



## Access, Autonomy, and Dignity: People with Disabilities and the Right to Parent



## Introduction

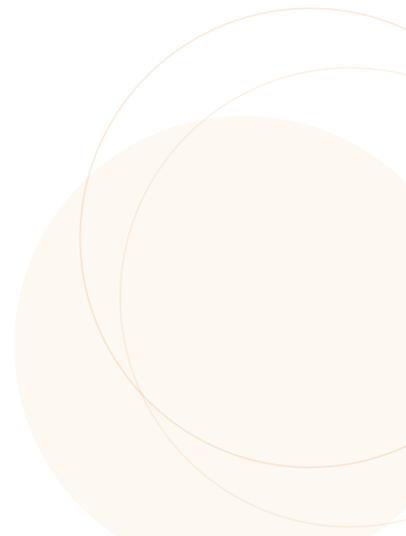
The reproductive health, rights, and justice movement and the disability justice movement have much in common. Both movements strive for a commitment to bodily autonomy and the right of each person to make their own health care decisions, and share an understanding that these are deeply connected to dignity and equality. However, the reproductive health, rights, and justice movement has not always emphasized the specific needs or challenges of people with disabilities, or sufficiently considered how their histories and experiences add nuance and complexity to the issues of reproductive health and choice.

Health equity, disability justice, and reproductive justice frameworks call on us to understand how these issues intersect in people's lives, how access to reproductive health care is shaped by disability status, and how policy solutions must center the needs of those with the greatest barriers. People with disabilities will not truly have access to reproductive health and rights until we can eradicate ableist notions of if, when, and how people with disabilities can have or not have children, as well as parent them safely, free from coercion, discrimination, and violence.

The issue briefs in this series explore four important areas of reproductive health, rights, and justice for people with disabilities: the right to parent, access to healthy sexuality and sex education, access to abortion, and access to contraception. This particular brief focuses on the right to parent and articulates specific concerns for people with disabilities, including those who experience multiple forms of marginalization. Additionally, it includes policy recommendations to protect the right to parent for people with disabilities.

**We have a long way to go. Join us in fighting for bodily autonomy and justice for everyone.**

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## Why Is the Right to Parent Important?

The desire to parent is deeply personal. People may decide to become parents for a host of reasons. These can include wanting to build family and community, to participate in the continuity of the human experience, to create shared genetic identity with others, to create change within their own lives, to follow their religious or spiritual beliefs, or even to satisfy a curiosity for a life experience that many have.

The reproductive justice framework recognizes this desire for parenthood while at the same time resists “pronatalism,” which sees women’s primary role as bearers of children in order to satisfy political, religious, or family goals. Reproductive justice maintains that parenting and having children is a human right, and decisions about reproduction should be made by individuals and couples based on their preferences and desires.<sup>4</sup>

However, this right is far from being realized – particularly for Black, Indigenous, and other people of color (BIPOC), immigrants, incarcerated individuals, and people with disabilities. As scholar and activist Dorothy Roberts said, “The right to bear children goes to the heart of what it means to be human. The value we place on individuals determines whether we see them as entitled to perpetuate themselves in their children. Denying someone the right to bear children – or punishing her for exercising that right deprives her of a basic part of her humanity.”<sup>5</sup>

Reproductive justice advocates describe how entire categories of people are deemed bad parents and are discouraged from having children simply because they do not reproduce within the confines of a white, middle-class, nuclear-family structure.<sup>6</sup> Certain marginalized social groups constantly face barriers to their right to parent and are periodically denied this “basic part of [their] humanity” through myriad discriminatory and unjust practices and policies.

The reproductive justice movement also advocates for the right to raise one’s family in a safe and healthy environment as fundamental to the right to parent. A safe environment includes, but is not limited to, accessible and high-quality health care, housing and neighborhood safety, access to sufficient nutritious food, affordable transportation and infrastructure, healthy social connections, and quality education.<sup>7</sup> Reproductive justice advocates also focus on addressing structural

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## The Legal Right to Parent in the U.S. Constitution

The right to parent is protected under the U.S. Constitution; while not explicitly referenced in the text, a number of other rights in the Constitution have been interpreted to safeguard the right of parents to have and raise their children. Among these are the rights to control one's child's education<sup>8</sup> and upbringing<sup>9</sup>; the right to custody and care of one's child<sup>10</sup>; the right to "personal choice in matters of marriage and family life"<sup>11</sup>; and the "sanctity of the family," which is interpreted as protecting family integrity or the right to stay together, as well as extending the definition of "family" beyond the bounds of the nuclear family.<sup>12</sup> In addition, government interference in custodial matters is not allowed unless it is in the "best interest of the child."<sup>13</sup> Applying this standard requires the state to find parental unfitness before terminating the relationship between parent and child,<sup>14</sup> signaling the importance and primacy of that relationship.

Despite these numerous protections, the right to parent has not been accessible or meaningful in the lives of many people, especially people with disabilities.

barriers that undermine some groups' ability to raise their children safely, including policies such as mass incarceration, family separation, and the discriminatory weaponization of the child welfare system.

Whatever our motivations for having children, each of us deserves the right and ability to have and raise children with dignity.

### The Right to Parent Is Undermined for People with Disabilities

Historically – and currently – both government and private actors have challenged and even violated the right of people with disabilities to parent, through ableist and discriminatory policies and practices. People with disabilities who are also people of color face the added disadvantages of structural racism and xenophobia. This unjust interference with their right and ability to parent occurs at all stages of a person's reproductive and parenting trajectory – from the ability to conceive, to having healthy pregnancies, to raising their children with autonomy and dignity.

## Forced sterilization

People with disabilities have long been subject to forcible sterilization laws, stripping them of the autonomy and ability to decide whether or how to parent.\* The legal foundation for this discriminatory and inhumane practice comes from the 1927 Supreme Court case of *Buck v. Bell*, which was decided at the height of the eugenics movement and which explicitly denied the right to parent to people with intellectual disabilities.<sup>15</sup> As a result, more than 65,000 people with mental and developmental disabilities were sterilized in the United States from the 1920s to the 1970s.<sup>16</sup> To date, the Supreme Court has not overruled this case, leaving state courts and legislatures to play the leading role in determining the reproductive rights of people with intellectual disabilities.<sup>17</sup>

People of color – along with low-income people, incarcerated people, and immigrants – have been disproportionately subjected to forced sterilization. First, because of overlapping racism and class prejudice, women of color and low-income women were especially vulnerable to being targeted under the laws sanctioned in *Buck v. Bell*.<sup>18</sup> In the 1960s, more than one-third of women of reproductive age in Puerto Rico were sterilized without meaningful informed consent as part of population control measures enforced by the U.S. and Puerto Rican governments.<sup>19</sup> Even as the Supreme Court recognized women’s reproductive autonomy in *Roe v. Wade*, up to 50 percent of Native American women were being forcibly sterilized by the U.S. government.<sup>20</sup> A 2013 report from the Center for Investigative Reporting found that at least 148 women incarcerated in California prisons received tubal ligations without their consent between 2006 and 2010.<sup>21</sup> Just one year later, the Associated Press reported on at least four instances of prosecutors in Nashville including birth control requirements in plea deals. In Tennessee, there have been recent examples of prosecutors including birth control requirements in plea deals, as well as judges coercively offering sentence reductions to incarcerated people if they underwent sterilization procedures.<sup>22</sup> And as recently as 2020, there were reports of mostly Latinx women in immigration detention facilities being subjected to forced hysterectomies.<sup>23</sup>

Forcible sterilization remains a live issue today for people with disabilities, despite it being internationally recognized as a human rights violation, an act of violence, a form of social control, and a

\* We recognize and celebrate that parenthood and family take many forms; a biological connection between parent and child is not – and should not be – a marker of the legitimacy or importance of such a relationship.

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violation of an individual's right to be free from torture and other cruel, inhuman, or degrading treatment or punishment.<sup>24</sup> In the United States, people with disabilities under guardianship or conservatorship in particular may be subjected to forcible sterilization or reproductive coercion. There are approximately 1.3 million active adult guardianship or conservatorship cases in the U.S. court system,<sup>25</sup> while research on the subject is very limited, advocates assert that those cases commonly involve restrictions on reproductive freedom and choice.<sup>26</sup> In just one current, high-profile example, pop singer Britney Spears, who is currently under a conservatorship arrangement due to a court determination that she has a disability, testified in court that she wishes to have children but is not being allowed to remove her IUD.<sup>27</sup> While it is not known if Spears identifies as a person with a disability, and her experience is not identical to that of permanent sterilization, her experiences of reproductive coercion and discrimination are far too common among people with disabilities.

### **Lack of accessibility and affordability of assisted reproductive technologies**

People with disabilities often consider using assisted reproductive technologies (ART) and techniques to become pregnant. ART is typically defined to include all treatments that involve the handling of eggs and sperm and/or embryos, such as in vitro fertilization (IVF), gamete intrafallopian transfer (GIFT), or tubal embryo transfer (TET).<sup>28</sup> Other fertility treatments, such as intrauterine insemination (IUI), may fall outside the scope of this definition but may nevertheless be essential to someone's ability to have a child.

ART can be incredibly difficult to access, as it requires people to find specialized medical providers, make numerous trips to a doctor's office (often on very short notice), undergo frequent testing and monitoring, and self-administer a complicated medical protocol involving a number of different medications, including injections.<sup>29</sup> The time and stress involved, along with the side effects of the medications, can take an immense physical and emotional toll. ART can also be very expensive, with one cycle of IVF commonly costing between \$12,000 and \$17,000.<sup>30</sup> Moreover, only 15 states require insurance companies to cover infertility treatment,<sup>31</sup> leaving many people who rely on ART having to pay out of pocket, often for multiple cycles of treatment.

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Unfortunately, ART is especially inaccessible to people with disabilities. First, people with disabilities are disproportionately covered by Medicaid; Medicaid typically does not cover the costs of ART, making the treatment prohibitively expensive for many.<sup>32</sup> Second, even if a disabled person is able to afford treatment, they are highly likely to encounter medical professionals who are not adequately experienced or trained to care for people with disabilities.<sup>33</sup> Finally, providers may screen out people with disabilities if they have misgivings regarding the fitness or appropriateness of the person's desire or ability to parent.<sup>34</sup> In combination, these factors mean that many people with disabilities who need or want to use ART to have a child are effectively foreclosed from the right to parent.

### Lack of access to high-quality maternal and prenatal health care

People with disabilities are generally underserved by health care providers for a variety of reasons. These include a lack of provider competency on the needs of people with disabilities, lack of accommodations in the facility, lack of transportation accessibility, and centuries of abuse and ill treatment by the medical establishment that has undermined trust.<sup>35</sup> People with disabilities also face frequent discrimination from providers who are ignorant of the specific challenges they face. This can be especially prevalent in the context of maternal and prenatal health care, where providers are often ill equipped to offer high-quality, culturally responsive care.<sup>†</sup> For example, people with disabilities frequently report that maternal health care providers are unwilling to provide them with care or do not have the knowledge to do so sufficiently, lack accessible office equipment like adjustable exam tables, and do not expend the time or resources necessary to understand disability-specific concerns related to pregnancy and childbirth.<sup>36</sup> In fact, many people with disabilities are deterred from accessing prenatal care due to the negative attitudes they face from health care providers, particularly toward their pregnancy and parenting.<sup>37</sup> Moreover, people with disabilities often find prenatal classes uninformative and unhelpful because class instructors are not knowledgeable about their disabilities and possible effects on pregnancy, labor, and delivery.<sup>38</sup>

<sup>†</sup> We recognize and respect that pregnant, birthing, postpartum, and parenting people have a range of gender identities, and do not always identify as “women” or “mothers.” In recognition of the diversity of identities, this paper prioritizes the use of non-gendered language where possible.

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For disabled people who are also people of color, this lack of access to high-quality, culturally responsive prenatal health care is further exacerbated by the structural racism driving the crisis in maternal health outcomes in the United States and the disproportionate harm to BIPOC birthing people.<sup>39</sup> In addition to the above, BIPOC people with disabilities often face compounded barriers, ranging from lack of language access, to not having their symptoms taken seriously, to having their expressed health goals ignored, and much more.<sup>40</sup>

This systemic ableism – especially when it intersects with racism – can put high-quality maternity care nearly out of reach for people with disabilities, with negative consequences for both parent and child. People with certain physical disabilities are, in fact, at heightened risk for pregnancy-related complications, such as low birth weight and cesarean delivery.<sup>41</sup> Additionally, research has found that women with sensory, intellectual, and developmental disabilities are at an increased risk of gestational diabetes and hypertensive disorders, as well as at significant risk for cesarean delivery.<sup>42</sup> Importantly, the research does not indicate that these risks are necessarily caused by the disability itself, but instead contends that these poor maternal health outcomes may be due to the social and economic stress that disabled women must consistently deal with,<sup>43</sup> as well as inadequate access to care.

### **Lack of access to adaptive technology necessary or useful for parenting tasks**

Parents with disabilities often take for granted that they can use commonly available supplies – such as strollers, baby carriers, cribs, and changing tables – in order to help them care for their children. However, these items are often unusable for parents with disabilities. As a result, adaptive or assistive technology (AT) is often necessary for parents with disabilities to perform parenting tasks independently.<sup>44</sup> AT can include baby slings/carriers, custom-built changing tables, co-sleeper cots, and swivel-base car seats, among many other things customized or specifically designed for people with disabilities.<sup>45</sup> According to a study, most parents with disabilities acquired or modified baby-care equipment, and many participants in the study reported benefiting tremendously.<sup>46</sup> However, there are few commercially available adaptive parenting supplies, and individuals voiced their frustration over the lack of availability and instead having to modify what is available or be forced to go without.<sup>47</sup> Furthermore, the costs of purchasing or modifying

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equipment are often prohibitive, especially as compared to similar equipment marketed to and usable by parents without disabilities.<sup>48</sup> In the absence of public funding for AT, the benefits they provide to both parents and children are out of reach for many. Another challenge is that even if a product exists and is relatively affordable, health care providers, caregivers, and others are often unfamiliar with available AT and do not have the experience or training necessary to recommend potential AT solutions or support parents in using them.<sup>49</sup> For all these reasons, parents with disabilities are often unable to access the AT that they need.

### **Lack of access to independent living services and supports to assist with parenting tasks**

Independent living services, such as personal care and assistance with activities of daily living, help preserve the autonomy of people with disabilities and help them live successfully in the community. In the context of parenting, people with disabilities who received physical assistance with parenting tasks report that this is an important parenting strategy for them.<sup>50</sup> These tasks could include lifting a baby in and out of the tub, giving a bottle, or burping after a feeding. Individuals who were able to access such assistance shared that they most commonly received help from a co-parent and/or from members of their extended families, and some also reported paying out of pocket for someone to assist with parenting tasks.<sup>51</sup>

At the same time, people with disabilities also report facing significant barriers to obtaining necessary support with parenting tasks. For those people with disabilities with personal care or assistant services – especially for those whose services are publicly funded – many reported not being allowed to use the services of this assistant to help with parenting tasks; by law, personal care assistants (PCAs) are commonly prohibited from providing such services.<sup>52</sup> Some people also reported feeling guilty for using these services, or were scared of being arrested and going to jail when they asked their PCA to help with child care.<sup>53</sup> This inability to seek and use publicly funded PCAs for assistance with necessary parenting tasks actively interferes with the right and ability to parent for people with disabilities.

### **Marriage penalties targeting people with disabilities**

When couples with disabilities receiving Supplemental Security Income (SSI) marry, they receive 25 percent less assistance in benefits than

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they would receive if they lived together but not as spouses.<sup>54</sup> This penalty also applies to unmarried couples who present themselves to the community as spouses.<sup>55</sup> In some cases, parents with disabilities may lose benefits and Medicaid coverage entirely if they marry, or hold themselves out as married to, the people they co-parent with.<sup>56</sup> To parents who rely on Medicaid-funded home and community-based services in order to live independently, the risk of losing benefits effectively makes it dangerous or impossible to live with their romantic partners and co-parents. This places a significant burden on the ability of parents with disabilities to build their families the way they choose.

### Losing children through the child welfare system

The child welfare system is arguably the starkest example of the state directly interfering with the right to parent. To be sure, protecting children from neglect and abuse is a legitimate and urgent priority. Unfortunately, the government system created to implement this responsibility is deeply flawed, because it was founded on – and continues to perpetuate – unfair prejudices about who is and is not fit to parent. As a result, people with low incomes, those from communities of color, and individuals with disabilities disproportionately get their children taken away by the state.

People with disabilities are particularly vulnerable to losing custody of their children, even though there is no evidence indicating that they are more likely to be unfit or pose a significant risk of child maltreatment. On the contrary, studies show that predictors for parenting difficulties (such as a history of physical or sexual abuse or substance use disorder in the parent’s family) are largely the same regardless of whether the parent is disabled; parental disability alone does not increase a child’s risk for negative outcomes.<sup>57</sup> Nevertheless, 35 states include disability as grounds for termination of parental rights.<sup>58</sup> One study found that roughly one out of every five children in foster care were removed from their families at least in part because of parental disability, and for one in 20, parental disability was the only reason.<sup>59</sup> The pathologizing of parents with disabilities results in a 22 percent higher risk of the state terminating their parental rights, compared with parents who are not disabled.<sup>60</sup> This aligns with data showing that parents with disabilities are disproportionately investigated and discriminated against by welfare agencies, the courts, and state legislatures.<sup>61</sup>

Unfortunately, disabled parents who are also people of color are likely to face even more compounded discrimination. Black parents are

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frequently unjustly surveilled and scrutinized by child welfare agencies and other government entities. Black mothers are especially likely to be monitored, regulated, and punished by the child welfare system.<sup>62</sup> They are separated from their children at disproportionately high rates and are more likely to permanently lose their children to the foster care system, despite the fact that most calls to Child Protective Services involving Black people do not involve issues of child abuse.<sup>63</sup> In fact, according to 2018 data, Black children comprise nearly 23 percent of all children in foster care, despite making up only 13.7 percent of the child population overall.<sup>64</sup>

Indigenous parents face similar discriminatory treatment by the government and child welfare system. Congress passed the Indian Child Welfare Act in 1978 to remedy the fact that Native American children were being removed from their families and communities at a much higher rate than non-Native children. However, American Indian families are still extremely vulnerable to having their children removed by state and local officials. For example, in Alaska, Native children make up 20 percent of the general child population but are 50 percent of the children in foster care; in Montana, Native children are 10 percent of the child population but one-third of the children in foster care.<sup>65</sup> And Indian children in South Dakota are 11 times more likely to be removed from their families and placed in foster care, compared to non-Indian children.<sup>66</sup> These same patterns are present across Indian country, to the detriment of Native children, families, and communities.<sup>67</sup>

Rather than using the state's power and resources to separate families, government should instead be investing in supporting families. However, research suggests that the government spends exponentially more on foster care and adoption than it does on services to support families and help keep them intact.<sup>68</sup> For example, a pilot study conducted in the 1990s in Santa Clara County, California found that for every dollar spent by the county on services and supports for disabled parents, it saved \$1.72 in federal, state, and county funds allocated to foster care.<sup>69</sup> Following the example of this research, Minnesota introduced a bill in 2017 establishing a pilot program that would provide state funds to assist parents with childrearing tasks and prevent the removal of children solely because of parental disability.<sup>70</sup> This and other similar policies have unfortunately not yet been enacted, and it is incumbent upon states to implement programs that prioritize and support the right to parent for people with disabilities, as a matter of equity and justice.

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## Proposals to Make the Right to Parent a Reality for People with Disabilities

**Ensure that health care providers, legal system personnel, child welfare agency staff, and others who come into contact with parents with disabilities have the training and resources to support the right to parent for people with disabilities.**

- Entities that oversee the education and ongoing training of people who work in systems within which parents with disabilities have frequent contact must receive comprehensive training about the history and present-day concerns around eugenics and forced sterilization, bias against people within systems, myths and stereotypes about the parenting abilities of people with disabilities, and the services and supports that parents with disabilities may need. This includes personnel in the health care system, particularly practitioners in obstetrics and pediatrics; legal system staff, including guardians ad litem, attorneys, and judges; and child welfare personnel, such as social workers and evaluators.

### **Build trust and shared commitment to disability justice.**

- **Actors within systems must build trust with the disability community.** It is not enough for institutions and systems to educate their staff, since decades of mistreatment and discrimination has done lasting damage to the trust between actors in these systems and the disability community. This trust is even further eroded for BIPOC people with disabilities. It is the responsibility of personnel within the health care, legal, and child welfare systems to reach out and build trust with the disability community and to demonstrate their commitment to providing culturally appropriate, equitable care and services, and to carry out the obligations they may have within their institutions in ways that do not shame, stigmatize, or discriminate against people with disabilities.
- **The reproductive health, rights, and justice movement must build trust with the disability justice movement.** The reproductive health, rights, and justice movement must demonstrate that it is committed to being inclusive and intersectional, responsive to critiques from allies in the disability justice movement, and ready to be thoughtful partners in working together to ensure meaningful reproductive autonomy and justice for all people.

### **Enact laws and policies that support the right to parent, as well as equity and justice, for people with disabilities.**

- **Federal and state policymakers should institute protections against forcible sterilization.** Furthermore, the U.S. Supreme Court should, if given the opportunity, formally overturn *Buck v. Bell*.

- **State and federal policymakers should pass protections against denying or terminating parental rights, especially the right to custody or visitation, as well as the ability to adopt, on the basis of disability.** These protections must account for the insidious way in which states deny custody on the basis of disability, such as by denying custody on the basis of an action or event that is tangentially connected to a parent’s disability.
- **Federal policymakers should abolish the “marriage penalty” for SSI and Medicaid.** This penalty often targets both married and unmarried partners who live together and co-parent, thus interfering with family life and depriving disabled parents of co-parenting support.
- **Federal policymakers should enable robust access to parenting supports and services for people with disabilities.**
  - ◆ Health insurance, including federal insurance programs, should cover assisted reproductive technologies, fertility treatment, and any disability-specific interventions necessary for conceiving and carrying a child, such as consultations with maternal-fetal medicine providers prior to conception.
  - ◆ The Centers for Medicare and Medicaid Services (CMS) should expand Personal Care Assistance (PCA) services to include assistance with parenting and child-rearing tasks. Additionally, parenting support should be added to the list of services available through Home and Community Based Services (HCBS) waiver. CMS should also expand the definition of durable medical equipment to include adaptive parenting equipment and look for other ways to make these technologies available and affordable for people with disabilities.
- **Federal policymakers should engage in robust oversight and enforcement of the Americans with Disabilities Act, especially Title II, which covers the court and child welfare systems.** These systems must be reformed so that all parental support and reunification programs are accessible to people with disabilities and responsive to their particular needs.
- **The U.S. Government must ratify the Convention on the Rights of Persons with Disabilities.** The Convention reaffirms that all people with disabilities must have access to all human rights and fundamental freedoms, and identifies areas where protections of the rights of people with disabilities must be reinforced.

## Endnotes

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- <sup>7</sup> *Ibid.*
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- <sup>10</sup> *Prince v. Commonwealth of Massachusetts*, 321 U.S. 158 (1944), <https://caselaw.findlaw.com/us-supreme-court/321/158.html>
- <sup>11</sup> *Cleveland Board of Education v. LaFleur*, 414 U.S. 632 (1974), <https://www.oyez.org/cases/1973/72-777>
- <sup>12</sup> *Moore v. East Cleveland*, 431 U.S. 494 (1977), <https://www.oyez.org/cases/1976/75-6289>
- <sup>13</sup> *Quilloin v. Wallcott*, 434 U.S. 246 (1978), <https://supreme.justia.com/cases/federal/us/434/246/>; *Troxel v. Granville*, 530 U.S. 57 (2000), <https://www.oyez.org/cases/1999/99-138>
- <sup>14</sup> See *Santosky v. Kramer*, 455 U.S. 745, <https://supreme.justia.com/cases/federal/us/455/745/>, which sets the “clear and convincing” standard for termination of parental rights.
- <sup>15</sup> Disability Justice. “The Right to Self-Determination: Freedom from Involuntary Sterilization,” 2021, <https://disabilityjustice.org/right-to-self-determination-freedom-from-involuntary-sterilization/>. It is worth noting that it is unclear whether Carrie Buck, the named plaintiff in this case, actually had a disability, or whether instead she was institutionalized for failing to meet the gender role expectations for a young woman at the time. Regardless, ableism can and does affect people with *perceived* disabilities as well as those who have a disability.
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The National Partnership for Women & Families is a nonprofit, nonpartisan advocacy group dedicated to advancing gender and racial equity in the workplace, improving access to affordable, quality health care that authentically meets the needs of all women and families and reduces inequities in health, and promoting reproductive freedom and justice, access to contraception and abortion care, and elimination of the stigma associated with abortion.

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The Autistic Self Advocacy Network is a nonprofit organization run by and for autistic people, created to serve as a national grassroots disability rights organization for the autistic community, advocating for systems change and ensuring that the voices of autistic people are heard in policy debates and the halls of power. ASAN works to advance civil rights, support self-advocacy in all its forms, and improve public perceptions of autism.

Learn more: [AutisticAdvocacy.org](https://AutisticAdvocacy.org)

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