful and outdated eugenic ideology; (2) it unceremoniously dismisses the mentally disabled individual’s Equal Protection and Due Process claims with little analysis or explanation; and (3) involuntary sterilization and compulsory vaccination are grossly incomparable and thus compulsory vaccination laws cannot serve as a justification for the decision.

First, the ideology upon which the Court based its decision is archaic and should not serve as the constitutional basis for state legislation regarding sterilization of their mentally disabled population. The *Buck* decision essentially asserts that sterilization is a matter of public health and that, as such, the rights of the individual to procreate must be subordinate to concerns of the state. The Court used a cost-benefit analysis, finding that the benefits to society in being free from feeble-minded offspring largely outweighed any loss of individual liberty experienced by depriving a person of the right to procreate.

Amusingly, the Court compared sacrificing one’s right to procreate to one giving his life to the military. The Court stated that because we expect some of our most upstanding citizens who are drafted to make the all-consuming sacrifice to serve and protect our country, we should view the sacrifice of not procreating as a far “lesser sacrifice.” In making this claim, the Court essentially

³⁹ *Id.* at 208.

⁴⁰ *Id.* at 207.

stated that discontinuing their genes was the least that the mentally disabled could do, since they use up so much public resources. The bias of the decision can only truly be understood through direct quote. Justice Holmes stated,

[w]e have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. 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. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.⁴¹

Notably, Nazi doctors used Justice Holmes' words as a part of their defense at the Nuremberg trials.⁴²

Second, the Court in this decision hastily dismissed individual rights and liberty concerns and ultimately embraced eugenics as valid, even socially beneficial, government action.⁴³ The *Buck* decision gave courts the ability to circumvent the difficult issues raised.⁴⁴ The Court dismissed Carrie's Equal Protection and Due Process Claims without providing any analysis or reasoning as to why her claims fail. Besides being based on outdated and bigoted notions, it is constitutionally unsound for its lack of analysis. Had the Court properly addressed Carrie's Equal Protection and Due Process Claims, it would have found the Virginia state law as violative of Carrie's Due Process protections. Furthermore, the *Buck* case is inconsistent with subsequent developments in constitutional law affording individuals liberty protection of their right to procreate and use contraceptives.

⁴¹ See *supra* note 30.

⁴² See Harry Bruinius, *Better for All the World: The Secret History of Forced Sterilization and America's Quest for Racial Purity* 11, 15 (2007).

⁴³ See Alfred L. Brophy & Elizabeth Troutman, *The Eugenics Movement in North Carolina*, 94 N.C. L. Rev. 1871 (2016).

⁴⁴ *Id.*

Lastly, a key foundation upon which Justice Holmes based his decision is not analogous as he suggested. In his cost-benefit analysis, Justice Holmes stated, “[t]he principle that sustains compulsory vaccinations is broad enough to cover cutting the Fallopian tubes.”⁴⁵ In order to understand the fault in this logic, we must analyze the compulsory vaccination decision Justice Holmes cites to.⁴⁶

In *Jacobson v. Commonwealth of Massachusetts*, the Court held a state statute requiring the vaccination of all of its inhabitants to be a valid exercise of police power.⁴⁷ In its holding, the Court subordinated individual privacy interests in not receiving a small pox vaccination to the state public health interest in preventing the spread of small pox.⁴⁸ The Court properly found the cost-benefit inquiry to weigh in favor of the public welfare.⁴⁹ There, the state legislature took a necessary and properly tailored action to prevent the proliferation of a highly contagious and deadly infectious disease.

One does not need to elaborate very much to explain how being mentally disabled differs from the epidemic of small pox. The latter is a highly infectious disease that disfigures its victims and oftentimes ends in the fatality of the victim. The former is not a disease nor is it contagious.⁵⁰ In the case of small pox, failure to take state action would have resulted in immeasurable damage to the human population, whereas no such risk accompanies procreation of those with mental disabilities. If the state failed to take action to sterilize the mentally disabled, no impending doom would have engulfed the state. In the case of *Jacobson*, the need for all-encompassing legislation

⁴⁵ See *supra* note 30, at 207.

⁴⁶ See *supra* note 34, at 320 (stating that the same public policy that underlies compulsory vaccination laws also supports sterilization of mentally disabled individuals).

⁴⁷ See *Jacobson v. Commonwealth of Massachusetts*, 197 U.S. 11, 38 (1905).

⁴⁸ *Id.* at 27.

⁴⁹ *Id.*

⁵⁰ However, mental disability can result from abnormalities of genes inherited by parents. It can also be caused by environmental factors such as use of drugs or alcohol during pregnancy, problems at birth, or injuries sustained after birth.

was necessary to prevent the spread of the highly infectious disease: one infected individual could potentially cause the demise of the remainder of the population. Accordingly, this justification must be recognized as invalid.

The reality, that the *Buck* decision is the constitutional premise upon which all state sterilization statutes are based, should stir state legislatures and judiciaries into action. Both must afford all available protections to counteract the stigmatization and undervaluation of the mentally disabled population caused by the *Buck* decision. While state legislation has come far since this decision, the historical context of sterilization should never be taken lightly. It is each state's duty to enact legislation to properly limit state power over the sexual and reproductive autonomy of mentally disabled individuals, as well as to aid the population in achieving its highest level of mental and physical health. The scope of this duty is best assessed under a Public Health Law lens.

III. LAW, STERILIZATION, AND PUBLIC HEALTH TODAY

Public Health Law is the study of the legal powers and duties of the state to assure the conditions for people to be healthy (to identify, prevent, and ameliorate risks to health in the population) and the limitations on power of the state to constrain the autonomy, privacy, liberty, propriety or other legally protected interests of individuals for the common good. The prime objective of public health law is to pursue the highest possible level of physical and mental health in the population, consistent with the values of social justice.⁵¹

Public Health Law is premised on the notion that the government has the primary responsibility for the public's health.⁵² The state has legal powers and duties to assure the conditions for people to be healthy, as well as the duty to limit the state's power to constrain individual rights.⁵³ Public health pursues high levels of health, consistent with social justice.⁵⁴

With women representing half of the population in the United States, the specific healthcare needs of the female population represent a substantial portion of the healthcare

⁵¹ See Larry Gostin & Lindsay F. Wiley, *Public Health Law: Power, Duty, Restraint*, p. 4 (3d ed. 2016).

⁵² *Id.* at 6.

⁵³ *Id.*

⁵⁴ *Id.*

system.⁵⁵ In the context of public health law, the United States Federal and state governments have the obligation to respect, protect, and fulfill rights related to women's sexual and reproductive health. This obligation does not exclude the mentally disabled population. Public health law requires that laws pertaining to sterilization of women, including those that are mentally disabled, be based on valid legal considerations and applied without prejudice.

With recent scientific, social and legal advances, the past thirty years have seen successful challenges to and the repeal of numerous compulsory, eugenics-based, sterilization laws.⁵⁶ Most early laws were based in state police power to control and prevent births of more mentally disabled individuals, or births of children that would become a drain on the public welfare system.⁵⁷ At present, eighteen states have statutes in place authorizing and governing sterilization of the mentally disabled.⁵⁸ Most of these modern sterilization statutes are grounded in the states' *parens patriae* authority, permitting sterilization in various situations if certain criteria are met.⁵⁹

Despite these noted legal advances, some state legislatures have failed to provide statutory provisions to guide sterilization of mentally disabled individuals.⁶⁰ Moreover, states that have enacted legislation regarding sterilization of mentally disabled individuals vary greatly in their

⁵⁵ See United States Census Bureau, *Quick Facts, United States*, available at <http://www.census.gov/quickfacts/table/SEX255215/00> (stating that as of July 1, 2015, female persons make up 50.8% of the United States population).

⁵⁶ See 49 Am. Jur. Proof of Facts 3d 101 (Originally published in 1998).

⁵⁷ *Id.*

⁵⁸ See Ark. Code Ann. §§ 20-49-201 to 20-49-207 (1991); Colo. Rev. Stat. Ann. §§ 27-10.5-128 to 27-10.5-131 (West Supp. 1997); Conn. Gen. Stat. Ann. §§ 45a-691 to 45a-700 (West 1997); Del. Code Ann. tit.16, §§ 5702–5716 (1995); Ga. Code Ann. §§ 31-20-1 to 31-20-6 (1996); Haw. Rev. Stat. Ann. §§ 560:5-601–612 (Michie 1997); Idaho Code §§ 39-3901 to 39-3910 (1998); Me. Rev. Stat. Ann. tit. 34, §§ 7001–7016 (West 1998); Miss. Code Ann. §§ 41-45-1 to 41-45-15 (1993); N.J. Stat. Ann. § 30:6D-5 (West 1997); N.C. Gen. Stat. §§ 35–36 to 36–50 (1990); Ohio Rev. Code Ann. § 5123.86 (Anderson Supp. 1997); Ore. Rev. Stat. §§ 436.205 to 436.335 (1995); S.C. Code Ann. §§ 44-47-10 to 44-47-100 (Law. Co-op. 1985); Utah Code Ann. §§ 62A-6-101 to 62A-6-116 (1996); Vt. Stat. Ann. tit. 18, §§ 8705–8716 (1987); Va. Code Ann. §§ 54.1.2974 to 54.1.2980 (Michie 1997); W. Va. Code §§ 27-16-1-5 (Michie 1992). The above statutes are enabling statutes, allowing courts to order action.

⁵⁹ See *supra* note 43.

⁶⁰ *Id.*

approaches to assessing propriety of sterilization procedures. Differing statutes provide for different substantive and procedural requirements to be met in the decision-making process.⁶¹ Such deviations among state standards leaves mentally disabled individuals vulnerable where state law is inadequate.

To ensure the greatest healthcare for both mentally disabled individuals and the general public, it is essential that all states adopt a minimum procedure to govern sterilization decisions. The level of protection afforded to mentally disabled individuals should not vary greatly depending on the state the individual lives in. Creating baseline procedures and requirements, and establishing relative uniformity of law, will result in tangible guidelines, improved understanding of sexual and reproductive health of the mentally disabled population, and a process that allows the judiciary to determine and reflect the best interest of the mentally disabled individual to the greatest extent possible.

The subsections below will suggest the appropriate scope, as well as set forth procedures to be included in each state's sterilization legislation. I will set forth various judicial approaches utilized in sterilization proceedings today. I will then assess the strengths and weakness of each approach. Following the analysis of presently employed judicial approaches, I will propose an approach for all states to incorporate into legislation. This approach will aim to strike the proper balance of protecting the individual's procreative interests while considering the best interests of the general public health.

a. Legislation Must Be Broad Enough to Ensure Full Protection

The standard for sterilization, or what must be proven at a sterilization hearing, varies significantly. While some states still embrace eugenic rationales for sterilization laws, most states

⁶¹ *Id.*

have altered the inquiry to whether the mentally disabled individual under consideration will be able to adequately care for a child and whether pregnancy and childbirth will physically or psychologically harm the individual.⁶² The former inquiry is postured to avoid potential child abuse and neglect issues that could arise where mentally disabled parents are unable to care for the child. It is important to frame this inquiry in the above way, as the inquiry will reveal any ulterior and impermissible motives, such as an attempt to avoid sapping state resources.

Legislation must be enacted in every state to achieve the highest level of health practicable, while still limiting government's control over individual autonomy and privacy interest. An absence of legislation governing sterilization decisions leaves mentally disabled individuals vulnerable to abuses such as involuntary or coerced sterilization.

Each state's legislation must address the following procedural issues. In regards to scope, sterilization legislation must define a baseline level of competency. Further, the legislation should set a permissible minimum age.⁶³ Most significantly, each state's legislation should require a competency hearing at the outset of each sterilization petition. In this hearing, the judge must determine whether the mentally disabled individual is capable of understanding sex, potential consequences of unprotected intercourse with the opposite sex, contraception, and whether the individual can meaningfully consent to this serious surgery. If the individual appears to have a significant understanding⁶⁴ of the procedure and its consequences, the judicial proceeding ends and the mentally disabled individual is free to undergo or forego the sterilization procedure.

⁶² Framing the issue in such a way gives proper weight to each of the interests in the balance of interests between the mentally disabled individual, the state, and potential children of the mentally disabled woman.

⁶³ It is most sensible to only allow women who have experienced puberty and who are fertile to undergo sterilization. Prior to puberty, it should never be considered unless for exigent health circumstances such as cancer in the reproductive system.

⁶⁴ This can be determined by considering factors such as: (1) the individual's IQ and education level; (2) the individual's education on the matter of sterilization; (3) the individual's ability to express understanding of the effects and permanence; (4) the individual's understanding of pregnancy and the demands of child care; (5) the individual's ability to express her own desires on the matter of her sterilization; and, (6) potential presumptions that

If the individual is found unable to give meaningful consent based on the factors assessed, then the judiciary must inquire as to whether the sterilization procedure is in the best interest of the individual.⁶⁵ While it may seem paternalistic and condescending to require a competency hearing for all mentally disabled individuals to undergo sterilization, it is ultimately for the benefit of the mentally disabled population. Requiring various procedural hurdles to be met prior to undertaking the permanent sterilization procedure will ensure that public health standards discussed in the following section are realized.

Efforts towards uniformity of law will protect the individual procreative rights of those seeking sterilization, as well as increase the standard of sexual and reproductive health country-wide. Such advances would result in meaningful improvements of healthcare decisions made on behalf of mentally disabled individuals.

b. The Judiciary Should Consider Various Factors In a Totality-of-the-Circumstances Approach

Before a comprehensive analysis of judicial treatment can be made, it is essential to discuss methods and tests utilized by various courts in sterilization petitions. Modern-day sterilization laws have substantive requirements to guide courts in their determination of whether an individual is competent and whether sterilization is in the mentally disabled individual's best interest.

Below, I will enumerate various approaches, along with an analysis of each approach's strengths and weaknesses. Finally, I will posit an approach that best promotes the public health standard.

i. "Mandatory Criteria" Rule

caretakers desire sterilization for improper reasons. These considerations are not an exclusive list. Judges may consider additional facts deemed relevant.

⁶⁵ This is the most essential part of the sterilization proceeding. Judicial inquiry into appropriateness of sterilization will occur only after an individual is deemed incompetent and thus unable to make a meaningful choice for themselves. It is essential that states adopt and tailor the ultimate proposed procedural requirements to ensure that individual and public health is best served.

Set forth in *In Re Hayes*, the mandatory criteria rule requires courts to strictly consider only certain criteria.⁶⁶ The court can only grant a sterilization petition if the criteria are satisfied by clear and convincing evidence.

Under the mandatory criteria rule, the court must consider comprehensive medical, psychological, and social evaluations of the individual, and to the greatest extent possible, take into account the view of the mentally disabled individual.⁶⁷ Further, the court must determine whether the individual is capable of making her own decision on sterilization and whether she is likely to develop sufficiently to make informed judgment about sterilization in the foreseeable future.⁶⁸ The court must consider whether there is a need for contraception, whether the individual is physically capable of procreation, and whether she is likely to engage in sexual activity in the near future under circumstance that will likely result in pregnancy.⁶⁹ The court must weigh these considerations against the individual's disability to determine if she is capable of caring for a child, even with reasonable assistance.⁷⁰ The court must also find that less drastic methods of contraception were attempted, but were proven unworkable.⁷¹ The method of sterilization proposed must be the least invasive method practicable.⁷²

This rule is has both positive and negative features. This judicial approach is beneficial and progressive in that it implements various substantive safeguards to ensure that the individual's health and wellness are the primary considerations. It requires petitioner to establish various factors in order to ensure that the permanent procedure is absolutely necessary and in the

⁶⁶ See *Matter of Guardianship of Hayes*, 93 Wash. 2d 228, 238 (1980).

⁶⁷ *Id.* at 238.

⁶⁸ *Id.*

⁶⁹ *Id.*

⁷⁰ See *supra* note 65, at 238.

⁷¹ *Id.*

⁷² *Id.*

individual's best interests. The analysis is properly focused on the health and abilities of the individual, rather than on inconvenience that pregnancy may impose on caregivers.

Importantly, the predominant negative aspect of this approach is that the burden of proof is very high for the petitioning party. While this high burden of proof is set to protect the individual's procreative autonomy, it may be so high that approval of petitions is unachievable for petitioners. For example, petitioners must prove by clear and convincing evidence that the individual is physically capable of procreation. While there are certain evident biological indicators of fertility, such as regular menstruation, to prove by clear and convincing evidence that the individual is fertile may require costly and inaccessible medical tests.

As explained throughout this comment, sterilization can be a positive and useful public health tool. To set an unreachable bar is to deprive the mentally disabled population of this valuable tool.

ii. "Best Interest" Standard

In the more flexible "best interest" standard, the judiciary may use its discretion in considering and weighing specified criteria in determining whether sterilization is in the mentally disabled individual's best interest.⁷³ Like the mandatory criteria standard, the petitioner must prove its claim with clear and convincing evidence.⁷⁴

In the *Matter of Grady*, the court applied the best interest standard and remanded the case because of failure to meet the clear and convincing standard of proof.⁷⁵ Despite its remand, the court extensively explained the best interest approach and its judicial application.

⁷³ See *Matter of Grady*, 85 N.J. 235, 266 (1981).

⁷⁴ *Id.*

⁷⁵ *Id.* at 266–67.

In determining the individual's best interest under this standard, courts should consider at least the following factors:

- (1) The possibility that the incompetent person can become pregnant⁷⁶;
- (2) The possibility that the incompetent person will experience trauma or psychological damage if she becomes pregnant or gives birth, and, conversely, the possibility of trauma or psychological damage from the sterilization operation;
- (3) The likelihood that the individual will voluntarily engage in sexual activity or be exposed to situations where sexual intercourse is imposed upon her;
- (4) The inability of the incompetent person to understand reproduction or contraception and the likely permanence of that inability;
- (5) The feasibility and medical advisability of less drastic means of contraception, both at present and in the foreseeable future;
- (6) The advisability of sterilization at the time of the application rather than in the future⁷⁷;
- (7) The ability of the incompetent person to care for a child, or the possibility that the incompetent may at some future date be able to marry and, with a spouse, care for a child;
- (8) Evidence that scientific or medical advances may occur within the foreseeable future which will make possible either improvement of the individual's condition or alternative and less drastic sterilization procedures; and,
- (9) A demonstration that the proponents of sterilization are seeking it in good faith and that their primary concern is for the best interests of the incompetent person rather than their own or the public's convenience.⁷⁸

The best interest approach requires that each factor be given appropriate weight as the particular circumstances dictate.⁷⁹ The *Grady* court stressed that the above factors are not meant to be an exclusive list when considering the appropriateness of sterilization.⁸⁰

While this standard considers many of the same factors as the mandatory criteria approach, it adds additional considerations, as well as states that the list is not exclusive. This approach allows for some judicial discretion, allowing the judge to tailor the analysis to the particular facts presented by each individual petition. It requires that evidence be established clearly and

⁷⁶ There need not be a showing that pregnancy is likely. The court can presume fertility if the medical evidence indicates normal development of sexual organs and the evidence does not otherwise raise doubts about fertility.

⁷⁷ While sterilization should not be postponed until unwanted pregnancy occurs, the court should be cautious not to authorize sterilization before it clearly has become an advisable procedure.

⁷⁸ See *supra* note 72, at 266-67.

⁷⁹ See *supra* note 72, at 266.

⁸⁰ *Id.*

convincingly, and further requires the petitioner to establish that the petition was filed in good faith. This approach strikes the appropriate balance to ensure that the health needs of the individual are best met. It requires parties filing petitions to overcome substantial hurdles, sets forth significant guidelines for the judge to follow, and still allows discretion on the part of the judge in analyzing the criteria in each particular case.

iii. “Medically Essential”

The medically necessary rule states that a court may only authorize a petition for sterilization where it is clearly necessary to preserve the life or physical or mental health of the individual.⁸¹ Sterilization is deemed medically essential if clearly necessary, in the opinion of experts, to preserve the life or physical or mental health of the mentally disabled person.⁸²

In *Matter of A.W.*, the court argued that this approach provides mentally disabled individuals protection from abuses that were prevalent in the past.⁸³ Further, it stated that this approach ensures that the proper interests are considered.⁸⁴ The court stated that it is “not the welfare of society, or the convenience or peace of mind of parents or guardians that these standards are intended to protect. The purpose of the standards is to protect the health of the minor retarded person, and to prevent that person's fundamental procreative rights from being abridged.”⁸⁵

This standard is extremely problematic and is the least beneficial standard from a public health perspective. All women have the fundamental right to use or not use any form of contraception. As stated in prior analysis, sterilization is one of the most commonly utilized contraception methods. The medically necessary standard deprives mentally disabled women from

⁸¹ See *Matter of A.W.*, 637 P.2d 366, 375 (Colo. 1981).

⁸² *Id.*

⁸³ *Id.* at 370.

⁸⁴ *Id.*

⁸⁵ See *supra* note 80, at 376.

using a form of contraception that all other women are free to use where it is not medically necessary. This standard is overzealous in its attempt to protect mentally disabled women from past abuses that have occurred. In its practical application, it does the opposite of what it sets out to achieve. This approach disenfranchises the majority of mentally disabled women, those who seek sterilization where it is not a medical emergency, from utilizing a valuable sexual health tool.

iv. “Substituted Judgment” Rule

The substituted judgment rule attempts to place the judge in the shoes of the mentally disabled individual.⁸⁶ Under this standard, the court dons “the mental mantle of the incompetent” and substitutes itself as closely as possible for the individual in the decision making process.⁸⁷

In utilizing the doctrine, the court does not necessarily assess what is the best decision but rather what decision the mentally disabled individual would make if she were fully competent.⁸⁸ “In short, if an individual would, if competent, make an unwise or foolish decision, the judge must respect that decision as long as he would accept (or be bound to accept) the same decision if made by a competent individual in the same circumstances.”⁸⁹ Prior to making a ruling on the matter, the judge should attempt to ascertain the mentally disabled individual’s preference for sterilization, parenthood, or other means of contraception.⁹⁰ The judge should try to make the same decision that would be made by the mentally disabled person, “but taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person.”⁹¹

⁸⁶ See *Matter of Guardianship of Roe*, 383 Mass. 415, 449 (1981).

⁸⁷ See *Matter of Moe*, 385 Mass. 555, 565, 432 N.E.2d 712, 720 (1982).

⁸⁸ See *supra* note 85, at 435.

⁸⁹ See *supra* note 85.

⁹⁰ *Id.* at 435.

⁹¹ *Id.* at 570.

This judicial approach has various benefits, but significant pitfalls. This approach's strength is also its weakness. More significantly than any of the other listed approaches, this approach considers the actual wishes and desires of the mentally disabled individual under consideration. Ascertaining the individual's desires allows the individual to have a legitimate say in her own health and wellbeing and respects the individual's bodily and procreative autonomy. However, it is likely a difficult and unfeasible undertaking to determine whether the mentally disabled individual, absent her disability, would be predisposed to make poor life decisions. This approach has good-intention, but the application will likely muddle judiciary judgment.

The aforementioned judicial frameworks have notable strengths that provide proper weight and consideration of numerous factors in sterilization proceedings. However, more must be done in order to achieve the greatest possible balance between the individual health and the public health. The below proposal both sets forth a comprehensive legal framework to be adopted by all state judiciaries, as well as brings significant public health issues experienced by mentally disabled individuals to the forefront. Lastly, it proposes broad policy modifications to be implemented by state and local governments in efforts to bridge the gap of inequality currently experienced by mentally disabled individuals in the area of healthcare.

IV. PUBLIC HEALTH AND LEGAL FRAMEWORK PROPOSAL

To properly protect the interests of the mentally disabled in regards to their sexual and reproductive health, each state should at minimum adopt a practical variation of the following judicial approach. Further, the federal, states, and local governments must take action to ensure that the health needs of the mentally disabled population are being met. At current, the health care system fails to be inclusive in a way that allows equality of treatment for the mentally disabled population. The mentally disabled population is disadvantaged by the current state of law, where

each state's legal and judicial approach to sterilization varies greatly. Each state has the duty and responsibility to adopt a baseline sterilization procedure to be followed to best protect the rights all mentally disabled individuals, no matter the state in which they reside.

In the sections below, I will first propose a minimum sterilization procedure that each state should adopt and tailor to best suit their individual state's structure. I will then discuss public health considerations such as sterilization as a public health tool, barriers to healthcare for the mentally disabled population, and steps that may be taken to overcome deficiencies in the healthcare system. Concerted action by the legislature and judiciary, as well as state and local governments will ensure protection for the mentally disabled population on all fronts.

a. Proposed Awareness-Based Standard

A standard that is based on the mentally disabled individual's level of competence will best strike a balance between the individual's best interest and other valid considerations. Essentially, I propose a judicial standard that is a hybrid between the best interest standard and the substituted judgment rule. This standard incorporates the best features of both the best interest standard and the substituted judgment standard.⁹² My proposed awareness-based standard, will weigh the mentally disabled individual's level of understanding of sex, pregnancy, child-bearing, and raising a child, in combination with expressed desires to engage in such activity, against competing factors such as inability to perform daily care for themselves. This standard sets out to practically approach the realities of raising a child as a mentally disabled individual. Where the individual exhibits a greater level of competence, her desires will be given more deference in the petition process. In

⁹² Notably, this standard incorporates consideration of the individual's competence and ability to have and care for children in the future. It differs from the best interest standard in that it does not require a showing of exhaustion of other contraception methods in certain situations. This too will be assessed in light of the individual's disability level. Where an individual is severely disabled, there is no need to exhaust other contraception methods. Where the individual is minorly to moderately disabled and has not expressed a desire to undergo the procedure, less permanent means of contraception should be attempted first. This is because those with lesser disability have a greater chance of raising a child.

contrast, where the individual has a more extreme mental disability, it logically follows that she will have less of an understanding of the above factors, and likely a lesser ability to successfully carry and raise a child. The below paragraphs will elaborate in the awareness-based standard in greater detail.

In determining appropriateness in sterilization petitions, it is important to take a totality-of-the-circumstances approach. All relevant factors must be reasonably considered and weighed **according to their realistic relevance**. Where an individual has minor to moderate mental disability, there is a greater chance that they will have some level of understanding of sex, pregnancy, and desire for raise children. As such, greater weight should be given to their desires in the sterilization petition proceedings.⁹³ This is because there is a greater likelihood that these individuals will be able to carry and care for children. Current understanding⁹⁴, or likelihood to be able to understand in the future, should be considered in light of the other factors enumerated in the best interest standard, as well as factors such as whether any assistance will be needed in caring for the child.

While the individual's family or caregiver's wishes should not be given an insurmountable level of weight in sterilization proceedings, it is important for policy reasons that their wishes are given consideration. Failure to give adequate weight to the wishes of family and caregivers could disincentivize such individuals from aiding mentally disabled individuals in home-settings. Ultimately, it is in mentally disabled individuals' best interest to not be institutionalized and to live "normalized" lives.

⁹³ This is where the substituted judgment aspect is incorporated. Where an individual has some level of understanding of the circumstances and expresses wishes on the outcome, even where the decision may be foolish, it must be given adequate weight.

⁹⁴ "Understanding" should be based on various factors. The individual's mental and social abilities, gleaned from I.Q., ability to communicate and the degree of such ability, whether the individual has received schooling of any kind, ability and degree in which the individual is able to perform her own daily care. This may be established by expert testimony, as well as testimony of those within the individual's daily life.

Building off of these considerations, it is the most sensible approach to, in addition to considering the best interest factors, view the interest of mentally disabled individuals and family-caregivers in conflict with each other. Where a mentally disabled has a greater understanding of the proceeding, and thus a greater interest in autonomy, and this individual has ability to provide even a minimal level of care for a child, their desires should be given greater weight. In contrast, where an individual is more severely disabled, and thus has a lesser understanding of the proceedings, and a lesser ability to care for a potential child, her desires, if stated, should be weighed to a lesser degree.⁹⁵ Approaching the inquiry as such will anchor the analysis in the practical considerations that arise with mental disability.⁹⁶

It is essential that states adopt the above judicial approach to better afford mentally disabled individuals with some level of uniformity in sterilization procedures. The above standard aims to best assess the individual's "best interest," whether that be foregoing the procedure because of some remote ability to care for a child, or to undergo the procedure due to certain inability to understand and succeed in carrying and raising a child. However, this judicial approach is merely a small step in the direction of betterment of adequate sexual and reproductive health for the mentally disabled community. It is essential that state and local governments take additional affirmative steps to realize equality of healthcare for the mentally disabled population.

b. Sterilization, Public Health, and Barriers to Healthcare

In short, to attain the greatest physical and mental health of the female population, women must have access to reproductive health care services, goods and facilities that are:

⁹⁵ This is based both on the premise that the individual will likely not be able to care for a child, as well as the fact that where an individual is more severely mentally disabled, they are likely to have a caregiver that is more involved in their daily life. Where such is the case, responsibility of a child will likely fall on a caregiver and thus they should be given consideration.

⁹⁶ This it not to say that those with greater disabilities have lesser sexual and reproductive rights. However, it is practically considering ALL factors that accompany mental disability it order to achieve the best interest of the individual, as well as the greatest level of public health.

(a) available in ample numbers; (b) accessible physically and economically; (c) accessible without discrimination; and (d) of good quality.⁹⁷ This goal should **not** exclude mentally disabled women. Positive outreach by the healthcare community in such a way is essential to achieving the highest possible level of health for the mentally disabled community.

Due to the stigmatization of the disabled population, and the commonly held notion that disabled women experience the wants and needs of womanhood to a lesser degree than their “able” counterparts, discrimination in the provision of sexual and reproductive health services to disabled women is prevalent.⁹⁸ While it would be ideal to state that those with disabilities should have the ability to found and maintain a family and to retain their fertility on an equal basis with others, there are practical reasons why it may sometimes be in the best interest of a mentally disabled individual to not undertake the obligation of childcare.

Despite these discernable reasons, persons with disabilities should be provided with comprehensive information and support to make informed decisions about reliable and safe contraceptive measures.⁹⁹ While an argument can be made that some mentally disabled individuals lack the mental capacity to make informed decisions based on such information, such information must be made available to the individual and her caregivers nonetheless. If there is any question of capacity, the court, not the caregiver or healthcare provider should determine whether the individual is able to make a meaningful decision.

The subsections below address the concerns of using sterilization as a public health tool, bring light to unmet health needs of the mentally disabled community, and set forth

⁹⁷ United Nations, Office of the High Commissioner, *Sexual and Reproductive Rights*, available at <http://www.ohchr.org/EN/Issues/Women/WRGS/Pages/HealthRights.aspx>.

⁹⁸ United Nations, Office of the High Commissioner, *Information Series on Sexual and Reproductive Health and Rights: Contraception and Family Planning*, available at http://www.ohchr.org/Documents/Issues/Women/WRGS/SexualHealth/INFO_Contra_FamPlan_WEB.pdf

⁹⁹ *Id.*

broad proposals of options the government may utilize to address the inequities mentally disabled individuals experience in receiving healthcare.

i. Sterilization as A Public Health Tool

Sterilization plays both various roles in achieving appropriate and adequate sexual and reproductive health care. Persons with mental disabilities, the most common developmental disability, face particular risks of being denied their rights in relation to contraception and family planning.¹⁰⁰ One is deemed mentally disabled when he or she has certain limitations in cognitive skills and functioning, including communication, social and self-care skills.¹⁰¹ In the United States, approximately 6.5 million people have an intellectual disability. As many as 200 million people of the global population have an intellectual disability.¹⁰²

The reproductive rights of the mentally disabled is a polarizing concern. For equality to be realized, support networks and health systems must be implemented to facilitate mentally disabled individuals in making informed procreative choices.¹⁰³ These networks must not only support the mentally disabled in their initial decision-making, but must also provide guidance and assistance in the outcomes of their decisions.

¹⁰⁰ See *supra* note 63.

¹⁰¹ See *What is Intellectual Disability?*, available at http://www.specialolympics.org/Sections/Who_We_Are/What_Is_Intellectual_Disability.aspx. (According to the American Association of Intellectual and Developmental Disabilities, an individual has intellectual disability if he or she fulfills three criteria: (1) an IQ below 70-75; (2) significant limitations in two or more adaptive areas (skills that are needed to live, work, and play in the community, such as communication or self-care); and, (3) the condition manifests itself prior to the age of 18).

¹⁰² *Id.*

¹⁰³ The question that follows for this is whether the mentally disabled woman is capable of forming an informed procreative choice. The possibility that some mentally disabled women may not be able to comprehend the choice or utilize the network put in place should not foreclose the resource from being made available to the mentally disabled population. It is conceivable that there are a substantial population of individuals with more minor mental disability who would benefit from such resources and support. Even where a mental disabled individual does not have the capacity to make informed decisions regarding their own sexual and procreative health, networks and resources will serve as an educational resource for caregivers.

In contrast, there are the practical and realistic considerations, based in common characteristics experienced by mentally disabled individuals, that support the conclusion that it may be harmful to both the mentally disabled individual and her potential offspring for her to carry and raise a child. A common effect of mental disability is difficulty with certain life skills due to diminished mental capabilities. Proponents for sterilization pose questions such as: does the individual understand the ramifications of unprotected intercourse with the opposite sex? Is it in the best interest of a mentally disabled female to undergo pregnancy if she does not comprehend body changes that attend pregnancy? If the disabled individual is not entirely able to care for herself, how can she care for a child through the various stages of its life? Issues of potential adoptions and an increased burden on the welfare state are also among legitimate concerns.

Whether for or against sterilization as a sexual health tool for the mentally disabled, the United States government has an immediate obligation to ensure that states take deliberate, tangible, and targeted steps towards fulfilling the right to sexual and reproductive health of the disabled population.¹⁰⁴ Disabled individuals have less access to health care services and consequently experience unmet health care needs.¹⁰⁵ **All** women, including mentally disabled women, have the right to accessible, affordable and adequate health care that takes into account **their particular needs as women**.¹⁰⁶

ii. Unmet Needs and Barriers to Healthcare of the Disabled Population

The International Classification of Functioning, Disability, and Health (ICF) defines disability as “an umbrella term for impairments, activity limitations and participation restrictions,

¹⁰⁴ See *supra* note 63.

¹⁰⁵ See *Disability and Health Fact Sheet*, World Health Organization, available at <http://www.who.int/mediacentre/factsheets/fs352/en/>.

¹⁰⁶ See *Women’s Health, Sexual, and Reproductive Rights*, Amnesty International, available at <http://www.amnestyusa.org/our-work/issues/women-s-rights/women-s-health-sexual-and-reproductive-rights>

or “the interaction between individuals with a health condition (e.g. cerebral palsy, Down Syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports).”¹⁰⁷ This definition properly describes the interplay between the disabled individual and the access to support available. Where a comprehensive approach is taken in the provision of healthcare, the level of difficulty an individual may experience due to her disability may be minimized or made more manageable.

People with disabilities have the same general health care needs as the overall population and thus need access to mainstream healthcare services.¹⁰⁸ However, reports show that the greater healthcare needs of those with disabilities are disproportionately unmet.¹⁰⁹ This is because there are prominent barriers to health care access for mentally disabled individuals.

Among the various barriers to healthcare, affordability of health services and transportation are two prominent barriers that prevent people with disabilities from receiving needed healthcare.¹¹⁰ Further, the lack of appropriate services for people with disabilities is an additional significant barrier.¹¹¹ Physical barriers, such as unequal access to buildings for those with mobility difficulties also pose a substantial barrier to access to health.¹¹² Furthermore, it is common for

¹⁰⁷ See *supra* note 71.

¹⁰⁸ *Id.*

¹⁰⁹ See *supra* note 71 (noting a recent survey of individuals with serious mental disorders, which showed that between 35% and 50% in developed countries, and between 76% and 85% in developing countries, received no treatment in the year prior to the study. Health promotion and prevention activities rarely target people those with disabilities. Women with disabilities receive less screening for cervical and breast cancer than women without disabilities. People with intellectual impairments and diabetes are less likely to have their weight checked. Disabled adolescents and adults are more likely to be excluded from sex education health programs).

¹¹⁰ *Id.* (stating 32-33% of non-disabled individuals are unable to afford health care compared to 51-53% of people with disabilities).

¹¹¹ *Id.*

¹¹² *Id.* (noting that women with mobility difficulties are often not able to access breast and cervical cancer screenings because examination tables are not height-adjustable and mammography equipment only accommodates women able to stand. Additionally, some mentally disabled women are not receptive to gynecological exams such as pap smears, that are essential in maintaining and monitoring a female’s reproductive health. Rather than imagining other

essential healthcare exams such, as pap smears, to be skipped because healthcare professionals are oftentimes not adequately equipped in handling mentally disabled individuals.¹¹³ Such barriers to the sizable, yet marginalized, disabled population require a substantial overhaul to the healthcare system as it relates to treatment of the disabled.

iii. Addressing Shortcomings of Healthcare Access for the Disabled

Public health law is based on the premise that governments should use their resources and powers to improve health outcomes for communities by taking steps such as improving access to quality, affordable healthcare services.¹¹⁴ To truly address the issue of inadequate healthcare access for the mentally disabled population, expansive reforms of the current system must be undertaken. Specifically, the following paragraphs address the premise that if a mentally disabled individual receives comprehensive sexual education and healthcare from the outset, it may not be necessary to undergo the permanent procedure of sterilization.¹¹⁵ The paragraphs below list steps to be taken in problematic areas and ways in which the government may alleviate current issues.

First, existing policies and services must be reviewed to identify and reduce areas of health inequalities.¹¹⁶ Once these areas are identified, improvements must be made to increase access and inclusion for the mentally disabled population.¹¹⁷

ways to monitor mentally disabled women's health, it is more common for caretakers doctors to forego these essential exams altogether).

¹¹³ *Id.* (stating that people with disabilities are more than twice as likely to report having found health care provider skills inadequate to meet their needs, four times more likely to report being treated poorly and almost three times more likely to report being denied care).

¹¹⁴ *Id.*

¹¹⁵ Again, educational and healthcare resources should be provided no matter the mental capacity of the individual. Even if a particular individual lacks the mental capacity to understand educational material, resources provided will serve as a resource for caretakers.

¹¹⁶ *See supra* note 71.

¹¹⁷ *Id.*; Access and inclusion can be increased by establishing concrete standards related to the care of persons with disabilities, paired with enforcement mechanisms to ensure these standards are upheld. Policy and legislation must be reshaped to have inclusive effects rather than exclusive effects.

Second, the government must address financial issues that often arise due to increased medical bills to care for those with mental disabilities.¹¹⁸ In the current healthcare climate, private health insurance dominates healthcare financing.¹¹⁹ To alleviate the increased burdens on financing experienced by mentally disabled individuals or those caring for mentally disabled individuals, the government should take action to ensure that people with disabilities are covered and that premiums are affordable for them.¹²⁰ Further, the government should take steps to ensure that people with mental disabilities equally benefit from public health programs.¹²¹ Additionally, the government should strive to alleviate pressure on those forced to finance healthcare services through out-of-pocket payments.¹²²

Third, the government must focus on reforming delivery of services to the mentally disabled population.¹²³ It must take steps to empower mentally disabled individuals and their caregivers in order to maximize the health of the mentally disabled population and the population as a whole.¹²⁴ This can be achieved by providing information, training, and peer support on all healthcare related topics.¹²⁵ Specifically, information and training must be delivered in a way that is accessible to the disabled community.¹²⁶

¹¹⁸ *Id.*

¹¹⁹ *Id.*

¹²⁰ *Id.*

¹²¹ *Id.*; To achieve this, the government can give health care providers financial incentives for making their services accessible, and for providing comprehensive health assessments, treatment and follow-ups.

¹²² *See supra* note 71. Federal and state governments must consider options to reduce or remove these payments to ensure that these individuals seek care when it is needed, rather than only when they can afford it.

¹²³ *Id.*

¹²⁴ *Id.*

¹²⁵ *Id.*

¹²⁶ *Id.*; In regards to the physical delivery of service, a broad range of reasonable accommodations should be taken to facilitate access to healthcare services for those with mobility difficulties.

Fourth, the government must address the education of healthcare professionals and their provision of care to the mentally disabled population.¹²⁷ Disability education must be integrated into undergraduate and continued education for those taking healthcare related classes.¹²⁸

Fifth, the government must take steps outside of the healthcare service community to ensure equality of care.¹²⁹ State and local governments must make a concrete effort to train community workers so that they can play a role in preventative healthcare services.¹³⁰

Sixth and lastly, the mentally disabled population must be further included in data and research conducted.¹³¹ By including those with disabilities in health care surveillance, evidence will be gathered that may assist healthcare providers to better treat and assist the mentally disabled community.¹³²

The above actions would result in palpable improvements in healthcare services for the mentally disabled and thus a betterment of the overall public health. Healthcare providers, mentally disabled individuals, and caregivers will be better equipped in making informed decisions on issues of sexual and reproductive health. Specifically, if a mentally disabled individual¹³³ receives comprehensive sexual education and healthcare from the outset, it may not be necessary to undergo the permanent procedure of sterilization. The permanent procedure would occur less for the “last ditch effort” reasons enunciated above, and would only be performed after education, understanding, and consideration on the issue.

V. CONCLUSION

¹²⁷ *Id.*

¹²⁸ *Id.*

¹²⁹ *Id.*

¹³⁰ *Id.*

¹³¹ *Id.*

¹³² *Id.*

¹³³ Or the individual’s caregivers where the individual lacks mental capacity to be educated on the matter.

In conclusion, the healthcare needs of the mentally disabled population must be addressed in a holistic manner. While there has been much improvement in recognizing the individual rights and liberties of mentally disabled individuals since the time of *Buck v. Bell*, much still needs to be done to ensure the mentally disabled have access to adequate sexual and reproductive healthcare. Sterilization, when sought for proper purposes, is a valuable public health tool. In accordance with the concept of public health, the government must take concrete steps to ensure the highest level of physical and mental health while limiting its power to constrain autonomy of mentally disabled individuals. The above social, legislative, judicial approaches suggested succeed in striking this balance.