

STERILIZING PEOPLE WITH MENTAL DISABILITIES WHO CANNOT  
GIVE INFORMED CONSENT: A CALL FOR NATIONAL STATUTORY  
UNIFORMITY AFTER STAKEHOLDER INPUT

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ABSTRACT

People with disabilities have been reproductively marginalized throughout the history of the United States. This history, especially as it has been informed by the Supreme Court's Ruling in Buck v. Bell, which upheld the involuntary sterilization of a woman labeled as having a disability, has led to a patchwork approach across the states as to whether and how people with disabilities who cannot give informed consent to medical procedures can be sterilized. This Note provides a summary of court and statutory approaches to this issue and argues that, especially

in light of the Disability Rights Movement, it is time for the United States to rebuke its history of marginalization; solicit stakeholder input, prioritizing those affected by such laws; and adopt a disability-informed approach to the sterilization of this population that minimizes continued marginalization.

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“Marriage and procreation are fundamental to the very existence and survival of the race. The power to sterilize, if exercised, may have subtle, far-reaching and devastating effects. In evil or reckless hands it can cause races or types which are inimical to the dominant group to wither or disappear. There is no redemption for the individual whom the law touches. Any experiment which the State conducts is to his irreparable injury. He is forever deprived of a basic liberty.” –Skinner v. Oklahoma ex rel. Williamson, 316 U.S. 535, 541 (1942).

#### INTRODUCTION

The sterilization of people with disabilities (PWD) who cannot give informed consent to a medical procedure (hereinafter PWD who cannot consent)<sup>1</sup> has a long and sordid history in the United States.<sup>2</sup> Furthermore, current laws regulating this practice vary greatly state by state.<sup>3</sup>

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<sup>1</sup> PWD is a common abbreviation of “persons with disabilities.” See Disability Acronym List, W. VA. UNIV. CTR. FOR EXCELLENCE IN DISABILITIES, <http://cedwvu.org/resources/disability-acronym-list> (last visited Feb. 26, 2019). Further, it is important to differentiate the group primarily discussed in this Note—those who cannot give informed consent for a medical procedure—from the general population of PWD because a significant proportion of the PWD community would be found competent to give informed consent under the law.

<sup>2</sup> See Part I, infra.

<sup>3</sup> See Part II, infra.

Considering the previous, significant abuse of this population in the United States through involuntary sterilization,<sup>4</sup> varied state laws which may subject these individuals to further abuse are unacceptable. Swift statutory action at the federal level is needed to correct this variance.

This Note offers an overview of this broad and urgent issue and a proposal for national action. First, it considers the history of sterilizing PWD who cannot consent in the United States and posits that any policy affecting the reproductive rights of people with disabilities must be informed by an awareness of historical and current marginalization. Second, this Note provides an accounting of the current state of the law by addressing the Supreme Court's' decisions on the subject, discussing the disparate positions of state courts, and providing a survey of relevant and current state statutory law. This discussion is meant to serve as the basis for recommendations for statutory actions and as a comprehensive survey, where such information has generally been scattered or incomplete in the past. Third, this Note provides recommendations to federal lawmakers. It first explains why lawmakers must collaborate with relevant stakeholders—including the disability community and the medical profession—when creating policy on this subject. Subsequently, this Note discusses specific procedural safeguards and enforcement mechanisms that must be enacted if lawmakers, in collaboration with these stakeholders, decide to allow the sterilization of PWD who cannot consent.

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<sup>4</sup> As demonstrated by a history of eugenic sterilization, described in Part I, infra.

I. PWD AS A REPRODUCTIVELY MARGINALIZED POPULATION:  
PAST AND PRESENT

Any policies regarding the sterilization of PWD who cannot consent must account for the significant reproductive abuses that PWD, including but not limited to those who cannot consent, have suffered and continue to suffer in the United States. Lawmakers considering which policies will best serve PWD who cannot consent, and society as a whole, should consider this history to avoid repeating past cruelties.

A. A Brief Overview of Eugenic Sterilization in the United States

Merriam-Webster defines “eugenics” as “the practice or advocacy of controlled selective breeding of human populations (as by sterilization) to improve the population’s genetic composition.”<sup>5</sup> Francis Galton—inspired by his half cousin, Charles Darwin—developed the most influential theory of eugenics.<sup>6</sup> In his seminal and infamous book, Hereditary Genius: An Inquiry into Its Laws and Consequences,<sup>7</sup> Galton applies the Darwinian idea of “survival of the fittest” to the human population, opining that those whom society deems unacceptable should be bred out of existence or forcibly exterminated.<sup>8</sup>

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<sup>5</sup> Definition of Eugenics, MERRIAM-WEBSTER, <https://www.merriam-webster.com/dictionary/eugenics> (last visited Apr. 23, 2018).

<sup>6</sup> See generally FRANCIS GALTON, HEREDITARY GENIUS: AN INQUIRY INTO ITS LAWS AND CONSEQUENCES (Gavan Tredoux ed., 2nd ed. 1892).

<sup>7</sup> Id. See also ADAM COHEN, IMBECILES: THE SUPREME COURT, AMERICAN EUGENICS, AND THE STERILIZATION OF CARRIE BUCK 46 (2016).

<sup>8</sup> COHEN, supra note 7, at 47.

The legal field subsequently embraced tenets of the eugenics movement, and laws allowing eugenic sterilization arose in the era before WWII. Harry Laughlin, a major proponent of the movement,<sup>9</sup> produced the following map to describe the state of eugenic sterilization in the United States in 1935:

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<sup>9</sup>. Harry Laughlin “was superintendent in charge of the Eugenics Record Office of the Department of Genetics of the Carnegie Institute of Washington, D.C., from its origin in 1910 until 1921 and director from 1921 until 1940. Dr Laughlin served as the eugenics expert for the Committee on Immigration and Naturalization, U.S. House of Representatives from 1921 to 1931; the Eugenics Associate to the Municipal Court at Chicago, 1921 to 1930; the U.S. immigration agent to Europe for the Department of Labor from 1923 to 1924; and was a member of the permanent Immigration Commission of the International Labor Office of the League of Nations in 1925.” Further, he wrote a model eugenic sterilization law that influenced the rise of such statutes in the U.S. Biography of Harry H. Laughlin, TRUMAN STATE UNIV. PICKLER MEM’L LIBR., <http://library.truman.edu/manuscripts/laughlinbio.asp> (last visited Feb. 26, 2019).

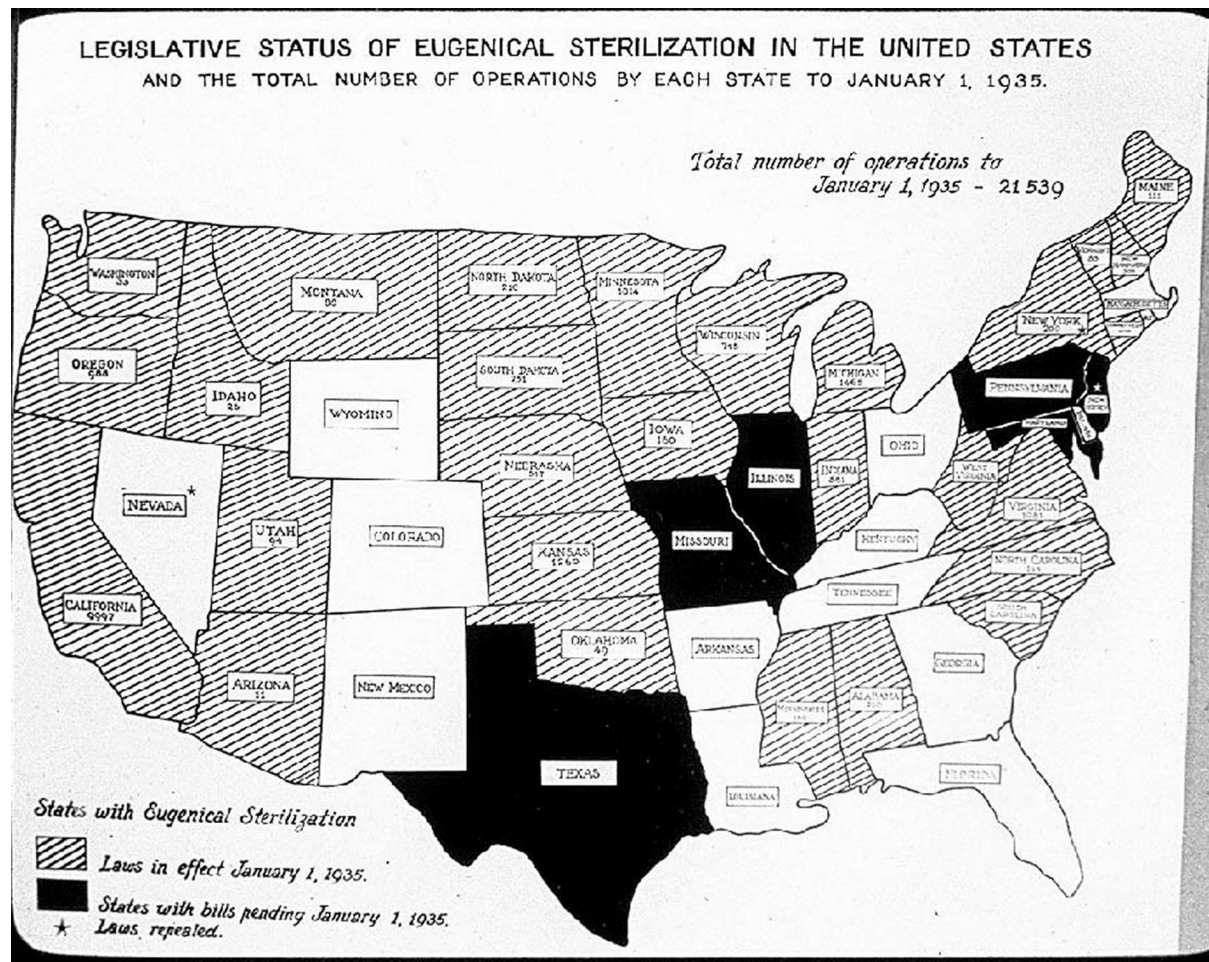


FIGURE 1<sup>10</sup>

Image Description: A seemingly hand-drawn map of “Legislative Status of Eugenic Sterilization in the United States and the Total Number of Operations by Each State to January 1, 1935.” 29 states are labeled as having laws including eugenical sterilization as of January 1, 1935, and seven states are labeled as having bills pending as of January 1, 1935. 3 states are labeled as having repealed laws regarding eugenical sterilization.

<sup>10</sup> Id.

The number of these discriminatory laws only grew, and eugenic sterilization became common practice.<sup>11</sup> Endorsed by the Supreme Court in a majority opinion by Justice Oliver Wendell Holmes in Buck v. Bell,<sup>12</sup> eugenic sterilization stripped the reproductive capabilities of thousands, including over 20,000 people in California,<sup>13</sup> approximately 7,600 people in North Carolina,<sup>14</sup> and 2,648 people in Oregon.<sup>15</sup> These atrocities continued throughout the 20th century, despite a repeal effort that began after World War II, and the last of the eugenic sterilization laws were

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<sup>11</sup>. Id.

<sup>12</sup>. Buck v. Bell, 274 U.S. 200, 207 (1927). For further discussion, see Part II.A.1, infra.

<sup>13</sup>. Mark G. Bold, It's time for California to compensate its forced-sterilization victims, LOS ANGELES TIMES, Mar. 5, 2015 (providing a brief history of eugenic sterilization laws and their implementation in California).

<sup>14</sup>. Jon Elliston, New numbers show slow pace of IDing N.C.'s sterilization victims, CAROLINA PUBLIC PRESS, Apr. 5, 2012 (“Under the program, administered by the N.C. Eugenics Board from the 1930s to the early 1970s, some 7,600 people were sterilized for being ‘feebleminded’ or having epilepsy or other purported shortcomings. Today, some 1,500 to 2,000 are estimated to still be alive.”).

<sup>15</sup>. Eugenics in Oregon, Or. State Libr. Digital Collection (Dec., 2017), <https://digital.osl.state.or.us/islandora/object/osl%3Aeugenics?display=list> (last visited Apr. 13, 2019).

officially repealed in Oregon in 1983, when the “Board of Social Protection” ceased giving approval for the practice.<sup>16</sup>

Many, if not most, of these people had been diagnosed with some sort of disability, whether the diagnosis was legitimate or not. The case of Carrie Buck, which ultimately reached the Supreme Court, exemplified the reproductive risks faced by PWD (or those regarded as having a disability), including but not limited to PWD who cannot consent.<sup>17</sup>

Carrie lived at Virginia’s Colony for Epileptics and the Feeble-Minded (the Colony).<sup>18</sup> She was diagnosed as “feeble-minded” so that Dr. Albert Priddy—the doctor in charge of the Colony—could sterilize her as a test case for Virginia’s newly enacted law allowing eugenic sterilization.<sup>19</sup> There is no evidence that Carrie actually had a disability or that a court appropriately sent her to this institution.<sup>20</sup> In fact, she was likely sent away because she was raped and became pregnant while living with a family that provided room and board in exchange for service work.<sup>21</sup> However, the Supreme Court upheld Carrie’s “diagnosis” of being feeble-minded and found that the state had the authority to sterilize those

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<sup>16.</sup> Id.

<sup>17.</sup> COHEN, supra note 7, at 35 (discussing the construction of the test case involving Carrie Buck).

<sup>18.</sup> Id.

<sup>19.</sup> Id. For further discussion of this case, see Part II.A.1, infra.

<sup>20.</sup> See generally id. at 15 to 35 (describing Carrie’s background and the events leading to her institutionalization).

<sup>21.</sup> Id.

diagnosed as such. She was then sterilized at the Colony.<sup>22</sup> Carrie's case demonstrates that in the not-so-distant past, having a disability or being regarded as having a disability put people at significant risk for reproductive marginalization.<sup>23</sup>

After WWII ended and the world learned of the horrors of Hitler's concentration camps, overt eugenic rationalizations for sterilization became less popular.<sup>24</sup> The marginalization and the reproductive abuse of PWD, however, continued throughout the 20th century and persists to this day.<sup>25</sup>

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<sup>22.</sup> Id. For further discussion of this case, see Part II.A.1, infra.

<sup>23.</sup> Reproductive marginalization refers to "treatment of a person, group, or concept as insignificant or peripheral" in the reproductive context. MERRIAM-WEBSTER, <https://www.merriam-webster.com/dictionary/marginalization> (last visited May 7, 2018). Marginalization occurs at the intersection of socially constructed identities when a person's identity does not align with that of those in power—generally white, cisgender, heterosexual, able-bodied men. See generally Kimberlé Crenshaw, Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics, 1989 U. OF CHICAGO LEGAL F., 139 (1997). Reproductive marginalization is this process in any reproductive context, including access to reproductive medical services, the use of sterilization procedures upon people who identify with marginalized identities, and the perpetration of sexual assault.

<sup>24.</sup> COHEN, supra note 7, at 309–15. (discussing the decrease in popularity of eugenics in the United States during and after WWII).

<sup>25.</sup> See Part I.B, infra. See also Katrina Anderson, Universal Periodic

## B. Contemporary Reproductive Marginalization and Abuse of PWD

Because PWD are a vulnerable population, they are more likely to be abused physically,<sup>26</sup> sexually,<sup>27</sup> and verbally.<sup>28</sup> Similarly, people with disabilities are more likely to be abused in a reproductive context, both in their personal lives and while seeking medical services.

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Review Fact Sheet, CENTER FOR REPRODUCTIVE RIGHTS, [https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/Women%20w%20Disabilities%20UPR%20Fact%20Sheet\\_FINAL.pdf](https://www.reproductiverights.org/sites/crr.civicactions.net/files/documents/Women%20w%20Disabilities%20UPR%20Fact%20Sheet_FINAL.pdf) (last visited Apr. 23, 2018) (“Approximately 18% of women in the U.S., or 28 million women, are living with a disability. Due to discrimination in both the private and public sphere, women with disabilities are two to three times more likely than nondisabled women to experience violence, including but not limited to sexual violence. They also face numerous barriers—physical, informational and economic—to accessing sexual and reproductive health services.”).

<sup>26.</sup> Id. See also Physical Abuse, DISABILITY JUSTICE, <https://disabilityjustice.org/physical-abuse> (last visited Feb. 26, 2019).

<sup>27.</sup> Anderson, supra note 25. See also NAT’L COUNCIL ON DISABILITY, Not on the Radar: Sexual Assault of College Students with Disabilities (Jan. 30, 2018) (discussing sexual assault of students with disabilities on university campuses).

<sup>28.</sup> Verbal and Psychological Abuse, DISABILITY JUSTICE, <https://disabilityjustice.org/verbal-and-psychological-abuse> (last visited Feb. 26, 2019).

People with disabilities are up to three times more likely to be sexually abused than their nondisabled peers,<sup>29</sup> and they are also more likely to be coerced into undergoing reproductive medical procedures by those close to them.<sup>30</sup> This collectively puts people with disabilities at higher risk for being reproductively abused by people in their personal lives, including guardians who may be able to request the person in question's sterilization, than the general population.<sup>31</sup> This violence "is compounded by the fact that the victims may be physically and financially dependent on those who abuse them. Furthermore, when they come forward to report such abuse, the medical (both physical and mental), legal, and social service systems are often unresponsive and inaccessible."<sup>32</sup>

In addition, people with disabilities face significant challenges when attempting to access reproductive medical care. Though people with disabilities require the same sexual and reproductive health services

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<sup>29</sup>. Anderson, supra note 25. See also Promoting Sexual and Reproductive Health for Persons With Disabilities 6, WORLD HEALTH ORGANIZATION [WHO] (2009), [https://www.unfpa.org/sites/default/files/pub-pdf/srh\\_for\\_disabilities.pdf](https://www.unfpa.org/sites/default/files/pub-pdf/srh_for_disabilities.pdf) (last visited Apr. 13, 2019).

<sup>30</sup>. Promoting Sexual and Reproductive Health for Persons With Disabilities, supra note 29.

<sup>31</sup>. Whether this is legal depends upon the state in which the PWD who cannot consent lives. See Part II, infra.

<sup>32</sup>. Promoting Sexual and Reproductive Health for Persons With Disabilities, supra note 29.

given to nondisabled peers, their care is often overlooked. Barriers to access include:

- lack of physical access, including transportation and/or proximity to clinics, and, within clinics, lack of ramps, adapted examination tables, etc.;
- lack of information and communication materials (e.g. lack of materials in Braille, large print, simple language, and pictures; lack of sign language interpreters);
- health-care providers' negative attitudes;
- providers' lack of knowledge and skills about persons with disabilities;
- lack of coordination among health care providers;
- lack of funding, including lack of health-care insurance.<sup>33</sup>

It would be hubris and folly to make any policy regarding the reproductive rights of people with disabilities without centering their experiences, difficulties, and abuses; when deciding policy at the intersection of disability and reproductive rights, lawmakers must consider the aforementioned heightened risk for abuse and insufficient accessibility to systems and services. If they do not, lawmakers risk exacerbating the marginalization of PWD who cannot consent, who are at higher risk than both the general population and the larger community of PWD for marginalization.

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<sup>33</sup>. Id. at 7.

## II. UNITED STATES LAW AND THE STERILIZATION OF PWD WHO CANNOT GIVE INFORMED MEDICAL CONSENT

A review of court decisions addressing the sterilization of PWD who cannot consent is an important prelude to the analysis of relevant statutes and any relevant policy decisions; too little attention has been paid to this country's legal history with PWD, and statutes and policies without such considerations are necessarily incomplete.

Because the Supreme Court has offered limited guidance on the subject and state courts have reached vastly varying decisions, this survey of judicial decisions underscores the urgent need for national uniformity. The stark divergence in judicial opinions regarding the sterilization of PWD who cannot consent—largely from the late 1970s and early 1980s—results in vastly different policies and judicial powers throughout the nation.<sup>34</sup> Because the decisions largely predate many advances in Reproductive Justice, the right to privacy, medicine, and the Disability Rights Movement, important conversations about Reproductive Justice and disability were likely not considered by these judges. Federal legislative action could resolve the stark differences across the fifty states and

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<sup>34</sup>. However, this is not exclusive—courts have been considering the sterilization of PWD who cannot consent in the context of a legislative vacuum as recently as 2008. See, e.g., V.H. v. K.E.J. (In re Estate of K.E.J.), 887 N.E.2d 704 (Ill. App. Ct. 2008) (holding that sterilization of a PWD who cannot consent is legal in the state of Illinois and setting out a six-factor test to ensure proper procedural protections).

provide national uniformity with input from all relevant stakeholders.<sup>35</sup> A survey of different judicial perspectives follows, with example cases discussed in depth to provide a detailed look at the differing approaches.

## A. Constitutional Law

### 1. Cases Explicitly Discussing Sterilization

The Supreme Court of the United States reviewed the sterilization of PWD who cannot consent in Buck v. Bell: the case in which Justice Holmes infamously declared that “three generations of imbeciles is enough.”<sup>36</sup> In this opinion, the Court struck down both Due Process and Equal Protection challenges to a Virginia statute that allowed the State to sterilize Carrie Buck because she had been institutionalized within Virginia’s Colony for Epileptics and the Feeble-Minded.<sup>37</sup> This decision was an endorsement of eugenics that allowed involuntary sterilization statutes to thrive nationwide until WWII dampened professional enthusiasm for the

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<sup>35</sup>. For a discussion of relevant stakeholders who must be consulted when forming this national policy, see Part III, infra.

<sup>36</sup>. Buck v. Bell, 274 U.S. 200.

<sup>37</sup>. Id.

practice.<sup>38</sup> Thus, the Supreme Court set precedent allowing the state to sanction the sterilization of those whom society deemed “incompetent.”<sup>39</sup>

Notably, in 1942, the Court modified its Buck precedent. In Skinner v. Oklahoma, the Court did not directly address the rights of PWD or PWD who cannot consent, but held that a statute allowing for disparate, punitive sterilization of people who committed similar crimes violated the Equal Protection Clause of the Fourteenth Amendment.<sup>40</sup> That said,

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<sup>38.</sup> See Part I, supra. Oregon’s Board of Social Protection, originally the Board of Eugenics, operated until 1981 and involuntarily sterilized 2,648 people. Eugenics in Oregon, OR. STATE LIBR. (Dec., 2017), <https://digital.osl.state.or.us/islandora/object/osl%3Aeugenics?display=list>.

<sup>39.</sup> Buck, 274 U.S. at 207 (“We 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. Three generations of imbeciles are enough.”) (citation omitted).

<sup>40.</sup> Skinner v. Oklahoma ex rel. Williamson, 316 U.S. 535, 542 (1942). At issue in this case was a statute that provided for the sterilization of “habitual criminals,” defined as those “who, having been convicted two or

restrictions on procreation are still used in criminal contexts today;<sup>41</sup>

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more times for crimes ‘amounting to felonies involving moral turpitude,’ either in an Oklahoma court or in a court of any other State, is thereafter convicted of such a felony in Oklahoma and is sentenced to a term of imprisonment in an Oklahoma penal institution.” *Id.* at 540 (citation omitted). The Court went on to state that, under this statute, “[m]achinery is provided for the institution by the attorney General of a proceeding against such a person in the Oklahoma courts for a judgment that such person shall be rendered sexually sterile.” This was found to be a violation of the Equal Protection Clause because under this statute, a person found guilty of embezzlement multiple times would not be sterilized, while a person convicted of stealing chickens could be sterilized, though the state otherwise treats the crimes in the same way. *Id.* at 539. After a recitation of the dangers of state sterilization, the Court stated “Sterilization of those who have thrice committed grand larceny, with immunity for those who are embezzlers, is a clear, pointed, unmistakable discrimination.” *Id.* at 541.

<sup>41</sup>. See State v. Oakley, 629 N.W.2d 200 (Wis. 2001) (holding that a condition of probation requiring a man convicted of three counts of intentionally refusing to support his children to avoid having another child unless he showed that he could support the child was valid); Cal. Penal Code § 645 (West 2005) (allowing medroxyprogesterone acetate treatment, a common type of chemical castration, for parolees who have committed specified sex offenses and providing that “If a person voluntarily undergoes a permanent, surgical alternative to hormonal chemical treatment for sex offenders, he or she shall not be subject to this section.”);

courts can still grant petitions to sterilize PWD who cannot consent, though this process is now governed by a variety of regulatory schemes across the states.<sup>42</sup> Buck v. Bell has never been explicitly overruled.

## 2. Cases Discussing Judicial Immunity in the Context of Sterilization

The Supreme Court again weighed in on the issue of the sterilization of PWD who cannot consent when it considered whether judicial immunity protected a state judge who had been sued for inappropriately approving a petition for sterilization.<sup>43</sup> In Stump v. Sparkman, a mother sought and was awarded approval of a petition that allowed her fifteen-year-old daughter to be sterilized under the guise of an appendectomy.<sup>44</sup> Although the daughter, Linda, attended public school and had

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See also Bill Rankin, Castration May Await Convicted Molester; Judge Orders Procedure if Life Sentence Without Parole is Not Served, THE ATLANTA J. AND CONSTITUTION, Jan. 13, 2000, at C1 (describing the use of castration as a possible punishment in a Georgia case concerning sex crimes; “When McDonald was sentenced to life without parole plus 30 years in prison, Superior Court Judge Dane Perkins added a special condition: if ever freed from incarceration, the 56-year-old Pearson man must be both surgically and chemically castrated.”).

<sup>42</sup>. See Part II, infra.

<sup>43</sup>. Stump v. Sparkman, 435 U.S. 349, 354 (1978).

<sup>44</sup>. Id. at 352–53 (“The petition was approved by Judge Stump on the same day. He affixed his signature as ‘Judge, DeKalb Circuit Court,’ to the statement that he did ‘hereby approve the above Petition by affidavit form on behalf of Ora Spitler McFarlin, to have Tubal Ligation performed

been promoted each year with her class, her mother described her as “somewhat retarded.”<sup>45</sup> Further, “Linda had been associating with ‘older youth or young men’ and had stayed out overnight with them on several occasions.”<sup>46</sup> Thus, because she was regarded as possibly having an intellectual disability and had engaged in behaviors of which her mother did not approve, her mother was able to have a petition for sterilization granted by a state judge.

Linda only learned of the sterilization when she later married and attempted to procreate.<sup>47</sup> She sued Judge Stump for the inappropri-

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upon her minor daughter, Linda Spitler, subject to said Ora Spitler McFarlin covenanting and agreeing to indemnify and keep indemnified Dr. John Hines and the DeKalb Memorial Hospital from any matters or causes of action arising therefrom.’ On July 15, 1971, Linda Spitler entered the DeKalb Memorial Hospital, having been told that she was to have her appendix removed. The following day a tubal ligation was performed upon her. She was released several days later, unaware of the true nature of her surgery.”).

<sup>45.</sup> Id. at 351. The word “retarded” is no longer an appropriate label for a person with an intellectual or developmental disability; however, to give a full impression of the cases and arguments at issue, the relevant language has not been changed by this author.

<sup>46.</sup> Id.

<sup>47.</sup> Id. at 352–53. Such a lack of knowledge has been startlingly common in this context, as many sterilizations were performed under the guise of or in addition to necessary medical services.

ate grant of her mother's petition. The Court held that Judge Stump was entitled to judicial immunity, essentially holding that courts of general jurisdiction were empowered to issue orders for sterilization.<sup>48</sup> The Court stated, "Because the court over which Judge Stump presides is one of general jurisdiction, neither the procedural errors he may have committed nor the lack of a specific statute authorizing his approval of the petition in question rendered him liable in damages for the consequences of his actions."<sup>49</sup> This doctrine holds even where the order is issued in error and the consequences are "tragic."<sup>50</sup>

The Court's decision in Stump clarified that judicial immunity protects judges working in state courts of general jurisdiction when they grant petitions for sterilization of PWD who cannot consent.<sup>51</sup> This is the only case that has considered sterilization of this population since Buck v. Bell, and the Court thus held that judges have broad power in granting such petitions.<sup>52</sup> This is the case even where there are mistakes (such as issuing orders for people who actually could give informed consent), there are

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<sup>48.</sup> Id. at 359–60.

<sup>49.</sup> Id.

<sup>50.</sup> Id. at 363–64.

<sup>51.</sup> Id. at 364 (holding that in the absence of either statutory or case law authority on point, "Indiana law vested in Judge Stump the power to entertain and act upon the petition for sterilization. He is, therefore, under the controlling cases, immune from damages liability even if his approval of the petition was in error.").

<sup>52.</sup> Id. at 363–64.

no procedural safeguards (allowing a person to be duplicitously sterilized under the guise of an appendectomy), or there are traumatizing consequences.<sup>53</sup>

Thus, the Court has generally declined to issue rulings on the subject of sterilization of PWD who cannot consent, but the limited times that It has considered the subject, It has allowed sterilization to occur without input from those affected<sup>54</sup> and permitted leeway in the granting of such petitions.<sup>55</sup> The facts of these cases themselves—and the limited

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<sup>53.</sup> Id.

<sup>54.</sup> In fact, the people sterilized in these cases had not even been told what was happening. In Stump v. Sparkman, as noted above, the person who was sterilized believed that she was undergoing an appendectomy. Id. at 359. Further, Carrie Buck, the plaintiff in Buck v. Bell was unaware of what was at issue throughout much of her case. See COHEN, *supra* note 7 at 296 (“For all of the guardians and lawyers and hearings and notice, Carrie had never been told the most critical fact: that the colony was trying to operate on her to prevent her from having children.”).

<sup>55.</sup> Even where a judge acted with no authority established under either statutes or case law and granted a petition for sterilization based upon a likely false reading of the situation, the Court held that he was protected when he did so. Stump, 435 U.S. at 364. Indeed, the Court stated that “The fact that the issue before the judge is a controversial one is all the more reason that he should be able to act without fear of suit,” implying that the sensitive nature of the issue cut in favor of more judicial deference. Id.

concern that the Court has shown for such plaintiffs—demonstrate that further procedural safeguards must be established.

## B. State Court Approaches

Because the Supreme Court has both not addressed the sterilization of PWD who cannot consent since Buck v. Bell and given authorization to courts of general jurisdiction to grant petitions for sterilization with Stump v. Sparkman,<sup>56</sup> the issue has been left to state courts. Approaches to

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<sup>56</sup>. For further discussion of the implications of Stump v. Sparkman, see Katie Barnhill, Comment, Substituted Judgement and Best Interests Analysis: Protecting the Procreative Medical Rights of the Mentally Incompetent in Texas, 50 HOUS. L. REV. 157, 179 (2012) (“[T]he U.S. Supreme Court declared in Stump v. Sparkman that judges who authorize sterilizations in the absence of express statutory authority are not acting in the absence of all jurisdiction and are protected by judicial immunity from damages resulting from the authorization of sterilization.”); and Hilary Eisenberg, Note, The Impact of Dicta in Buck v. Bell, 30 J. CONTEMP. HEALTH L. & POL’Y 184, 193 (2013) (“When the petition was approved in 1971, there was no statutory authority governing sterilization of incompetent persons or minors, and no case law existed prohibiting submission and judicial approval of such a petition. Because there was no statute to challenge, the issue to be decided concerned the scope of the judge’s judicial immunity in granting the petition, which required a judge to have acted within his jurisdiction when claiming immunity. The Supreme Court found that because there was no statute or prohibitive case law on the matter, the jurisdiction was broad enough to include the circuit court

adjudicating whether sterilization is necessary and legal when the individual lacks capacity to consent to a medical procedure have varied, especially in the absence of relevant state statutes. The differing judicial approaches to the question are discussed below. A survey of state statutes regulating the practice, many of which are informed by judicial approaches, follows.<sup>57</sup>

State courts have varied in whether and how they have found authority to grant petitions for sterilization of PWD who cannot consent, and three approaches that have been taken are outlined below. The courts have generally declined to find sterilization of PWD who cannot consent unconstitutional, likely because of the Supreme Court's holding in Buck v. Bell, explicitly upholding the practice.<sup>58</sup> The disparity in these approaches only emphasizes the need for national leadership informed by stakeholder experiences.

#### 1. State Court Approach #1: Barring Access to Sterilization Infringes a Constitutional Right

Multiple state courts have found that because PWD who cannot consent are entitled to the same right to privacy that gives people without

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judge. Though the Supreme Court indicated that the judge did err as a matter of law, it declined commentary on sterilization laws for incompetent persons. Instead, the Supreme Court focused on the issue of proper jurisdiction, and ruled that legal error notwithstanding the judge had judicial immunity because he was within his jurisdiction to rule on the matter.”).

<sup>57</sup>. See Part II, infra.

<sup>58</sup>. Buck, 274 U.S. at 207.

mental disabilities access to sterilization, a state policy denying sterilization to this population is an unconstitutional deprivation.<sup>59</sup> Under this analysis, because a person without a disability would be entitled to sterilization under Griswold v. Connecticut, Einstadt v. Baird, and other cases establishing the right to privacy in a reproductive context, denying access to sterilization to a person on the basis of their disability is impermissible.

The following cases are among the most cited in this area and were some of the first to establish that PWD who cannot consent could be sterilized if certain procedural safeguards and judicial findings were met. Furthermore, the cases exemplify many of the constitutional arguments relevant to both common and statutory law on this subject. These include (1) the right to sterilization is protected under the right to privacy in the federal constitution; (2) this right cannot be denied to people based upon disability status; and (3) where a person cannot exercise the right on her own, a guardian or court can exercise it for her.

a. In re Grady

In In re Grady, one of the most influential judicial decisions on the subject,<sup>60</sup> the New Jersey Supreme Court weighed the history of

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<sup>59</sup>. See, e.g., V.H. v. K.E.J. (In re Estate of K.E.J.); In re A.W., 637 P.2d 366 (Colo. 1981); In re Debra B., 495 A.2d 781 (Me. 1985); In re Moe, 432 N.E.2d 712 (Mass. 1982).

<sup>60</sup>. 72 decisions have cited this case, according to LexisNexis, and much legal scholarship describes In re Grady as influential in promulgating the best-interests standard, discussed below. See William A. Kraiss, Note and Comment, The Incompetent Developmentally Disabled Person's

compulsory sterilization of PWD who cannot consent, the state's duty to protect the welfare of the same population, and the facts of the case in front of them. The court held:

“The right to choose among procreation, sterilization and other methods of contraception is an important privacy right of all individuals. Our courts must preserve that right. Where an incompetent person lacks the mental capacity to make that choice, a court should ensure the exercise of that right on behalf of the incompetent in a manner that reflects his or her best interests.”<sup>61</sup>

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Right of Self-Determination: Right-to-Die, Sterilization and Institutionalization, 15 AM. J.L. AND MED. 333, 355 (1989) (“The most influential case applying the best interest test to the issue of sterilization is In re Grady.”); Vanessa Volz, Note, A Matter of Choice: Women with Disabilities, Sterilization, and Reproductive Autonomy in the Twenty-First Century, 27 WOMEN'S RTS. L. REP. 203, 208 (2006) (“A 1981 decision, In re Grady, was one of the first cases to establish that a judge is the appropriate decision maker in determining the sterilization of a disabled woman who is not living in an institution.”); Christine Ryan, Note, Revisiting the Legal Standards that Govern Requests to Sterilize Profoundly Incompetent Children: In Light of the “Ashley Treatment,” Is a New Standard Appropriate?, 77 FORDHAM L. REV. 287, 306 (2008) (“For cases involving the sterilization of an incompetent minor, courts have typically followed a general pattern, such as that followed in the case of In re Grady.”).

<sup>61</sup>. In re Grady, 426 A.2d at 475.

Though the court recognized that such sterilization would not be “voluntary” in the traditional sense of the word, the justices also decided that it was not “compulsory,” as there were parties involved—the guardians—ostensibly effectuating the person in question’s best interests.<sup>62</sup> Because the sterilization would not be “compulsory,” the court explained that the case did not implicate the ugly history of involuntary state sterilization of those with mental disabilities; indeed, the court discussed this history at length, likely to demonstrate awareness of the “awesome” implications of its own decision.<sup>63</sup>

To find a right to the sterilization that was neither “voluntary” nor “compulsory,” the court situated its holding among those decisions interpreting the Constitution to include a right to privacy.<sup>64</sup> The court reasoned that if the sterilization was being sought voluntarily and without the presence of a disability, a person would be able to access this medical procedure without state interference under Griswold v. Connecticut and Einstadt v. Baird.<sup>65</sup> The court stated that the “right to prevent conception” discussed in the latter case complements Skinner v. Oklahoma’s fundamental right to procreate.<sup>66</sup> While recognizing that a right to sterilization has not been explicitly recognized by the Supreme Court, this court held that just such a right would logically fall under the Court’s

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<sup>62.</sup> Id. at 473.

<sup>63.</sup> Id. at 471–73.

<sup>64.</sup> Id. at 473–74.

<sup>65.</sup> Id. at 473.

<sup>66.</sup> Id. at 473.

holdings regarding the right to privacy and cited multiple lower court decisions that do explicitly recognize a right to sterilization.<sup>67</sup> Therefore, the court found that access to sterilization as a form of contraception was a constitutional right.

Further, the In re Grady court heavily relied upon its own precedent regarding the right to privacy of PWD who cannot consent. The court discussed at length In re Quinlan, in which the father of a woman in a vegetative state asked the court to allow him to discontinue the extraordinary measures being used to keep her alive, ultimately heeding her previously expressed wishes.<sup>68</sup> Here, the court found, “Presumably this right [to privacy] is broad enough to encompass a patient’s decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman’s decision to terminate pregnancy under certain conditions.”<sup>69</sup>

The court analogized Le Ann Grady, the woman in question in In re Grady, to Karen Quinlan, who also could not give informed consent to

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<sup>67.</sup> Id. at 474 (“A right to sterilization has yet to receive express constitutional protection from the United States Supreme Court. Several lower courts, however, have acknowledged its existence. Hathaway v. Worcester City Hospital, 475 F.2d 701 (1st Cir. 1973); Ruby v. Massey, 452 F.Supp. 361 (D.Conn.1978); Peck v. Califano, 454 F.Supp. 484 (D.Utah 1977); Ponter v. Ponter, 135 N.J.Super. 50, 55, 342 A.2d 574 (Ch. Div.1975).”).

<sup>68.</sup> See generally In re Quinlan, 355 A.2d 647 (N.J. 1976).

<sup>69.</sup> Id. at 663.

the medical procedures at issue. Reasoning from this analogy, the court found that implicit in the right to privacy is the right to make a meaningful choice between alternatives: in the case before them, this meant a meaningful choice between the right to contraception and the right to attempt procreation.<sup>70</sup> However, as in In re Quinlan, the court found that just because a person is unable to make this choice does not mean that they<sup>71</sup> should be deprived access to a procedure that would otherwise further their best interests:<sup>72</sup> “To preserve that right and the benefits that a

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<sup>70.</sup> In re Grady, 426 A.2d at 474.

<sup>71.</sup> In this Note, I use “they” as a gender-neutral, singular pronoun in addition to a plural pronoun to encompass all gender identities.

<sup>72.</sup> The court assumes that a person who is capable of giving informed consent and making a meaningful choice between these alternatives does so by making a decision in her “best interests;” the court thus assumes that the correct choice—the one most aligned with her best interests—can be determined and implemented by a third Party. This underlying assumption has been criticized by scholars who point out that people making reproductive decisions may not only consider what is best for them, but other, emotional factors, which a court will not be able to weigh in the same way for a person with a mental disability. See MARTHA A. FIELD AND VALERIE A. SANCHEZ, EQUAL TREATMENT FOR PEOPLE WITH MENTAL RETARDATION: HAVING AND RAISING CHILDREN 93 (1999) (“The purpose of such best interests analysis is to protect legally incompetent people from exploitation, but in doing so it does not provide equality. It does not give people labeled ‘incompetent’ the same right of choice that other people

meaningful decision would bring to her life, it may be necessary to assert it on her behalf.”<sup>73</sup>

In sum, merely because a person is not able to assert a right does not mean that it disappears entirely, and it is sometimes appropriate for a court to assert the right on their behalf. In articulating this conclusion, the court set out the best-interests standard, discussed below, to ensure access to the right to privacy, which includes sterilization that will further the person in question’s wellbeing.<sup>74</sup>

b. Conservatorship of Valerie N.

Four years later, the California Supreme Court similarly held that a statutory scheme that did not allow for the sterilization of PWD who cannot consent violated this population’s constitutional rights: “We conclude that the present legislative scheme, which absolutely precludes

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have. Not only can they not make their own choice, but also the person deciding for them must always choose ‘in their best interests,’ a formulation that limits their options in comparison to other people. Procreative choice is not a subject of decisionmaking on which persons are particularly prone to act in their best interests, as rationally calculated. Emotional and nonrational considerations on the part of the person deciding whether to parent often play a large role, perhaps appropriately. A choice that is made **for** a person differs inherently from a decision by the person herself, and a wholly rational decision also differs from other people’s decisions.”) (emphasis in original).

<sup>73</sup>. In re Grady, 426 A.2d at 475.

<sup>74</sup>. Id. at 483.

the sterilization option, impermissibly deprives developmentally disabled persons of privacy and liberty interests protected by the Fourteenth Amendment to the United States Constitution, and article I, section 1 of the California Constitution.”<sup>75</sup>

As discussed in Conservatorship of Valerie N., before the facts at issue had occurred, the California legislature had passed a statute drafted and suggested by the California Law Revision Commission—Section 2356 of the California Probate Code—which stated in section (d) that “[a]ward or conservatee may be sterilized only as provided in Section 7254 of the Welfare and Institutions Code.”<sup>76</sup> Section 7254 outlined procedural processes intended to protect this population from compulsory sterilization in line with eugenic interests; however, the legislature repealed Section 7254 before enacting the new statute, leaving no way for courts to authorize the sterilization of anyone deemed a ward or conservatee.<sup>77</sup>

Soon after, the parents and guardians of Valerie N., a woman with an intellectual disability who expressed interest in sexual relations and physical contact with men, sought to have their daughter sterilized as a form of birth control.<sup>78</sup> The parents tried to obtain a court order authorizing the procedure, but the trial judge denied the petition. Though the judge “believed both that sterilization was in order and that subdivision

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<sup>75.</sup> Conservatorship of Valerie N., 707 P.2d 760, 771–72 (Cal. 1985).

<sup>76.</sup> Id. at 767.

<sup>77.</sup> Id.

<sup>78.</sup> Id. at 761–63.

(d) of section 2356 was unconstitutional,” the statutory scheme—complete with repeal of Section 7254—did not allow him an avenue to grant the petition.<sup>79</sup>

Valerie’s parents appealed, and the case reached the California Supreme Court. The resulting opinion cites cases supporting both the right to marriage and procreation<sup>80</sup> and the right to not bear children by use of contraception,<sup>81</sup> describing both as encompassed by the right to privacy extant in both the Constitution of the United States and the California Constitution.<sup>82</sup>

In an effort to defend the statutory scheme, the state put forward multiple interests for the court’s consideration. The state first asserted that

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<sup>79.</sup> Id. at 764.

<sup>80.</sup> Id. at 772 (stating “The right to marriage and procreation are now recognized as fundamental, constitutionally protected interests” and citing extensive case law to this point).

<sup>81.</sup> Id. (“So too, is the right of a woman to choose not to bear children, and to implement that choice by use of contraceptive devices or medication, and, subject to reasonable restrictions, to terminate a pregnancy. These rights are aspects of the right of privacy which exists within the penumbra of the First Amendment to the United States Constitution. . . . They are also within the concept of liberty protected against arbitrary restrictions by the Fourteenth Amendment.”) (citations omitted).

<sup>82.</sup> Id. (The right to privacy “is express in section 1 of article I of the California Constitution which includes among the inalienable rights possessed by all persons in this state, that of ‘privacy.’”) (citations omitted).

“the interest of the state in safeguarding the right of an incompetent **not** to be sterilized justifies barring all nontherapeutic sterilization of conservatees who are unable personally to consent.”<sup>83</sup> In response, the court pointed to statutes regarding contraception and abortion that allowed guardians to make reproductive decisions on behalf of the person in question in other contexts.<sup>84</sup> The court reasoned that, because the legislature had found these statutes valid enough to pass into law, the state interest in this case must actually be in preserving the ability to have children, which would be cut off irreversibly in the case of sterilization and sterilization alone.<sup>85</sup> The court did not find this interest persuasive. The person’s ability to procreate could be controlled by guardians through either contraception or abortion; the limitation of only sterilization persuaded the court that the interest was not compelling enough to pass strict scrutiny.<sup>86</sup>

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<sup>83.</sup> Id. at 774.

<sup>84.</sup> Id. at 774.

<sup>85.</sup> Id.

<sup>86.</sup> Id. (“The state interest therefore must be in precluding the option of sterilization because it is in most cases an irreversible procedure. Necessarily implicit in the interest asserted by the state is an assumption that the conservatee may at some future time elect to bear children. While the prohibition of sterilization may be a reasonable means by which to protect some conservatees’ right to procreative choice, here it sweeps too broadly for it extends to individuals who cannot make that choice and will not be able to do so in the future. The restriction prohibits sterilization when this

Furthermore, the state argued that “the ban is, nonetheless, necessary because past experience demonstrates that when the power to authorize sterilization of incompetents has been conferred on the judiciary it has been subject to abuse.”<sup>87</sup> This refers to the United States’ and California’s deplorable history of eugenic sterilization.<sup>88</sup> The court did not find this persuasive, either: “Again, however, the rationale fails since less restrictive alternatives to total prohibition are available in statutory

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means of contraception is necessary to the conservatee’s ability to exercise other fundamental rights, without fulfilling the stated purpose of protecting the right of the conservatee to choose to bear children. That right has been taken from her both by nature which has rendered her incapable of making a voluntary choice, and by the state through the powers already conferred upon the conservator.”).

<sup>87</sup>. Id. at 774–75.

<sup>88</sup>. See Part I, supra; Sarah Zhang, A Long-Lost Data Trove Uncovers California’s Sterilization Program, THE ATLANTIC (Jan. 3, 2017), <http://www.theatlantic.com/health/archive/2017/07/california-sterilization-records/511718> (“During the height of the eugenics movement, California sterilized 20,000 patients deemed feeble-minded or insane.”); and Elizabeth Cohen and John Bonifield, California’s Dark Legacy of Forced Sterilizations, CNN, (Mar. 15, 2012), <https://www.cnn.com/2012/03/15/health/california-forced-sterilizations/index.html> (“Thirty-two states had eugenics programs, but California was in a league of its own. The Golden State sterilized more than twice as many people as the next state, Virginia, which sterilized 8,300.”).

and procedural safeguards as yet untried in this state. Respondent offers no evidence of abuse in other jurisdictions in which the option has been made available.”<sup>89</sup> Because the court had no evidence of abuse in sterilization practices in other states,<sup>90</sup> it declined to recognize this interest as compelling.<sup>91</sup>

The court reasoned that, under Roe v. Wade, because the right to privacy is a “fundamental, constitutionally protected right of all other adult women,”<sup>92</sup> the same right could not be denied to women with developmental disabilities without a strict scrutiny justification—a compelling state interest that “may be no broader than necessary to protect that interest.”<sup>93</sup> Under that analysis, the California Supreme Court found that the ban on sterilization of this population was unconstitutional.<sup>94</sup>

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<sup>89.</sup> Conservatorship of Valerie N., 707 P.2d 760.

<sup>90.</sup> See Part III.C, infra, discussing the difficulty of enforcing procedural safeguards and the likely largely invisible abuse of these statutes, as exemplified by the Ashley X. case.

<sup>91.</sup> Conservatorship of Valerie N., 707 P.2d 760.

<sup>92.</sup> Id. at 772.

<sup>93.</sup> Id. at 774; The court also found that strict scrutiny was appropriate under state constitutional law. Id. (“Similarly, in assessing any restriction on the exercise of a fundamental constitutional right, we must determine whether the state has a compelling interest that is within the police power of the state in regulating the subject, whether the regulation is necessary to accomplish that purpose, and if the restriction is narrowly drawn.”).

<sup>94.</sup> Id. at 777 (“True protection of procreative choice can be

## 2. State Court Approach #2: Jurisdictional Bar in Cases of First Impression

In contrast, some state courts have declined to grant petitions for sterilization, citing jurisdictional issues.<sup>95</sup> For example, in Frazier v. Levi, the Texas Supreme Court considered an application for sterilization of a “mentally incompetent ward” based on “social and economic grounds only.”<sup>96</sup> This pre-Stump v. Sparkman case found that because the legislature had not acted to delegate the power to issue such court orders to the judiciary, “[a]ny order authorizing the operation proposed by the appellant would be in excess of the power delegated by the statutes of Texas and would be invalid.”<sup>97</sup> The court thereby denied all courts in

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accomplished only if the state permits the court-supervised substituted judgment of the conservator to be exercised on behalf of a conservatee who is unable to personally exercise this right. Limiting the exercise of that judgment by denying the right to effective contraception through sterilization to this class of conservatees denies them a right held not only by conservatees who are competent to consent, but by all other women. Respondent has demonstrated neither a compelling state interest in restricting this right nor a basis on which to conclude that the prohibition contained in section 2356, subdivision (d), is necessary to achieve the identified purpose of furthering the incompetent’s right not to be sterilized.”).

<sup>95</sup>. These decisions occur where there is no legislative action.

<sup>96</sup>. Frazier v. Levi, 440 S.W.2d 393, 393 (Tex. Civ. App. 1969).

<sup>97</sup>. Id. at 395.

Texas the ability to grant such petitions in a case that is still good law in Texas today.<sup>98</sup>

Similarly, the Supreme Court of Missouri in In re M.K.R. refused to assess the constitutionality of sterilization of a PWD who cannot consent, addressing only jurisdictional questions.<sup>99</sup> The court held that, although statutes regarding juvenile court powers should be construed liberally to further the interests of the children it serves (the person with a disability in question in this case was only 13 years old), the juvenile code could not be read to reach sterilization; further, “[n]or for that matter do we find any constitutional or statutory provision empowering any court in this state to order the involuntary sterilization of any person.”<sup>100</sup>

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<sup>98.</sup> Id. See also Disability Rights Texas, Legally Adequate Consent, [https://www.disabilityrightstx.org/files/Legally\\_Adequate\\_Consent.pdf](https://www.disabilityrightstx.org/files/Legally_Adequate_Consent.pdf) (“Neither the parent of a minor child nor the guardian of an adult may consent to sterilization in the State of Texas. Furthermore, in Texas, not even a court can order or authorize sterilization. However, a person with a disability, including an IDD or mental illness, who has given legally adequate consent can be sterilized. Thus, only the person with the disability herself can consent.”). Although Stump v. Sparkman stated that courts would have jurisdiction over such claims, the Texas courts have never revisited this issue; neither has the Texas legislature passed any statutes on the subject. Therefore, courts are barred from granting petitions for sterilization in Texas.

<sup>99.</sup> In re M.K.R., 515 S.W.2d 467, 468 (Mo. 1974).

<sup>100.</sup> Id. at 470.

Thus, unlike In re Grady, in which the court was willing to find a middle ground between voluntary and compulsory sterilization for people with mental disabilities, the Texas and Missouri courts were far less willing to recognize this gray area or to extend court authority to these petitions. While such decisions appear to be less common post–Stump v. Sparkman,<sup>101</sup> the principle that courts in these states are not allowed to issue orders about sterilization still stands, and the issuance could only occur when a person can give legally adequate consent.

### 3. State Approach #3: Finding but Refusing to Use Delegated Authority

Even post–Stump v. Sparkman, and even where the court found that there was jurisdiction over such sterilization petitions, the Supreme Court of Wisconsin still refused to act on public policy grounds.<sup>102</sup> After considering the jurisdictional question and deciding, unlike the Texas and Missouri Supreme Courts, that jurisdiction existed even without a specific statutory delegation of power,<sup>103</sup> the court, nonetheless, refused

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<sup>101.</sup> However, it has been noted that Stump v. Sparkman is not necessarily controlling on other states. See In re Guardianship of Eberhardy, 307 N.W.2d 881, 888 (Wis. 1981) (“Sparkman is not controlling on Wisconsin courts, because the issue in Sparkman was judicial immunity, where for policy reasons a judge’s authority traditionally has been construed broadly. Also, the United States Supreme Court’s interpretation of another state’s law does not bind this court in respect to interpreting its own law.”).

<sup>102.</sup> Id. at 899.

<sup>103.</sup> Id. at 885 (“This view of jurisdiction, founded solely upon statutory authorization, is too narrow and does not comport with the precedents of

to consider the petition in front of it or the standards by which petitions should be judged.<sup>104</sup>

In In re Guardianship of Eberhardy, the Wisconsin Supreme Court was asked to decide whether a Wisconsin trial court had the authority to authorize the guardians of a twenty-two-year-old woman with a mental disability to consent to sterilization on her behalf because they feared she would become sexually active in the future.<sup>105</sup> At the original hearing, the guardians had asserted that sterilization would be in the best interest of their daughter, likely relying on the recent decision in In re Grady.<sup>106</sup>

The court, however, refused to adopt a “best interest” analysis or any other procedure that would allow PWD who cannot consent to be sterilized.<sup>107</sup> After considering Wisconsin’s history of eugenic sterilization,<sup>108</sup>

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this court. We conclude that, under the Constitution of the State of Wisconsin, the circuit court had the jurisdiction to approve of the proposed tubal ligation; and, additionally, we conclude that the statutes acknowledge the plenary jurisdiction of Wisconsin circuit courts.”).

<sup>104.</sup> Id. at 889.

<sup>105.</sup> Id. at 882.

<sup>106.</sup> Id. at 884.

<sup>107.</sup> Id. at 899.

<sup>108.</sup> Wisconsin had previously enacted and repealed a eugenic sterilization statute. However, the court determined that the repeal of the eugenic sterilization statute did not give enough public policy guidance by the legislature to make a determination on how it should proceed. Id. at 890 (“The repeal of the mandatory eugenic sterilization law is irrelevant

the Supreme Court's decisions on the right to privacy,<sup>109</sup> and other states' approaches to the issue,<sup>110</sup> the court concluded that:

“[T]he question is not choice because it is sophistry to refer to it as such, but rather the question is whether there is a method by which others, acting in behalf of the person's best interests and in the interests, such as they may be, of the state, can exercise the decision. Any governmentally sanctioned (or ordered) procedure to sterilize a person who is incapable of giving consent must be denominated for what it is, that is, the state's intrusion into the determination of whether or not a person who makes no choice shall be allowed to procreate. The public policy of the state is inevitably involved. If this court were to conclude that, under the facts of this case, Joan Eberhardy should be sterilized, we would be deciding more than the best interests of a particular

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to public policy or the court's jurisdiction in respect to nonmandatory therapeutic or contraceptive sterilization procedures of uninstitutionalized incompetent persons. We conclude, therefore, that the legislative history of the 1913 sterilization law neither sanctions nor precludes sterilization under the circumstances posed in this case.”).

<sup>109.</sup> Id. at 891–92.

<sup>110.</sup> Specifically, the court devoted much discussion to In re Grady, finding that this court's reasoning, while persuasive, was also based mainly upon New Jersey precedent, which would not be applicable in Wisconsin. Id. at 892–93.

person in a particular situation. We would be deciding that it is appropriate and not contrary to public policy to order the sterilization of a person when a court decides it is in the best interests of that person to do so.”<sup>111</sup>

Thus, the court also rejected the New Jersey Supreme Court’s attempt to recognize a gray area between “voluntary” and “compulsory” sterilization, went on to recognize that the court did not have significant expertise in this area,<sup>112</sup> and concluded that “a court is not an appropriate forum for making policy in such a sensitive area.”<sup>113</sup> Essentially, the court, even after acknowledging its power, other state’s decisions, and the necessity of policy in this area, refused to engage in what it likely would have deemed judicial activism, punting the decisionmaking process to the legislature.<sup>114</sup>

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<sup>111.</sup> Id. at 893.

<sup>112.</sup> Id. at 895 (“What these facts demonstrate is that courts, even by taking judicial notice of medical treatises, know very little of the techniques or efficacy of contraceptive methods or of thwarting the ability to procreate by methods short of sterilization.”).

<sup>113.</sup> Id.

<sup>114.</sup> Id. at 898 (“We accordingly conclude that it would be inappropriate to either permit the sterilization of Joan Eberhardy where there has been no determination by the legislature of the state’s public policy defining what is in Joan’s (and others’) best interests, or to attempt to set forth at length guidelines when we know that a court is not the preferred branch of government to enunciate general rules of public policy. This task should

Overall, judicial perspectives on this issue range greatly, and the varied approaches have resulted in vastly different policies through the nation. Where New Jersey uses the best-interests standard,<sup>115</sup> Wisconsin courts refused to act.<sup>116</sup> Texas engages in an essential ban on sterilization in these cases<sup>117</sup> that California would likely hold unconstitutional.<sup>118</sup> Many state legislatures, however, have attempted to assert state public policy through legislative action, which is explored below.

### C. Statutory Approaches

Many, though not all, states have used statutes to address the intersection of mental disability, consent, and sterilization.<sup>119</sup> These states provide various protections: guaranteed representation by an attorney<sup>120</sup>

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initially be the legislature's.”).

<sup>115.</sup> See In re Grady, 426 A.2d.

<sup>116.</sup> See In re Guardianship of Eberhardy, 307 N.W.2d 881.

<sup>117.</sup> See Frazier v. Levi, 440 S.W.2d.

<sup>118.</sup> See Conservatorship of Valerie N., 707 P.2d 760.

<sup>119.</sup> However, even in states where there is no relevant statute, as noted and discussed above, the absence of statutory direction does not keep courts within a state from either precluding sterilization of people with disabilities (See Frazier v. Levi, 440 S.W.2d 393, discussed above and precluding such sterilization in Texas) or establishing procedures for the issuance of court orders for such sterilizations (See In re Guardianship of Hayes, 608 P.2d 635 (Wash. 1980) establishing the best-interests standard for the state of Washington).

<sup>120.</sup> These states include California (CAL. PROB. CODE § 1954 (West

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2016)), Colorado (COLO. REV. STAT. § 25.5-10-233(f)(2) (2014)), Connecticut (CONN. GEN. STAT. § 45a-694 (2017)), Delaware (DEL. CODE ANN. TIT. 16 § 5710(1) (2017)), Georgia (GA. CODE ANN., § 31-20-3(c)(7) (2012)), Hawai'i (HAW. REV. STAT. § 560:5-607(b) (1993)), Idaho (IDAHO CODE § 39-3905 (2011)), Kansas (KAN. STAT. ANN. 59-3075(e)(5) (2005)), Maine (ME. STAT. TIT. 34-B § 7013(2) (2018)), Minnesota (MINN. STAT. § 524.5-313(4)(ii) (2016)), Vermont (VT. STAT. ANN. TIT. 18 § 8710 (2017)), and Virginia (VA. CODE ANN. § 54.1-2976(2) (2013)). Other states provide counsel on limited conditions, such as at the court's discretion or in the case of indigency. See 755 ILL. COMP. STAT. 5/11a-17.1(d) (2016) ("The court (1) may appoint counsel for the ward if the court finds that the interests of the ward will be best served by the appointment, and (2) shall appoint counsel upon the ward's request, if the ward is objecting to the proposed sterilization, or if the ward takes a position adverse to that of the guardian ad litem."), N.C. GEN. STAT. § 35A-1245(c) (2017) ("A copy of the petition shall be served on the ward personally. If the ward is unable to comprehend the nature of the proposed procedure and its consequences and is unable to provide an informed consent, the clerk shall appoint an attorney to represent the ward in accordance with rules adopted by the Office of Indigent Defense Services."), N.D. CENT. CODE 25-01.2-11(2) (2002) ("If the developmentally disabled person cannot afford counsel, the court shall appoint an attorney not less than ten days before the hearing."), N.J. STAT. ANN 30:6D-5(4) (West 2009) ("In the event that a person cannot afford counsel, the court shall appoint an attorney not less than 10 days before the hearing."), OHIO REV. CODE ANN. § 5123.86(C) (West 2010) ("Before approving the surgery,

or guardian ad litem<sup>121</sup> and notice on the respondent is generally

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the court shall notify the Ohio protection and advocacy system created by section 5123.60 of the Revised Code, and shall notify the patient of the rights to consult with counsel, to have counsel appointed by the court if the patient is indigent, and to contest the recommendation of the chief clinical officer.”), and OR. REV. STAT. § 436.265 (2017) (“(1) If the respondent requests counsel but is determined to be financially eligible for appointed counsel at state expense, the court shall appoint suitable counsel to represent the respondent at state expense. (2) If the respondent is not represented by counsel and appears to be unable to request counsel, the court shall appoint suitable counsel to represent the respondent.”).

<sup>121</sup>. These states include Arkansas (ARK. CODE ANN. § 20-49-201(c) (2018)), Hawai'i (HAW. REV. STAT. § 560:5-604 (1993)), Illinois (755 ILL. COMP. STAT. 5/11a-17.1(c) (2016)), Utah (UTAH CODE ANN. § 62A-6-111(1) (LexisNexis 2018)), and Wyoming (WYO. STAT. ANN. § 3-2-202(a)(ii)(C) (2017)). Other states provide for a guardian ad litem in limited circumstances. See GA. CODE ANN., § 31-20-3(c)(1) (2012) (“If no such parent or parents survive or can be found after reasonable effort or if such parent or parents are mentally incompetent, the petition shall contain the written consent of a guardian ad litem who shall be appointed by the probate court and who shall make investigation and report to such court before the hearing shall commence, provided that such guardian ad litem shall be a duly qualified and licensed member of the State Bar of Georgia.”) and VT. STAT. ANN. TIT. 18 § 8710 (2017) (“The court may also require appointment of a guardian ad litem to represent the interest of the

required.<sup>122</sup> Further, six states statutorily require the consideration of a respondent's wishes.<sup>123</sup>

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respondent.”).

<sup>122.</sup> See ARK. CODE ANN. § 20-49-203(b) (2018), CAL. PROB. CODE § 1953 (West 2016), COLO. REV. STAT. § 25.5-10-233(f)(4) (2018), CONN. GEN. STAT. § 45a-693 (2017), DEL. CODE ANN. tit. 16 § 5708 (2018), GA. CODE ANN., § 31-20-3(c)(3) (2012), HAW. REV. STAT. § 560:5-605 (1993), IDAHO CODE § 39-3906 (2011), ME. STAT. tit. 34-B § 7007(2) (2018) (providing for notice of the hearing to determine capacity for informed consent) in conjunction with ME. STAT. tit. 34-B § 7012 (2018) (providing for notice of the hearing to determine whether the order for sterilization should be granted), N.C. GEN. STAT. § 35A-1245(c) (2017), N.D. CENT. CODE 25-01.2-11(1)(a) (2002), OR. REV. STAT. § 436.255 (2) (2017), UTAH CODE ANN. 1953 § 62A-6-110 (2018), VT. STAT. ANN. tit. 18, § 8709 (2017), VA. CODE ANN. § 54.1-2976(2) (2013), WYO. STAT. ANN. § 3-2-202(a)(ii)(C) (2017).

<sup>123.</sup> See CAL. PROB. CODE § 1957 (West 2016) (“To the greatest extent possible, the court shall elicit and take into account the views of the individual for whom sterilization is proposed in determining whether sterilization is to be authorized.”), COLO. REV. STAT. § 25.5-10-233(6)(b) (2018) (“Prior to ordering sterilization, the court must find: . . . That the court has heard from the person regarding that person’s desires, if possible, and the court has considered the desires of the person.”), CONN. GEN. STAT. § 45a-697 (2017) (“Notwithstanding the finding of the court, the respondent can refuse sterilization, provided the court concludes that the respondent understands the nature and consequences of such refusal.”),

These safeguards typically occur at an adversarial court hearing in response to a petition for sterilization made by the respondent's guardian. In these hearings, the petitioner must generally meet the statutory

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755 ILL. COMP. STAT. 5/11a-17.1(c) (2016) ("Outside the presence of the guardian, the guardian ad litem shall personally observe the ward prior to the hearing and shall inform the ward orally and in writing of the contents of the verified motion for authority to consent to sterilization. Outside the presence of the guardian, the guardian ad litem shall also attempt to elicit the ward's position concerning the motion, and any other areas of inquiry deemed appropriate by the court at or before the hearing, the guardian ad litem shall file a written report detailing his or her observations of the ward; the responses of the ward to any of the inquiries detailed in this Section."), ME. STAT. tit. 34-B, § 7008(3) (2018) ("If the person seeking sterilization or for whom sterilization is sought has any preference as to a disinterested expert by whom he would prefer to be examined, the court shall make a reasonable effort to accommodate that preference."), UTAH CODE ANN. § 62A-6-108(3) (LexisNexis 2018) ("The court shall interview the subject of sterilization to determine his understanding of and desire for sterilization. The expressed preference of the person shall be made a Part of the record, and shall be considered by the court in rendering its decision. The court is not bound by the expressed preference of the subject of sterilization; however, if the person expresses a preference not to be sterilized, the court shall deny the petition unless the petitioner proves beyond a reasonable doubt that the person will suffer serious physical or psychological injury if the petition is denied.").

prescribed standard by clear and convincing evidence.<sup>124</sup> The standard generally falls into one of three categories—the best-interests standard,

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<sup>124.</sup> See CONN. GEN. STAT. § 45a-699(b) (2017), DEL. CODE ANN. tit. 16, § 5712(b)(3) (2009), GA. CODE ANN. § 31-20-3(5) (2012), HAW. REV. STAT. § 560:5-608(a) (LexisNexis 2015), IDAHO CODE § 39-3909(1) (2011), 755 ILL. COMP. STAT. 5/11a-17.1(h) (2010), ME. STAT. tit. 34-B, § 7013(4) (2018), MINN. STAT. § 524.5-313(4)(ii) (2016), N.D. CENT. CODE § 25-01.2-11(4) (2002), OR. REV. STAT. § 436.305(3) (2017), VT. STAT. ANN. tit. 18, § 8711(e) (2017), and VA. CODE ANN. § 54.1-2977(A) (2013). Four states deviate from this pattern. New Jersey states only that “In the proceedings, the burden of proof shall be on the Party alleging the necessity of the procedure.” N.J. STAT. ANN. § 30:6D-5 (West 2009). California requires that the petitioner meet the burden of “beyond a reasonable doubt.” CAL. PROB. CODE § 1958 (West 2016). Utah requires the petitioner to meet the clear and convincing evidence standard under UTAH CODE ANN. § 62A-6-112(2) (LexisNexis 2018) unless the respondent expresses a wish not to be sterilized. UTAH CODE ANN. § 62A-6-108(3) (LexisNexis 2018) (“The court is not bound by the expressed preference of the subject of sterilization; however, if the person expresses a preference not to be sterilized, the court shall deny the petition unless the petitioner proves beyond a reasonable doubt that the person will suffer serious physical or psychological injury if the petition is denied.”). Additionally, North Carolina requires that the sterilization be medically necessary for a court order to be issued. N.C. GEN. STAT. § 35A-1245(e)(2) (2017).

the medical standard, or the hybrid standard—each of which are explored below.

### 1. The Best-Interests Standard

The best-interests standard was first discussed in In re Hayes and In re Grady.<sup>125</sup> Since these decisions, many states have adopted a best-interests standard or a modified version of it by statute, and it remains

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<sup>125.</sup> Previous cases had considered what a judge would have to decide to find that sterilization would be in the best interests of someone with a mental disability who could not give informed consent to the procedure. See In re Guardianship of Hayes, 608 P.2d at 641 (“[I]t must be proved by clear, cogent and convincing evidence that there is a need for contraception. The judge must find that the individual is (1) physically capable of procreation, and (2) likely to engage in sexual activity at the present or in the near future under circumstances likely to result in pregnancy, and must find in addition that (3) the nature and extent of the individual’s disability, as determined by empirical evidence and not solely on the basis of standardized tests, renders him or her permanently incapable of caring for a child, even with reasonable assistance.”); North Carolina Ass’n. for Retarded Children v. North Carolina, 420 F. Supp. 451 (Dist. Ct. 1976) (considering the legitimacy of a statute regarding sterilization of this population); and Wyatt v. Aderholt, 368 F. Supp. 1383, 1385 (Dist. Ct. 1974) (“Prior to approving the proposed sterilization of any resident, the Review Committee shall: . . . (e) Determine whether the proposed sterilization is in the best interest of the resident.”). However, In re Grady and In re Hayes were the first to explicitly enumerate a long list of concerns.

one of the most popular approaches to making judicial decisions on these matters.

In In re Hayes, the mother of a sixteen-year-old girl with a mental disability brought a petition for her sterilization to a Washington State court.<sup>126</sup> The trial court dismissed the petition on a motion for summary judgment on the ground it had no authority to issue an order for sterilization of a PWD who cannot consent.<sup>127</sup> The case was appealed to the Supreme Court of the state, which concluded that “the court may grant such a petition in the rare and unusual case that sterilization is in the best interest” of a PWD who cannot consent and set out a standard by which Washington courts need to comply:

“[I]t must be proved by clear, cogent and convincing evidence that there is a need for contraception. The judge must find that the individual is (1) physically capable of procreation, and (2) likely to engage in sexual activity at the present or in the near future under circumstances likely to result in pregnancy, and must find in addition that (3) the nature and extent of the individual’s disability, as determined by empirical evidence and not solely on the basis of standardized tests, renders him or her permanently incapable of caring for a child, even with reasonable assistance.

Finally, there must be no alternatives to sterilization. The judge must find that by clear, cogent and convincing evidence

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<sup>126.</sup> In re Guardianship of Hayes, 608 P.2d at 636.

<sup>127.</sup> Id.

(1) all less drastic contraceptive methods, including supervision, education and training, have been proved unworkable or inapplicable, and (2) the proposed method of sterilization entails the least invasion of the body of the individual. In addition, it must be shown by clear, cogent and convincing evidence that (3) the current state of scientific and medical knowledge does not suggest either (a) that a reversible sterilization procedure or other less drastic contraceptive method will shortly be available, or (b) that science is on the threshold of an advance in the treatment of the individual's disability."<sup>128</sup>

Furthermore, the court stated “[t]here is a heavy presumption against sterilization of an individual incapable of informed consent that must be overcome by the person or entity requesting sterilization.”<sup>129</sup> This case set out the framework by which Washington courts decide whether sterilization is in the best interest of a person with a mental disability who cannot give informed consent—the Washington legislature has never deemed it necessary to overrule the court statutorily, thereby endorsing one of the first instances of the best-interests standards in the United States.

About a year later, In re Grady set out the following factors for the determination of whether a court order for sterilization should be granted in the case of a PWD who cannot consent:

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<sup>128.</sup> Id. at 641.

<sup>129.</sup> Id.

“(1) The possibility that the incompetent person can become pregnant. There need be no 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.

(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 the present time’ and under foreseeable future circumstances.

(6) The advisability of sterilization at the time of the application rather than in the future. 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.

(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.

(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."<sup>130</sup>

The court went on to state "[t]hese factors should each be given appropriate weight as the particular circumstances dictate. The list is not meant to be exclusive. The ultimate criterion is the best interests of the incompetent person."

Variations of the best-interests standard have been adapted by nine states.<sup>131</sup> In some states, the court may order sterilization only if it is in

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<sup>130.</sup> In re Grady, 426 A.2d at 483. The court noted that this analysis was fully applicable only to women and stated "A similar analysis should be made where sterilization is requested for a male, although we recognize that some of the above factors do not apply. It may be much more difficult to meet the best interests standard in sterilization for males. But we see no justification for applying a different standard. We treat males and females equally when we require that sterilization be authorized only when it is in their best interests." Id. at n. 10.

<sup>131.</sup> These states include Connecticut, Hawai'i, Idaho, Illinois, Maine, Minnesota, North Dakota, Oregon, and Vermont. See CONN. GEN. STAT. § 45a-699 (2017), HAW. REV. STAT. § 560:5-608 (2015), IDAHO CODE

the respondent's best interests, without elaborating much, if at all, on how trial courts should ascertain said interests.<sup>132</sup> Other states have adapted

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§ 39-3909(4) (2011), 755 ILL. COMP. STAT. 5/11a-17.1 (2010), ME. STAT. tit. 34-B § 7010 (2018), MINN. STAT. § 524.5-313(c)(4)(ii) (2016), N.D. CENT. CODE § 25-01.2-11(4) (2002), OR. REV. STAT. § 436.305(1) (2017), VT. STAT. ANN. tit. 18 § 8711(c)(3) (2017).

<sup>132.</sup> See CONN. GEN. STAT. § 45a-699(a) (2017) (stating only that “The court shall give its consent to sterilization only if it finds by clear and convincing evidence that such operation or procedure is in the best interests of the individual and shall furnish findings to support its conclusion”), 34-B ME. 34-B STAT. tit. § 7010 (2018) (stating only that “The parent, spouse, guardian or custodian of any person found unable to give informed consent for sterilization may petition the District Court, in the county of residence of the person being considered for sterilization, to determine if sterilization is in the best interest of that person.”), MINN. STAT. § 524.5-313(c)(4)(ii) (2016) (“In every case the court shall determine if the procedure is in the best interest of the ward. In making its determination, the court shall consider a written medical report which specifically considers the medical risks of the procedure, whether alternative, less restrictive methods of treatment could be used to protect the best interest of the ward, and any recommendation of the commissioner of human services for a public ward.”), and N.D. CENT. CODE § 25-01.2-11(4) (2002) (stating only that “An order allowing the procedure or treatment may not be granted unless the Party alleging the necessity of the procedure or treatment proves by clear and convincing evidence that the procedure is in the best interest of the

some or all of the factors from In re Grady, making improvements relevant to the state. Many states require consideration of the respondent's fertility,<sup>133</sup> the likelihood that the respondent will engage in sexual activity,<sup>134</sup> the feasibility of less permanent alternatives and the possibility of future medical advancements,<sup>135</sup> and whether the petitioners are seeking the sterilization in good faith.<sup>136</sup> Most states also consider psychological harm to the respondent as a result of sterilization<sup>137</sup> or the stress of caring for or giving up a child.<sup>138</sup> Some states provide that evidence regarding

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recipient and that no less drastic measures are feasible.”).

<sup>133.</sup> See HAW. REV. STAT. § 560:5-608(d)(1) (2015), IDAHO CODE § 39-3909(4)(a) (2011), 755 ILL. COMP. STAT. 5/11a-17.1(h)(2) (2010) (requiring an assessment of fertility, though not locating this within the best-interests assessment), OR. REV. STAT. § 436.205(1)(a) (2017), and VT. STAT. ANN. tit. 18 § 8711(c)(3)(A) (2017).

<sup>134.</sup> See HAW. REV. STAT. § 560:5-608(d)(3) (2015), IDAHO CODE § 39-3909(4)(b) (2011), 755 ILL. COMP. STAT. 5/11a-17.1(h)(5)(B) (2010), OR. REV. STAT. § 436.205(1)(b) (2016), and VT. STAT. ANN. tit. 18 § 8711(c)(3)(B) (2017).

<sup>135.</sup> See HAW. REV. STAT. § 560:5-608(d)(4) (2015) and (5), IDAHO CODE § 39-3909(4)(f) (2011), and OR. REV. STAT. § 436.205(1)(c) (2017).

<sup>136.</sup> See HAW. REV. STAT. § 560:5-608 (2018).

<sup>137.</sup> See HAW. REV. STAT. § 560:5-608(d)(2) (2018), IDAHO CODE § 39-3909(4)(e) (2011), and 755 ILL. COMP. STAT. 5/11a-17.1(h)(5)(A) (2010).

<sup>138.</sup> See HAW. REV. STAT. § 560:5-608(d)(2) (2018), IDAHO CODE § 39-3909(4)(d) (2011), 755 ILL. COMP. STAT. 5/11a-17.1(h)(5)(A) (2010), OR. REV.

the extent of the person's disability must be shown, but they explicitly state that the evidence cannot come exclusively from standardized tests.<sup>139</sup> Other states require that the proposed method of sterilization be the least invasive viable procedure.<sup>140</sup> Illinois courts can consider any

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STAT. § 436.205(1)(e) (2016) (considering the respondent's ability to care for a child), and VT. STAT. ANN. tit. 18 § 8711(c)(3)(C) (2017) (considering the respondent's ability to care for a child).

<sup>139.</sup> See IDAHO CODE § 39-3909(4)(c) (2011) ("The nature and extent of the person's disability, as determined by empirical evidence and not solely the basis of standardized tests, renders him or her permanently incapable of caring for a child, even with reasonable assistance."), and OR. REV. STAT. § 436.205(1)(e) (2017) ("The nature and extent of the individual's disability, as determined by empirical evidence and not solely on the basis of standardized tests, renders the individual permanently incapable of caring for and raising a child, even with reasonable assistance.").

<sup>140.</sup> See IDAHO CODE § 39-3909(4)(g) (2011) ("The proposed method of sterilization entails the least invasion of the body of the individual"), 755 ILL. COMP. STAT. 5/11a-17.1(h)(4) (2016) (stating "The court has considered less intrusive alternatives and found them to be inadequate in this case," though not locating this within the best-interests analysis), MINN. STAT. § 524.5-313(c)(4)(ii) (2016), N.D. CENT. CODE § 25-01.2-11(4) (LexisNexis 2002), OR. REV. STAT. § 436.205(1)(d) (2016), and VT. STAT. ANN. tit. 18 § 8711(c)(3)(E) (LexisNexis 2017).

other factors applicable to a determination of the best interests of the respondent.<sup>141</sup>

The best-interests standard continues to be the approach most utilized by state legislatures. However, the statutory implementation of this standard has been varied, demonstrating that even where an approach is utilized, legislatures have not been uniform in describing it.

## 2. The Medical Standard

Three states, Delaware, North Carolina, and Georgia, require some showing of medical necessity before granting a petition for the sterilization of a PWD who cannot consent.<sup>142</sup> This replaces the individual's, the

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<sup>141.</sup> See 755 ILL. COMP. STAT. 5/11a-17.1(h)(5)(d) (2016) (“Any other factors that assist the court in determining the best interest of the ward relative to the proposed sterilization.”).

<sup>142.</sup> Delaware requires that a petitioner show that “a. The respondent is presently incapable of giving informed consent to sterilization; b. The respondent is more likely than not to remain so incapable either permanently or for the foreseeable future and that all attempts to render the respondent capable of giving informed consent have been and are likely to remain ineffectual; c. The benefit to the respondent from the sterilization **outweighs any known medical contraindications** to the procedure to be performed; d. If the respondent is not sterilized, the respondent is more likely than not to procreate and all less drastic **medically advisable** alternative means to prevent procreation are or have been ineffective; e. **If the respondent is female, pregnancy would present a substantial danger to the life or health of the respondent;** and f. The procedure to

judge's, and the guardian's decisionmaking for the respondent with one or more doctors' judgement. However, medical necessity is not uniformly defined even among the states that utilize the standard, as demonstrated by a comparison of the three states' approaches.

The North Carolina standard of "medical necessity"<sup>143</sup> appears far more restrictive than the Delaware standard, which requires that

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be performed is the **least drastic medically or hygienically indicated means of sterilizing the respondent.**" DEL. CODE ANN. § 5712(3) (2017) (emphasis added). In contrast, North Carolina requires that "The procedure is **medically necessary** and is not solely for the purpose of sterilization or for hygiene or convenience." N.C. GEN. STAT. § 35A-1245(e)(2) (2003) (emphasis added). Yet another approach entails the deferment of judgement to the medical community. See GA. CODE ANN., § 31-20-3(3) and (5) (2012) ("Prior to the hearing on the application, evidence shall be presented to the court that a sterilization procedure has been approved for the person alleged to be subject to this Code section by a committee of the medical staff of the accredited hospital in which the operation is to be performed. . . . After the hearing, if the judge of the probate court shall find by clear and convincing evidence, from the evidence above specified, that the person alleged to be subject to this Code section is a person subject to this Code section and that the condition of such person is irreversible and incurable, he shall enter an order and judgment authorizing the physician to perform such sterilization procedure in accordance with subsection (d) of this Code section.").

<sup>143</sup>. See note 144, infra.

“pregnancy would present a substantial danger to the life or health of the respondent.”<sup>144</sup> However, varying definitions of “medical necessity” exist, and the North Carolina Code does not give guidance on how courts should proceed in an ethically challenging situation; individual judges may interpret the standard differently.<sup>145</sup> This discretion could

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<sup>144.</sup> DEL. CODE ANN. § 5712(3)(c) and (e) (2017).

<sup>145.</sup> Compare CIGNA, Medical Necessity Definitions, <https://www.cigna.com/healthcare-professionals/resources-for-health-care-professionals/clinical-payment-and-reimbursement-policies/medical-necessity-definitions> (last visited Apr. 19, 2018) (“‘Medically Necessary’ or ‘Medical Necessity’ shall mean health care services that a Physician, exercising prudent clinical judgment, would provide to a patient for the purpose of evaluating, diagnosing or treating an illness, injury, disease or its symptoms, and that are: in accordance with the generally accepted standards of medical practice; clinically appropriate, in terms of type, frequency, extent, site and duration, and considered effective for the patient’s illness, injury or disease; and not primarily for the convenience of the patient or Physician, or other Physician, and not more costly than an alternative service or sequence of services at least as likely to produce equivalent therapeutic or diagnostic results as to the diagnosis or treatment of that patient’s illness, injury or disease.”) with Mike Olmos, What “Medically Necessary” Means and How It Affects Your Medicare Coverage, MEDICARE.GOV (Sep. 16, 2018) <https://medicare.com/resources/what-medically-necessary-means-and-how-it-affects-your-medicare-coverage> (“health-care services or supplies needed to prevent, diagnose, or treat an illness,

allow for the Delaware code, which actually references a danger to the life or health of a pregnant woman, as abortion laws must,<sup>146</sup> to be far more restrictive (at least in terms of pregnant women) than North Carolina's standard.

Both North Carolina and Delaware give more direction regarding when sterilization is appropriate than Georgia's deference to a board of medical professionals.<sup>147</sup> While a judge makes the final determination under this statute, the construction of the statute requires the input of multiple medical professionals, who will advise the judge of their opinion.<sup>148</sup>

While these approaches present a veneer of acceptability by deferring to medical professionals on the subject, it is not clear that these standards are adequately directive or will appropriately serve the interests of people with disabilities.<sup>149</sup>

### 3. Hybrid Standards

Some states attempt to blend the benefits of multiple approaches, resulting in hybrid statutes. Two states in particular have attempted to

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injury, condition, disease, or its symptoms and that meet accepted standards of medicine.”).

<sup>146.</sup> Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 US 833 (1992).

<sup>147.</sup> GA. CODE ANN., § 31-20-3(c)(3) (2012).

<sup>148.</sup> Id.

<sup>149.</sup> For further discussion, see Part III, infra.

explicitly combine elements of multiple standards, and these approaches are discussed in detail below.

a. Utah

Utah has adopted a hybrid statute which combines the best interest standard, discussed above, with a standard that no state has adopted on its own: the “substituted judgment” standard, requiring a judge to imagine themselves in the place of the PWD who cannot consent and make the decision they believe the person would make for themselves. In doing so, Utah combined the approach taken by the In re Grady court with that of the Massachusetts Supreme Court in In re Moe, which held that when deciding whether to grant a petition for sterilization of a PWD who cannot consent, “the court does not decide what is necessarily the best decision but rather what decision would be made by the incompetent person if he or she were competent,” even if this decision seems “foolish” to the court.<sup>150</sup>

This approach—while seeking to preserve the autonomy of the respondent as much as possible<sup>151</sup>—is open to critique. The court runs into difficulty when confronted with a person who has experienced mental disability for their entire life; where a court might be able to elicit testimony about the person’s willingness to undergo medical procedures when they were previously able to give informed consent,<sup>152</sup> this is impossible in cases in which the respondent has had a lifelong mental disability.

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<sup>150.</sup> In re Moe, 432 N.E.2d 712.

<sup>151.</sup> Id.

<sup>152.</sup> As was the case in Cruzan by Cruzan v. Director, Mo. Dep’t of

Furthermore, the court itself directed that “[t]he result of the judge’s exercise of discretion should be the same decision which would be made by the incompetent 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.’”<sup>153</sup> This is, in itself, an impossibility.<sup>154</sup>

Despite these difficulties, the Utah legislature decided to implement this standard for determining a petition for sterilization,<sup>155</sup> and, indeed, the court in In re Moe partially addressed these concerns:

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Health, 497 U.S. 261 (1990).

<sup>153.</sup> In re Moe, 432 N.E.2d at 723 (quoting Superintendent of Belcher-town State School v. Saikewicz, 370 N.E.2d 417 (Mass. 1977)).

<sup>154.</sup> For further discussion, see FIELD AND SANCHEZ, supra note 72 at 98 (“It appears, then, that Moe requires the judge him- or herself to assess and evaluate the impact of the mental retardation, both on what the woman now wants to do and on her capability to do it. The rationale is that if she were competent she would take this factor into account. While on one level this seems to make sense, it is also noteworthy that the ‘if competent’ Part of the test allows the judge to dismiss the perspective of the person who will be subject to the operation, departing from the fundamental purpose of the substituted judgement formulation. The perspectives of the competent population concerning disability intervene through this ‘if competent’ facet of the test, empowering them to decide whether to allow her wishes.”).

<sup>155.</sup> UTAH CODE ANN. § 62A-6-108(1) (LexisNexis 2018).

“The inability, however, of an incompetent to choose, should not result in a loss of the person’s constitutional interests. To speak solely in terms of the “best interests” of the ward, or of the State’s interest, is to obscure the fundamental issue: Is the State to impose a solution on an incompetent based on external criteria, or is it to seek to protect and implement the individual’s personal rights and integrity? We reject the former possibility. Each approach has its own difficulties, but the use of the doctrine of substituted judgment promotes best the interests of the individual, no matter how difficult the task involved may be. We admit that in this case we are unable to draw upon prior stated preferences the individual may have expressed. An expression of intent by an incompetent person while competent, however, is not essential. . . . The courts thus must endeavor, as accurately as possible, to determine the wants and needs of this ward as they relate to the sterilization procedure.”<sup>156</sup>

To this end, the Utah legislature utilizes parts of both approaches.<sup>157</sup> UTAH CODE ANN. § 62A-6-108(1) lists nine factors that a court should take into consideration when making its decision.<sup>158</sup> Later in the statute,

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<sup>156.</sup> In re Moe, 432 N.E.2d at 720.

<sup>157.</sup> UTAH CODE ANN. § 62A-6-108(1) and (4) (LexisNexis 2018).

<sup>158.</sup> This section states:

“If the court finds that the subject of sterilization is not capable of giving informed consent, the court shall consider, but not by way

UTAH CODE ANN. § 62A-6-108(4) states that “[w]hen adjudicating a petition

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of limitation, the following factors concerning that person:

- (a) the nature and degree of his mental impairment, and the likelihood that the condition is permanent;
- (b) the level of his understanding regarding the concepts of reproduction and contraception, and whether his ability to understand those concepts is likely to improve;
- (c) his capability for procreation or reproduction. It is a rebuttable presumption that the ability to procreate and reproduce exists in a person of normal physical development;
- (d) the potentially injurious physical and psychological effects from sterilization, pregnancy, childbirth, and parenthood;
- (e) the alternative methods of birth control presently available including, but not limited to, drugs, intrauterine devices, education and training, and the feasibility of one or more of those methods as an alternative to sterilization;
- (f) the likelihood that he will engage in sexual activity or could be sexually abused or exploited;
- (g) the method of sterilization that is medically advisable, and least intrusive and destructive of his rights to bodily and psychological integrity;
- (h) the advisability of postponing sterilization until a later date; and
- (i) the likelihood that he could adequately care and provide for a child.”

UTAH CODE ANN. § 62A-6-108(1) (LexisNexis 2018).

for sterilization the court shall determine . . . what decision regarding sterilization would have been made by the subject of sterilization, if he were capable of giving informed consent to sterilization. The decision regarding sterilization shall be in the best interest of the person to be sterilized.”<sup>159</sup>

This standard laudatorily attempts to find the best outcome for the respondent by combining two approaches to a difficult issue that occasionally may be mutually exclusive. One can imagine a case in which a woman does not wish to be sterilized for religious reasons, even if she were somehow able to give informed consent for long enough to consider the issue. Depending on the individual circumstances, however, a court may find that this decision would not be in her best interest. In this case, what is a Utah court to do? It is common knowledge that people do not necessarily act rationally, and it is certainly the case that people may or may not act in their own best interests when it comes to reproductive decisions. Utah’s statutory scheme does not address this issue.

b. California

Another novel, hybrid statutory approach to this issue has been adopted in California, where the relevant statute reads:

“The court may authorize the conservator of a person proposed to be sterilized to consent to the sterilization of that person only if the court finds that the petitioner has established all of the following **beyond a reasonable doubt**:

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<sup>159</sup>. UTAH CODE ANN. § 62A-6-108(4) (LexisNexis 2018).

(a) The person named in the petition is incapable of giving consent to sterilization, as defined in Section 1951, and the incapacity is in all likelihood permanent.

(b) Based on reasonable medical evidence, the individual is fertile and capable of procreation.

(c) The individual is capable of engaging in, and is likely to engage in sexual activity at the present or in the near future under circumstances likely to result in pregnancy.

**(d) Either of the following:**

**(1) The nature and extent of the individual's disability as determined by empirical evidence and not solely on the basis of any standardized test, renders him or her permanently incapable of caring for a child, even with appropriate training and reasonable assistance.**

**(2) Due to a medical condition, pregnancy or childbirth would pose a substantially elevated risk to the life of the individual to such a degree that, in the absence of other appropriate methods of contraception, sterilization would be deemed medically necessary for an otherwise nondisabled woman under similar circumstances.**

(e) All less invasive contraceptive methods including super-vision are unworkable even with training and assistance, inapplicable, or medically contraindicated. Isolation and segregation shall not be considered as less invasive means of contraception.

(f) The proposed method of sterilization entails the least invasion of the body of the individual.

(g) The current state of scientific and medical knowledge does not suggest either (1) that a reversible sterilization procedure or other less drastic contraceptive method will shortly be available, or (2) that science is on the threshold of an advance in the treatment of the individual's disability.

(h) **The person named in the petition has not made a knowing objection to his or her sterilization.** For purposes of this subdivision, an individual may be found to have knowingly objected to his or her sterilization notwithstanding his or her inability to give consent to sterilization as defined in Section 1951. In the case of persons who are nonverbal, have limited verbal ability to communicate, or who rely on alternative modes of communication, the court shall ensure that adequate effort has been made to elicit the actual views of the individual by the facilitator appointed pursuant to Section 1954.5, or by any other person with experience in communicating with developmentally disabled persons who communicate using similar means."<sup>160</sup>

Though most of the elements listed in this statute mirror the best-interests standard,<sup>161</sup> several different or additional provisions make the

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<sup>160</sup>. CAL. PROB. CODE § 1958 (West 1990) (emphasis added).

<sup>161</sup>. Compare with In re Grady, 426 A.2d 467, discussed supra Part II.B.1.b.

California statute more difficult to meet. First, California requires the standard of proof of “beyond a reasonable doubt,”<sup>162</sup> which is significantly higher than the standard of “clear and convincing evidence” that most states have adopted.<sup>163</sup>

Second, CAL. PROB. CODE § 1958(d) combines the best-interests approach with the medical necessity standard, providing multiple avenues for petitioners to show that sterilization is necessary—either by showing inability to parent, even with reasonable assistance under CAL. PROB. CODE § 1958(d)(1), or by showing medical necessity under CAL. PROB. CODE § 1958(d)(2). This allows petitioners more flexibility in bringing their case and provides for multiple situations in which the issue of sterilization may arise.

Third, though CAL. PROB. CODE § 1958(d) may give the appearance of flexibility for the petitioner, CAL. PROB. CODE § 1958(h) specifically requires the court not only to consider the wishes of the respondent, as other state statutes do,<sup>164</sup> but it bars the court from issuing an order requiring sterilization if the respondent has expressed an objection. This goes further than other states, the most comparable of which is Utah, requiring the standard of proof to be raised to beyond a reasonable doubt in the case of objection by the petitioner under UTAH CODE ANN. § 62A-6-108 (West

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<sup>162.</sup> CAL. PROB. CODE § 1958 (West 1990).

<sup>163.</sup> See generally note 124, supra (describing laws requiring the clear and convincing evidence standard).

<sup>164.</sup> See generally note 123, supra (describing laws that require consideration of the respondent’s wishes).

1988). Therefore, California is the only state to combine the best-interests standard with the medical standard while also giving the respondent ultimate vetoing power on the entire process.

These hybrid approaches attempt to garner the benefits of multiple standards and should be treated as a predictable outcome of the laboratory of the states; nevertheless, further analysis is needed to determine whether they improve upon the other standards and adequately address the issues they set out to fix.

### c. Other Approaches

Other state statutes provide less direction as to whether a petition for sterilization should be granted. Often, the limited direction that courts do receive comes as statutes regarding either services for people deemed “incompetent” or the powers of their guardians. For example, Kansas provides only that:

“A guardian shall not have the power . . . to consent, on behalf of the ward, to the sterilization of the ward, unless approved by the court following a due process hearing held for the purposes of determining whether to approve such, and during which hearing the ward is represented by an attorney appointed by the court.”<sup>165</sup>

This provides only two safeguards to the respondent: due process, a highly debated concept, and the right to counsel. Such limited guidelines allow for significant judicial discretion in how these hearings occur, which could result in unethical or unhelpful decisions.

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<sup>165</sup>. KAN. STAT. ANN. § 59-3075(e)(5) (2005).

Similarly, though Arkansas requires a hearing, the state only requires that the court “set forth in writing separate findings as to each of the statements and allegations contained in the petition.”<sup>166</sup> All that is required for a petition is:

- “(1) The name, age, sex, residence, and post office address of the alleged incompetent;
- (2) The name, residence, and post office address of any guardians of the person alleged incompetent;
- (3) The names and addresses, so far as known or can reasonably be ascertained, of the persons most closely related to the alleged incompetent by blood or marriage;
- (4) The name and address of any person or institution having the care and custody of the alleged incompetent; and
- (5) That the alleged incompetent is incompetent, as defined in § 20-49-101(3).”<sup>167</sup>

Such vague guidelines and the lack of legislative direction are discouraging and potentially harmful.

Ohio gives even more power to the guardian of the person, requiring a court hearing on the issue only if the PWD who cannot consent does not have a guardian.<sup>168</sup> Again, this allows for an abuse of discretion

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<sup>166</sup>. ARK. CODE ANN. § 20-49-204(c) (LexisNexis 2018).

<sup>167</sup>. ARK. CODE ANN. § 20-49-202(b) (LexisNexis 2018).

<sup>168</sup>. OHIO REV. CODE ANN. § 5122.271(C) (West 2013) (“If, after providing the information required under division (A) of this section to the patient, the chief clinical officer or attending physician concludes that a patient

not only on the part of the judge, but also on the part of the person's guardian.

In comparison, New Jersey states that:

“No person receiving services for persons with developmental disabilities at any facility shall . . . be subjected to . . . sterilization without the express and informed consent of the person, if an adult who has mental capacity, **or of the person's guardian ad litem specifically appointed by a court for the matter of consent to these proceedings**, if a minor

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is physically or mentally unable to receive the information required for surgery under division (A)(1) of this section, or has been adjudicated incompetent, the information may be provided to the patient's natural or court-appointed guardian, who may give an informed, intelligent, and knowing written consent. If a patient is physically or mentally unable to receive the information required for surgery under division (A)(1) of this section and has no guardian, the information, the recommendation of the chief clinical officer, and the concurring judgment of a licensed physician who is not a full-time employee of the state may be provided to the court in the county in which the hospital is located, which may approve the surgery. Before approving the surgery, the court shall notify the Ohio protection and advocacy system created by section 5123.60 of the Revised Code, and shall notify the patient of the rights to consult with counsel, to have counsel appointed by the court if the patient is indigent, and to contest the recommendation of the chief clinical officer.”).

or an adult who lacks mental capacity or a person administratively determined to have a mental deficiency.

Either the party alleging the necessity of the procedure or the person or the person's guardian ad litem **may petition a court of competent jurisdiction to hold a hearing to determine the necessity of the procedure at which the client is physically present, represented by counsel, and provided the right and opportunity to be confronted with and to cross-examine all witnesses alleging the necessity of the procedure.** In the proceedings, the burden of proof shall be on the party alleging the necessity of the procedure. In the event that a person cannot afford counsel, the court shall appoint an attorney not less than 10 days before the hearing. An attorney so appointed shall be entitled to a reasonable fee to be determined by the court and paid by the county from which the person was admitted, providing limited direction as to how these decisions must be considered.<sup>169</sup>

This statute also suffers from the weaknesses discussed above—a vague or nonexistent direction on how to care for the interests of the person with the disability creates the potential for abuse. New Jersey seems to, at least, have incorporated some of the more common procedural protections in this field of law, possibly hoping that such protections would both allow the person with the disability to have their interests

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<sup>169</sup>. N.J. STAT. ANN § 30:6D-5(a) (2018).

guarded while giving the court latitude to consider the individual characteristics of each case.

While this final consideration is important, it is misplaced in the context of a population that has historically been marginalized, ignored, and abused.<sup>170</sup> Where people with disabilities have been subjected to reproductive coercion in significant numbers in the past<sup>171</sup> and continue to be the subject of significant abuse,<sup>172</sup> such judicial discretion is not war-

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<sup>170.</sup> See Part I, supra.

<sup>171.</sup> See Part I, supra.

<sup>172.</sup> See Disability Justice, Abuse and Exploitation of People with Developmental Disabilities (2018), <https://disabilityjustice.org/justice-denied/abuse-and-exploitation> (last visited Apr. 13, 2019) (“Abuse and exploitation are constant dangers for people with developmental disabilities. In fact, they are four to ten times more likely to be abused than their peers without disabilities. Compared to the general population, people with developmental disabilities are at greatest risk of abuse and [t]end to be abused more frequently, [a]re abused for longer periods of time, [a]re less likely to access the justice system, [a]re more likely to be abused by a caregiver or someone they know . . . [a]re more likely to remain in abusive situations.”) (citations omitted); Disability Rights California, Abuse, Neglect, and Crimes Against People with Disabilities (last visited Apr. 20, 2018), <https://www.disabilityrightsca.org/what-we-do/programs/abuse-neglect-and-crimes-against-people-with-disabilities> (“People with disabilities are at a higher risk of abuse, neglect and being victims of crime. Estimates show they are at least four to ten times more likely victims than

ranted. Legislatures must show that they have considered the United States' abusive past, that they care about protecting people with disabilities' reproductive rights (whether the right to have a child or to access sterilization), and intend to engage in action consistent with these considerations by requiring those making decisions on such petitions to make certain findings. What findings, exactly, must be made should be informed by engagement with stakeholders on which approaches are serving or not serving the interests of people with disabilities.

### III. RECOMMENDATIONS

The inconsistency throughout both common and statutory law should be resolved with national legislative action. No action should be taken, however, without (1) a clear understanding of the current law, which this Note has attempted to provide; (2) input from stakeholders affected by the law; and (3) the inclusion of significant procedural safeguards, such as the rights of PWD who cannot consent, the burden of proof that the petitioner must meet, and the enforcement mechanisms necessary to protect those implicated by the process.

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people without disabilities are.”); World Health Organization [WHO], Violence Against Adults and Children With Disabilities (2018), <http://www.who.int/disabilities/violence/en> (last visited Apr. 13, 2019) (discussing scholarly work demonstrating that people with disabilities are at a higher risk for abuse than their nondisabled peers).

## A. Acquire Input From Stakeholders

The law has failed to listen to the voices of those with disabilities for too long, especially in the reproductive context.<sup>173</sup> Only recently has the federal legislature shown concern for people with disabilities enough to enact statutory protection by passing the Americans with Disabilities Act (ADA).<sup>174</sup> This pattern must be broken before any lawmaking body weighs in on the reproductive rights of those with disabilities. As such, this Note does not take a stance on whether the best interests—medical, hybrid, or another standard—is the most appropriate for national legislation, as this author believes that it would be irresponsible to propose any particular statutory scheme without significant input from stakeholders.

### 1. Disability Rights Advocates

The Disability Rights Movement (DRM) has grown from grassroots activism to an academic and advocacy movement in a short period of time.<sup>175</sup> The DRM centers the experiences of those with disabilities and challenges common preconceptions, such as that PWD are infantile or

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<sup>173</sup>. See Part I.A, supra discussing the eugenics movement.

<sup>174</sup>. Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990).

<sup>175</sup>. Jerry Alan Winter, The Development of the Disability Rights Movement as a Social Problem Solver, 23 DISABILITY STUD. Q. 33 (2003).

childlike,<sup>176</sup> do not experience sexual desire,<sup>177</sup> and cannot be good parents.<sup>178</sup> As such, the unique perspective of Disability Rights Advocates, particularly those who identify as people with disabilities, must be at the forefront of any discussion on the subject. As the DRM's oft-quoted motto states, "Nothing about us without us."<sup>179</sup> No law should be made

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<sup>176.</sup> Emmanuel Smith, Adults With Disabilities are not "Kids", DES MOINES REG. (Nov. 13, 2015), <https://www.desmoinesregister.com/story/opinion/readers/2015/11/13/adults-disabilities-not-kids/75526536> (last visited Apr. 13, 2019) ("As a person with a severe disability I see the consequences of these disparities of language in my everyday life. The infantilizing of people with disabilities is a form of discrimination, even if done unintentionally. Adults are adults and are worthy of the respect that carries, irrespective of intellectual or physical development.").

<sup>177.</sup> Tiffany Carlson, 10 Misconceptions About Sex and Disability, THE MOBILITY RESOURCE (May 6, 2013), <https://blog.themobilityresource.com/blog/post/10-misconceptions-about-sex-and-disability> (last visited Apr. 13, 2019).

<sup>178.</sup> NATIONAL COUNCIL ON DISABILITY, Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children (Sep. 27, 2012), <https://www.ncd.gov/publications/2012/Sep272012> (last visited Apr. 13, 2019).

<sup>179.</sup> Eli A. Wolff and Mary Hums, "Nothing About Us Without Us"—Mantra for a Movement, THE HUFFINGTON POST, (Sep. 6, 2017), [https://www.huffingtonpost.com/entry/nothing-about-us-without-us-mantra-for-a-movement\\_us\\_59aea450e4b0c50640cd61cf](https://www.huffingtonpost.com/entry/nothing-about-us-without-us-mantra-for-a-movement_us_59aea450e4b0c50640cd61cf) ("People with disabilities have a

that affects people with disabilities without input from the community: PWD must be included in this conversation.

## 2. Medical Community

Furthermore, a full literature review of the ethical considerations of performing a sterilization surgery on a PWD who cannot consent should be performed before the legal inconsistencies across the country are harmonized. While such an undertaking is beyond the scope of this Note, it would provide lawmakers with necessary ethical guidance. It should be remembered, however, that the medical model of disability is often in tension with other models of disability championed by the DRM.<sup>180</sup> The

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voice that should and must be at the table from the beginning of any planning process and should never simply be an after-thought. Language, words, and actions can help us fight some of these daily battles. One example of words that can help insure people with disabilities are not cast aside is the phrase ‘Nothing About Us Without Us.’ These empowering words form a mantra that has fueled the disability rights movement over the years. To quote James Charlton who authored a book by this same title, the term ‘Nothing About Us Without Us,’ ‘expresses the conviction of people with disabilities that they know what is best for them.’ This mantra became the rallying call for the United Nations Convention on the Rights of Persons with Disabilities and continues to have relevance and significance more than ever.”).

<sup>180</sup>. The Social and Medical Model of Disability, UNIV. OF LEICESTER (Oct. 13, 2015), <https://www2.le.ac.uk/offices/accessability/staff/accessabilitytutors/information-for-accessability-tutors/>

concerns of people with disabilities should be weighed more strongly than the concerns of the medical community, as it is the people with disabilities who will ultimately be affected.

#### B. Implement Significant Procedural Safeguards if Sterilization is Allowed

Because Buck v. Bell established that it is constitutional to sterilize a PWD who cannot consent<sup>181</sup> and many foundational cases have held that depriving the entire population of access to a sterilization procedure

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the-social-and-medical-model-of-disability (last visited Apr. 19, 2019) (“The medical model of disability views disability as a ‘problem’ that belongs to the disabled individual. It is not seen as an issue to concern anyone other than the individual affected. For example, if a wheelchair using student is unable to get into a building because of some steps, the medical model would suggest that this is because of the wheelchair, rather than the steps. The social model of disability, in contrast, would see the steps as the disabling barrier. This model draws on the idea that it is society that disables people, through designing everything to meet the needs of the majority of people who are not disabled. There is a recognition within the social model that there is a great deal that society can do to reduce, and ultimately remove, some of these disabling barriers, and that this task is the responsibility of society, rather than the disabled person.”).

<sup>181</sup>. This is likely the reason that few, if any, cases hold that any such operation is unconstitutional. Instead, courts have held that the procedure would be illegal on jurisdictional grounds. See Part II.A, supra and Part II.B, supra.

is unconstitutional,<sup>182</sup> a ban on sterilization of PWD who cannot consent likely would be held unconstitutional. Lawmakers, however, should listen to people with disabilities and their advocates, as noted above, and consider such a ban if this is what the population states will best serve them.

Assuming that such a ban would be unconstitutional, this author advocates that national lawmakers and stakeholders consider the following nonexhaustive suggestions while drafting legislation regarding the sterilization of PWD who cannot consent.

#### 1. The Right to an Adversarial Hearing, Counsel, and Notice

The rights to an adversarial hearing, counsel, and notice of the petition are some of the most common safeguards in states that have statutorily addressed sterilization of PWD who cannot consent.<sup>183</sup> These rights, however, are not universal.<sup>184</sup> If sterilization of PWD who cannot consent is to be nationally instituted, so should these rights be, as they afford the PWD who cannot consent basic due process rights in the context of significant reproductive and medical decisions.

#### 2. The Right to an Adversarial Hearing

The right to an adversarial hearing protects the interests of the PWD who cannot consent by ensuring that there is a forum in which not only the petitioner's but also the respondent's perspective is considered. In real life, if the decision is up to the medical practitioner asked to perform

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<sup>182.</sup> See Part II.B, supra.

<sup>183.</sup> See Part II.C, supra.

<sup>184.</sup> Id.

the surgery, there is a very real risk that the PWD who cannot consent's concerns will not be heard, especially if the person has difficulty communicating.<sup>185</sup> Similar issues will arise if the decision is left up to a medical board or a courtroom in which the parties are not both allowed to share their perspectives. As such, as in many areas of law, an adversarial hearing will provide the best chance for a person with a disability's perspective to be heard.

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<sup>185</sup>. Doctors often treat people with disabilities differently than patients without disabilities. See WHO Quality Rights Initiative—Improving Quality, Promoting Human Rights, WORLD HEALTH ORGANIZATION [WHO] (2019), [http://www.who.int/mental\\_health/policy/quality\\_rights/en/](http://www.who.int/mental_health/policy/quality_rights/en/) (“The care available in mental health facilities around the world is not only of poor quality but in many instances actually hinders recovery.”); Juliann Garvey, When Doctors Discriminate, N.Y. TIMES (Aug. 10, 2013), <https://www.nytimes.com/2013/08/11/opinion/sunday/when-doctors-discriminate.html> (last visited Apr. 13, 2019) (“At least 14 studies have shown that patients with a serious mental illness receive worse medical care than ‘normal’ people. Last year, the World Health Organization called the stigma and discrimination endured by people with mental health conditions ‘a hidden human rights emergency.’”); Joseph Shapiro, Medical Care Often Inaccessible to Disabled Patients, NPR (Sept. 13, 2007) (discussing the difficulties that people with disabilities have when trying to find accessible medical care).

### 3. The Right to Counsel

An adversarial hearing may be completely ineffectual if the PWD who cannot consent is without counsel. People associated with marginalized populations already have difficulty obtaining representation if counsel is not provided to them,<sup>186</sup> and there is no reason to doubt that the situation differs when it comes to PWD who cannot consent and sterilization. Without counsel, a PWD who cannot consent granted an adversarial hearing may not be able to adequately represent their own interests, especially where under complex statutory frameworks such as the best interest or hybrid standards.

### 4. The Right to Notice

An adversarial hearing also would be irrelevant if the PWD who cannot consent is not given notice of the hearing. Many states that have already addressed sterilization of PWD who cannot consent statutorily provide notice to the respondent,<sup>187</sup> and this should be incorporated into any adopted national legislation. Such notice avoids situations such as that in Stump v. Sparkman, where a woman was sterilized without her

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<sup>186.</sup> THE ORG. FOR ECON. CO-OPERATION AND DEV. (OECD) AND OPEN SOC'Y FOUNDATIONS, Issues Brief: Leveraging the SDGs for Inclusive Growth: Delivering Access to Justice for All 2 (2016) ("An estimated four billion people around the world live outside the protection of the law, mostly because they are poor or marginalized within their societies.").

<sup>187.</sup> See note 122, supra.

knowledge during a routine appendectomy after a hearing allowed for her sterilization without her consent.<sup>188</sup>

Some may argue that such notice requirements are unnecessary, as the people bringing the petitions for sterilization are likely to be the guardians of the respondent. This argument is not compelling. There is no guarantee the party to bring the petition will be a guardian, and lawmakers should heed the warnings of cautionary tales such as Stump v. Sparkman<sup>189</sup> or the “Mississippi Appendectomies.”<sup>190</sup>

## 5. Burden of Proof

Any national legislation regarding PWD who cannot consent and sterilization must establish a high burden of proof—beyond a reasonable doubt. While the beyond a reasonable doubt standard is generally reserved for criminal contexts, both California and Utah have adopted a

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<sup>188.</sup> Stump v. Sparkman, 435 U.S. 349.

<sup>189.</sup> Id.

<sup>190.</sup> Courtney Hutchison, Sterilizing the Sick, Poor to Cut Welfare Costs: North Carolina’s History of Eugenics, ABC NEWS (Aug. 4, 2011) (“‘Mississippi appendectomies, they were called,’ Kluchin says, ‘because they would tell women that they needed to get their appendix out, but then sterilize them.’ For women, the procedure involved an incision to the abdomen and the tying off of the fallopian tubes. If done correctly, this doesn’t affect hormones or libido, making it possible for women to live their entire lives unaware that they had been sterilized.”).

version in the context of PWD who cannot consent and sterilization.<sup>191</sup>

The rest of the nation should follow their example.

Because of the United States' and the medical profession's long history of sterilizing people against their will and using disability as an excuse to do so, PWD who cannot consent are uniquely at risk for abuse by this procedure.<sup>192</sup> Those who have made these decisions in the past, including Justice Oliver Wendell Holmes, so often did so to the severe detriment of this population that lawmakers should now hold petitioners and decisionmakers to a higher standard—that of beyond a reasonable doubt. Thus, if we are to permit the sterilization of PWD who cannot consent, the standards adopted by lawmakers in consultation with Disability Rights Advocates and the medical profession should stipulate that certain provisions must be proven beyond a reasonable doubt.

### C. Enforcement Mechanisms

In addition, lawmakers—if they are to adopt standards for the sterilization of PWD who cannot consent—must ensure that appropriate and effective enforcement mechanisms are included in the adopted legislation. Because people with disabilities are more likely to be marginalized and abused than the general population,<sup>193</sup> they are likely less likely to have access to a tort system and legal restitution than their nondisabled peers; therefore, enforcement mechanisms must check decisionmakers as they grant petitions for sterilization.

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<sup>191.</sup> See Part II.C.3.a, supra and Part II.C.3.a, supra.

<sup>192.</sup> See Part I, supra.

<sup>193.</sup> See Part I, supra.

Specifically, lawmakers should learn from the Ashley X case, of the 2000's. In this case, a six-year-old girl underwent interventions that included surgical removal of her uterus and breast buds, as well as high-dosage hormone therapy to limit her growth and physical sexual development.<sup>194</sup> No court order was sought, as Seattle Children's Hospital allowed the procedures to go forward on false legal information.<sup>195</sup> The procedures only came to light because the doctors who performed the procedure published on it later, advocating for the treatment that they claimed made the girl's and her parents' lives easier.<sup>196</sup> In effect, a small child's body was physically altered for the convenience of her caretakers by male doctors who did not go through the court process required by Washington law.<sup>197</sup>

Because of this case and the ensuing investigation by Disability Rights Washington (formerly Washington Protection & Advocacy System or WPAS), Seattle Children's Hospital has agreed to:

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<sup>194.</sup> David R. Carlson and Deborah A. Dorfman, Investigative Report Regarding the "Ashley Treatment", WASH. PROT. & ADVOC. SYS. (May 8, 2007), <https://dredf.org/public-policy/ethics/investigative-report-regarding-the-ashley-treatment/#marker117> (last visited Apr. 13, 2019).

<sup>195.</sup> Id.

<sup>196.</sup> Id. See also Daniel F. Gunther and Douglas S. Diekema, Attenuating Growth in Children With Profound Developmental Disability: A New Approach to an Old Dilemma, ARCHIVES OF PEDIATRIC AND ADOLESCENT MED., 1013 (2006).

<sup>197.</sup> Carlson and Dorfman, supra note 194.

—”Give notice to WPAS of requested sterilization of persons with developmental disabilities so that it can continue to act as a watchdog on behalf of individuals with disabilities.

—Take the following additional steps to protect the rights of children with developmental disabilities for whom the ‘Ashley Treatment’ or other growth-limiting interventions are sought:

—Develop and implement a policy to prohibit growth-limiting medical interventions on persons with developmental disabilities without a court order. The policy will ensure that all appeal periods and appeals, if any, are exhausted before any procedures are performed;

—Give notice to WPAS of requested “Ashley Treatment” and other growth-limiting interventions of persons with developmental disabilities so that it can continue to act as a watchdog on behalf of individuals with disabilities; and improve internal controls and oversight to assure that no such procedures can take place without the necessary court order. To the extent that it is medically viable, the policy will include provisions to monitor the prescriptions for high dosages of hormones that the Hospital’s pharmacy has been asked to fill; and

—Include a disability rights advocate on the Hospital’s Ethics Committee. The Committee will also bring in experts in particular relevant areas as it relates to medical care and interventions for individuals with developmental disabilities, as appropriate.”<sup>198</sup>

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<sup>198</sup>. Id.

These standards should be implemented by federal law if national lawmakers are to address the sterilization of PWD who cannot consent. While there likely will still be violations of such policies, requiring an organization founded upon disability rights principles to be involved in the process as a watchdog will help to ensure that such violations occur less frequently. In addition, the watchdog organization should be in communication with all medical professionals authorized by their state medical organizations to perform such sterilizations, and this author suggests that such authorization be a separate credentialing process that requires sensitivity training on disability and reproductive issues.

Furthermore, as medical technology advances and interventions like those used in Ashley X become more popular,<sup>199</sup> the law should account

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<sup>199</sup>. Ed Pilkington, The Ashley Treatment: 'Her Life is as Good as We Can Possibly Make it', THE GUARDIAN, Mar. 15, 2012, <https://www.theguardian.com/society/2012/mar/15/ashley-treatment-email-exchange> (last visited Apr. 13, 2019) (quoting Ashley X.'s father: "As far as we know, Ashley was the first in the world to receive this treatment. These other families learned about the treatment through Ashley's story and got in touch with us for help. After the story came out in 2007, more than a thousand families and caregivers reached out to us in support of the treatment, based on their direct experience in caring for 'pillow angels'. Many families who heard Ashley's story and were still early in this journey of caring for their special children, realized that this treatment significantly improves their children's quality of life. Because of the controversy and that Seattle children's hospital was no longer providing the treatment, some of these

for the possibilities of bodily invasion and privacy rights violations that may intersect with the sterilization of PWD who cannot consent. To that end, watchdog organizations and those that they oversee should be required to consult on cases in which the reproductive autonomy of a person with a disability is implicated, barring those situations in which emergency procedures are necessary to preserve a person's life or health. Even these cases, though, should be subject to review by watchdog organizations after they are performed to ensure that medical professionals are not abusing their discretion.

Such accountability is necessary because of the past and continued abuses of people with disabilities. These measures would not prohibit the practice if lawmakers, in consultation with Disability Rights Advocates and the medical profession, decide that sterilization for PWD who cannot consent should be available, but it will ensure that those organizations and doctors who are engaging in such procedures are doing so ethically.

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families reached out to us for help. Given our limited means of helping them, we set up a private discussion group for them to meet and help one another, which worked out. At this point, we're in contact with six families who concluded the treatment successfully and at least as many who are in progress. There are other families in contact who are still searching for providers. We estimate that we're in contact with less than 10% of the families who are successful in providing the treatment to their children. Families who have found doctors that are willing to help their children have no need to contact us.”).

## CONCLUSION

The Disability Rights, medical, and legal communities must collaborate to create a national framework that adequately serves PWD who cannot consent. The current state of sterilization of PWD who cannot consent varies so greatly by state that national statutory action is necessary. Additionally, there is such a strong history of reproductively marginalizing PWD that a lack of action and uniformity leaves people at risk for repeated abuses.

However, in creating such legislation, lawmakers must learn from past mistakes and abuses to engage with stakeholders, learn what will best serve the disability community, and put forward a comprehensive statutory framework. Such a framework should be accompanied by basic safeguards, including the rights to an adversarial hearing, counsel, and notice, a high burden of proof, and enforcement mechanisms to prevent future abuse.

This is a significant request of law and policymakers, especially in the context of a fractured and intense political climate. However, similar, if not the same, law and policymakers have been attempting to silence PWD for the entirety of this country's history. It is time to listen to those whom the laws, and the injustices, affect.

