

## Access, Autonomy, and Dignity: Abortion Care for People with Disabilities







### Introduction

The reproductive health, rights, and justice movement and the disability justice movement have much in common. Both movements strive for 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 access to abortion and barriers for people with disabilities, and includes policy recommendations to ensure that abortion is truly accessible for all people.

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

People with disabilities will not truly have access to reproductive health and rights until we can eradicate ableist notions.

### **Reproductive Justice**

Reproductive justice is a term that was coined in the early 1990s by a group of Black women who sought to create a movement that was inclusive of and explicitly centered people with marginalized identities, including people of color, LGBTQ people, and people with disabilities. SisterSong, a leading reproductive justice organization, defines reproductive justice as "the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities."<sup>1</sup>

Reproductive justice reframes the conversation from "choice" to "access," because a legal right to abortion is meaningless if people cannot realistically access this care. Unfortunately, millions of people do not actually have access, making choice unattainable.<sup>2</sup> Reproductive justice includes much more than just abortion, which by itself is not enough to ensure that people subject to discrimination and structural oppression have the power and resources necessary to protect their health, safety, economic security, and equity. Reproductive justice understands that these communities also face barriers to accessing contraception, comprehensive sex education, prenatal care, living wages to support their families, supportive workplace policies, intimate partner violence assistance, and much more. The reproductive justice framework recognizes that people do not live single-issue lives.

This framework also incorporates the concept of "intersectionality," a term coined by legal scholar Kimberlé Crenshaw. Drawing on Black feminist and critical legal theory, intersectionality refers to the multiple social forces and identities through which power and disadvantage are expressed and legitimized. Intersectionality helps explain the realities of people who have multiple identities in which they experience oppression, and how they not only contend with the harms of each of those separate identities (for example, being Black and being a person with a disability), but also experience compounded and unique harms at the particular intersection of those identities (for example, being a Black person with a disability).<sup>3</sup> Reproductive justice reframes the conversation from "choice" to "access," because a legal right to abortion is meaningless if people cannot realistically access this care.

### Why Is Access to Abortion Important?

## Access to abortion is a matter of bodily autonomy and dignity.

Every person should have the right to determine what happens – or does not happen – to their own body. It is one of our most basic human rights, one that is foundational to both reproductive and disability rights and justice. Deciding whether or when to have a child is fundamentally about asserting autonomy over our own bodies. Access to abortion helps to make this right a reality by giving people control over their own reproductive futures. Abortion access is also intrinsically tied to dignity because it allows us to maintain a level of respect for our own bodies and our own decisions about whether and how to expand our families – and encourages society to respect our decisions as well. Importantly, while abortion is typically framed as being central to women's lives, transgender, nonbinary, and gendernonconforming people also have abortions and should have access to all reproductive health care that is affirming of their dignity and is free of discrimination and stigma.\*

People with disabilities understand all too well how society, the medical establishment, other systems, and even other individuals feel ownership over their own bodies. People with disabilities are frequently told how to live, whether they can or should have children, whether they can or should have sex, what interventions they "need" for their bodies or minds, among other intrusions. As just one example, Karin Willison, a blogger who lives with cerebral palsy, detailed having to negotiate with her mother about cutting her hair because keeping it short would be "easier for [her] and other people to take care of."4 She also described an experience with a former caregiver who expressed repulsion that Karin menstruated, saying, "Most people like you do something about it."<sup>5</sup> These anecdotes convey an all-too-common experience for people with disabilities: other people making decisions small and large about their bodies based not on what is best for that individual but instead on what is easy, convenient, or comfortable for others. These beliefs are also shared by the courts, which have failed repeatedly to acknowledge the bodily autonomy of people with

\* In recognition of this fact, this paper uses gender-neutral language wherever possible; however, this paper does use the term "women" in some instances, especially where that terminology is in the research or cited source.

People with disabilities understand all too well how society, the medical establishment, other systems, and even other individuals feel ownership over their own bodies. disabilities. For example, Supreme Court Justice Kavanaugh – when he was a D.C. Circuit Court judge – wrote in an opinion about the right to self-determination of people with disabilities, "Accepting the wishes of patients who lack (and have always lacked) the mental capacity to make medical decisions does not make logical sense."<sup>6</sup>

Bodily autonomy is particularly vital for Black, Indigenous, and other people of color (BIPOC) communities who have faced racism, discrimination, violence, and trauma throughout history. One of the most salient perpetrators has been – and continues to be – the medical establishment, through reproductive coercion, forced sterilization, unethical experimentation, and ongoing discrimination and bias. For example, the practices of gynecology and obstetrics in the United States were built on abusive and inhumane experimentation on enslaved Black women, including developing cesarean and other surgical procedures on women without anesthesia.<sup>7</sup> And the first birth control pill — heralded as a tool for the liberation of middle-class white women — was tested on women in Puerto Rico, often without their knowledge or consent.<sup>8</sup> BIPOC people and people with disabilities have also disproportionately been subject to forced sterilization laws<sup>†</sup> – and remain so to this day.<sup>9</sup>

The ability to control our own reproductive lives helps enable us to participate fully in society. Not having the power to make decisions about our own bodies and reproduction strips us of our agency, undermines our efforts to participate fully in our own lives and communities, and defeats our self-determination. People with disabilities need and deserve access to abortion to exercise full autonomy over their own bodies and lives on their own terms.

## Access to abortion is critical for people's mental and physical health.

Abortion is basic health care to which people need access in order to live healthy and fulfilling lives. Approximately one in four women will have an abortion by age 45,<sup>10</sup> and more than 95 percent of people who choose to get an abortion feel that their decision was the right one for them.<sup>11</sup> Furthermore, being denied a wanted abortion undermines people's physical and mental health. Women who were denied an

<sup>†</sup> Learn more about the history of people with disabilities and forced sterilization in the Right to Parent brief that is part of this series at <u>nationalpartnership.org/</u> <u>ReproandDisabilityParenting</u>. 95% of people who choose to get an abortion feel that their decision was the right one for them. abortion and then gave birth report worse health outcomes up to five years later, as compared to women who received a desired abortion.<sup>12</sup> One longitudinal study of women who were denied abortion care found that, compared to women able to access the care they needed, they were more likely to experience serious medical complications during the end of their pregnancies, including eclampsia, and death. They were also more likely to suffer anxiety and to remain in relationships where interpersonal violence is present.<sup>13</sup>

For people with disabilities, better and more equitable access to the full range of high-quality health care, including abortion care, may be especially important. Structural inequities in the health care system cause people with disabilities to experience inequities in access to care and health outcomes. Nearly one in 10 people with disabilities lacks health insurance.<sup>14</sup> Even for those who are able to access health insurance, research suggests that having a physical disability increases the likelihood of having unmet health needs and poor health outcomes.<sup>15</sup> Adults with disabilities are nearly twice as likely as people without disabilities to report unmet health needs because of barriers to care.<sup>16</sup>

The intersection of access to abortion care and maternal health is particularly important to some people with disabilities who are at a heightened risk of pregnancy-related health complications,<sup>17</sup> or who may rely on medications that are contraindicated during pregnancy. This is all the more pressing for BIPOC people with disabilities; compared to white women, Black women are more than three times as likely – and American Indian/Alaska Native women are twice as likely – to die from a pregnancy-related complication.<sup>18</sup> Solving this maternal health crisis is imperative, so that people who so choose can have healthy pregnancies; this includes ensuring that abortion care is an accessible option for people for whom pregnancy may be dangerous.

Moreover, not only do people need access to abortion broadly, but also must have access to the method of abortion that feels right to them or is the safest for their body. This includes both going to a clinic for an abortion procedure and taking medication abortion in one's own home – free from restrictions and stigma. Having a range of safe and effective options is central to protecting people's health and lives. For people with disabilities, better and more equitable access to the full range of highquality health care, including abortion care, may be especially important.

#### Access to abortion helps maintain one's economic security.

The ability to decide the number and spacing of one's pregnancies is an economic justice and security issue; both pregnancy and raising children have enormous economic impacts both on a person's and their family's economic realities. Moreover, being denied an abortion can have disastrous consequences for one's economic security. For example, a woman who is denied access to abortion care is more likely to fall into poverty than a woman who can get the care she needs.<sup>19</sup> Abortion access is also linked to greater workforce participation and higher lifetime earnings - women who are denied an abortion have more than three times greater odds of being unemployed six months later than women who are able to access abortion care.<sup>20</sup> In addition, access to abortion benefits children and families, most directly by allowing people to take on the costs of having children when they are best able to or have the resources necessary to care and provide for the children they already have. Denying abortion care also has negative socioeconomic, as well as developmental, consequences for a person's existing children.<sup>21</sup>

Economic security is particularly challenging for people with disabilities, who are disproportionately low-income. This is due in large part to systemic discrimination, a broken and expensive health care system, and being disproportionately excluded from the workforce. Only one in four people with disabilities is employed, compared to more than twothirds of people without disabilities, almost triple the rate (274 percent).<sup>22</sup> Furthermore, in 2019 – the latest year for which data are available – the gap in median income for people with disabilities compared to people without disabilities was nearly \$12,000, meaning people with disabilities make approximately 66 cents for every dollar earned by people without disabilities. Consequently, people with disabilities are twice as likely to live in poverty as are people without disabilities.<sup>23</sup> These issues are further compounded for BIPOC people with disabilities. Compared to white people with disabilities, Black people with disabilities are almost 55 percent more likely to live in poverty.<sup>24</sup> In addition, Black and Latino people with disabilities have unemployment rates that are approximately 50 percent higher than white people with disabilities.<sup>25</sup>

Having a disability can also impose additional costs on people and their families, such as medical bills, transportation, home modifications,

**1**IN **4** people with disabilities is employed, compared to more than two-thirds of people without disabilities

ONLY

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

The right to abortion under the U.S. Constitution was established in the 1973 Supreme Court case Roe v. Wade. While the core of that right has since been upheld many times in cases such as Planned Parenthood v. Casey, Whole Women's Health v. Hellerstedt, and most recently in June Medical Services v. Gee, those cases have also steadily chipped away at meaningful access to abortion care.<sup>26</sup> The right to abortion is increasingly under threat and could be greatly eroded or even overturned within the next few years, given the Supreme Court's current composition. The addition of three Trump appointees – Justices Gorsuch, Kavanaugh, and Coney Barrett – has resulted in a Court with a majority of members who are opposed to abortion rights.<sup>27</sup>

Nevertheless, it is not enough for abortion to be a right on paper; people need real access in order to achieve true reproductive freedom. For too many, including many people with disabilities, access falls drastically short, even as the legal right continues to exist.

and personal assistants.<sup>28</sup> People with disabilities who rely on Medicaid-funded long-term services and supports in order to live in the community, and/or who rely on Supplemental Security Income, are typically subject to draconian income and asset limits that make it difficult or impossible to escape from poverty.<sup>29</sup> Furthermore, independent living supports that are available to people with disabilities are often not available to assist with parenting-related tasks.<sup>30</sup> All of these factors together mean that people with disabilities – and especially BIPOC people with disabilities – face systemic challenges to achieving economic security. Therefore, they must make decisions about whether or when to become a parent or grow their families within that context.

Although access to abortion is not enough on its own to ensure economic security for people with disabilities, it is a necessary component to creating a more equitable and just society, where everyone has the power and ability to make the best decisions for themselves and their families.

### **Accessing Abortion Care**

While the Constitution grants the right to abortion, for many people, it is little more than a "right" in theory and is far from guaranteed in real life. Access to abortion care varies considerably based on a number of factors, including where you live, your income, whether you have health insurance, and if so, what kind of coverage you have.

First, access to abortion care varies widely from state to state. The Guttmacher Institute classifies 29 states as "hostile" to abortion rights, and only 16 as supportive.<sup>31</sup> In 2020, 27 state policies restricting abortion were enacted, while only 21 policies to expand access were enacted; and in the first six months of 2021 alone, 90 new abortion restrictions were enacted, making it already the worst year for abortion rights on record.<sup>32</sup> This is against a backdrop where states have enacted more than 500 abortion restrictions since 2010, but fewer than 100 measures to protect or expand abortion access. Even during a year where a global pandemic raged, states such as Oklahoma, Idaho and Utah preemptively banned abortion in the event that Roe v. Wade is overturned, and Tennessee and Texas (among others) banned abortion as early as six weeks, which is before most people even know they are pregnant. However, other states, albeit fewer, moved in a more proactive direction; for example, Massachusetts affirmed people's right to abortion, expanded the pool of health care workers able to provide abortion services, and removed parental consent requirements.<sup>33</sup> These opposing developments increased the disparity of access based on zip code. As just one example of the consequences of these disparities, an estimated 3.3 million people live in an "abortion desert" – a location where people must travel more than 100 miles to reach the nearest abortion provider.<sup>34</sup>

Additionally, insurance coverage plays a large role in determining who has access to abortion care. Far too many people do not have insurance coverage, a number that has risen over the past few years,<sup>35</sup> and therefore must pay the full cost of abortion care themselves. Abortion care itself can be cost-prohibitive,<sup>36</sup> and when you add the extra costs of transportation, child care, lodging, and other travel expenses, along with the opportunity cost of missing school or work, people are often forced to choose between paying for rent or food and accessing abortion care.<sup>37</sup> Even people with insurance

Access to abortion care varies considerably based on a number of factors, including where you live, your income, whether you have health insurance, and if so, what kind of coverage you have.

often do not have coverage for abortion care. For example, due to the Hyde Amendment, those who have insurance coverage through a government-sponsored program, including Medicaid and Medicare, are blocked from using their health insurance to pay for their abortions and must pay the full cost themselves. In 2016, 38 percent of disabled people were covered by Medicaid, and 27 percent were covered by Medicare.<sup>38</sup> This can be compounded for BIPOC people with disabilities, because BIPOC people as a whole – due to income inequality driven, in part, by structural racism and discrimination<sup>39</sup> – are much more likely to access health insurance through Medicaid: roughly one out of three Black, Hispanic, and American Indian/Alaska Native people, compared to just under one in seven white people.<sup>40</sup> Consequently, the ban on federal government coverage of abortion care disproportionately impacts BIPOC people with disabilities.

For people with disabilities, other factors might be barriers to abortion care. These can be logistical barriers, such as a lack of accessible transportation, which can make it hard to leave their area, or difficulty scheduling appointments around transportation constraints. Many people with disabilities rely on faith-based providers for assistance with transportation, personal care, and making medical appointments,<sup>41</sup> as described in more detail below, these providers may be subject to religious refusal regulations that enable them to deny assistance with abortion-related care. When combined with targeted restrictions of abortion providers (TRAP laws) and other regulations that impede access to care or shrink the pool of providers, this can put abortion care entirely out of reach. People with disabilities also often have to contend with a lack of understanding from insurance companies and providers about their specific needs and what services can be covered or provided.<sup>42</sup> There can also be barriers related to intersecting identities and personal characteristics, such as immigration status, sexual orientation, or gender identity. At a minimum, the clinic or medical office must comply with the Americans with Disabilities Act (ADA). But beyond that, it must be actually accessible for people with a range of disabilities and needs. Furthermore, people with disabilities who also live at the intersection of another marginalized identity face compounded barriers to accessing care, ranging from lack of language access, to not having their symptoms taken seriously, to having their expressed health goals ignored.<sup>43</sup> The intersections of systemic racism and ableism in particular can put care entirely out of reach.

The intersections of systemic racism and ableism in particular can put care entirely out of reach.

### **Reason Bans**

In recent years, state legislatures have introduced abortion restrictions that target certain pregnancy conditions and populations. Commonly known as "reason bans," these restrictions ban abortions on the basis of the race and/or sex of the fetus, and/ or on the basis of a fetal diagnosis. Abortion bans based on the race or sex of the fetus rely on harmful racist rhetoric – for example, anti-abortion billboards have proclaimed "the most dangerous place for an African American/Latina is in the womb" – and stereotypes – such as falsely believing that Asian American and Pacific Islanders (AAPI) terminate pregnancies due to a preference for male children.<sup>44</sup> Similarly, bans based on a fetal diagnosis only interfere with the right to abortion care, under the false pretense of stopping discrimination against people with disabilities, while in actuality doing nothing to address – and potentially even increasing – the structural discrimination that people with disabilities face.

In 2013, North Dakota became the first state to ban abortion based on a fetal diagnosis. Now three other states have similar restrictions.<sup>45</sup> This number could increase, as in 2021 alone, fetal diagnosis bans have been introduced in eight states and passed into law in Arizona and South Dakota.<sup>46</sup> Passed under the guise of "protecting people with disabilities," these bans do nothing to help the communities they purport to serve. Abortion bans based on a fetal diagnosis do not address the discrimination people with disabilities face or misinformation directed at prospective parents of people with disabilities, nor do they respond to the needs of people with disabilities, such as access to health care, economic security, housing, or other social supports. These bans may have a chilling effect on patients who wish to obtain relevant medical information about a pregnancy and discuss that information openly with their doctor. Moreover, they disproportionately restrict the reproductive rights of people with heritable disabilities. People who claim to care about disability rights should instead fight to improve the social, political, physical, and economic contexts within which people with disabilities are making decisions about their lives. We must also fight to ensure that people receive accurate, stigma-free information about prenatally diagnosed disabilities, including information about self-reported quality of life and life outcomes for people with the same disability. The focus should be on changing societal structures, not restricting individual decision-making.

These bans pit the disability community against the reproductive health, rights, and justice community, rather than allowing us to focus on shared values of autonomy, dignity, equality, and self-determination.

### Specific Concerns around Abortion Access for People with Disabilities

In addition to general access concerns, people with disabilities often face additional, particular barriers when accessing abortion care.

## Provider discrimination and lack of competent, trustworthy health care providers

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>47</sup> People with disabilities also face frequent discrimination from providers who are ignorant of the specific challenges they face - and from providers who assume that their health care needs in some areas are nonexistent. This is particularly prevalent in the context of reproductive health care, as providers often do not ask people with disabilities about contraception or abortion needs because they assume they are asexual, infertile, or simply incapable of having sex.<sup>48</sup> Alternately, some providers assume that people with disabilities who are pregnant will always want an abortion. This flawed assumption is often based on an erroneous and harmful belief that people with disabilities cannot parent adequately, or that people with disabilities will not want to "perpetuate the disability" an attitude informed by eugenics and disability stigma.<sup>49</sup>

These issues are further compounded for BIPOC and LGBTQ people with disabilities who also face numerous additional barriers in accessing health care, including a history and current practice of abuse, systemic racism, and bias in health care that also undermines trust in providers.<sup>50</sup> If people with disabilities struggle to access basic health care, accessing abortion care – which is further pushed out of reach and stigmatized – can be nearly impossible.

### Guardianship and the recognition as competent to decide

People with disabilities, particularly people with intellectual disabilities, may not be viewed as competent to decide the course of their own health care, including whether to continue or terminate a pregnancy. Many people with disabilities are forced into guardianship People with disabilities are generally underserved by health care providers. - a legal arrangement that strips the person of some or even all of their rights, from deciding where they live to whether they will receive medical care and what kind. Instead, legally appointed guardians are given the power of "substituted decision-making," in other words the ability to make decisions for - instead of with - people with disabilities.<sup>51</sup> Sometimes, these decisions are informed by harmful stereotypes and false beliefs, and can be contrary to the wishes of the person with disabilities. In the context of abortion care, this means people with disabilities could be forced into receiving an unwanted abortion or having to continue a pregnancy they did not want. In some states, court approval may be required before a person with a disability can get abortion care.<sup>52</sup> While it is important to protect against concerns around coercion in these cases, states must balance this concern against the importance of access to wanted reproductive health care. Applying court approval requirements without respect to whether the abortion is actively sought by the pregnant person diminishes the autonomy of people with disabilities, further delegitimizing their competence to decide what care is appropriate for their own bodies and lives.

### **Religious refusals**

While the right to religious liberty is protected from governmental intrusion by law, politicians have been expanding this right to create blatantly discriminatory laws and policies.<sup>53</sup> On their face, these laws allow health care and other service providers to refuse to engage in certain activities if doing so would violate their religious or moral beliefs. In practice, laws and policies that carve out religious exemptions or refusals have been weaponized to enable discrimination against vulnerable communities, from openly discriminating against LGBTQ people in foster care and adoption, to denying access to health care based on the service someone is receiving or their sexual orientation or gender identity.<sup>54</sup>

People with disabilities are among those particularly vulnerable to the harms caused by religious refusal laws. For example, people with disabilities may be residents of group homes, nursing homes, intermediate care facilities, or other institutional settings, many of which are run by religious organizations that seek to impose on others their own beliefs about abortion, contraception, and premarital sex. Alternatively, they may be served by caregivers or in-home aides from religiously affiliated staffing agencies. Because some people Applying court approval requirements without respect to whether the abortion is actively sought by the pregnant person diminishes the autonomy of people with disabilities with disabilities need assistance from their facility, transportation provider, and/or aide to access medical care, they may be directly prevented from accessing abortion by that institution or person claiming a religious "exemption" from their duty to care for people with disabilities. Importantly, this is on top of the religious refusals people with disabilities may encounter in the health care system itself – whether from providers who generally refuse to provide access to abortion care, or who may refuse to provide such care specifically to people with disabilities.

### High rates of sexual assault and intimate partner violence

People with disabilities are three-and-a-half times more likely than people without disabilities to experience sexual assault.<sup>55</sup> This number is even higher for people with intellectual disabilities, who are nearly seven times more likely to experience sexual assault than people without disabilities.<sup>56</sup> And fewer than one in six cases of sexual assault against people with intellectual disabilities is committed by a stranger – meaning the caregivers people with disabilities count on the most could be the perpetrators.<sup>57</sup> In the event that sexual assault results in a pregnancy, people with disabilities may need access to abortion care. However, a caregiver or guardian may either force an abortion or deny access to a desired abortion following the sexual violence.<sup>58</sup> Therefore, the risk of sexual abuse and assault invokes bodily autonomy concerns for people with disabilities in multiple ways, and exposes them to compounded trauma.

People with disabilities are also significantly more likely to experience intimate partner violence, as compared to people without disabilities.<sup>59</sup> The lack of access to abortion care could disproportionately impact people with disabilities who may be seeking to leave an abusive intimate partner and who may find their short- and long-term safety further compromised by the inability to access such care. People with disbilities are **3.5X** more likely than people without disabilities to experience sexual assault.

# Proposals to Protect and Enact Abortion Access for People with Disabilities

### Ensure that health care is accessible for people with disabilities.

- Medical facilities must consult with the disability community in their area to
  ensure they are as accessible as possible to everyone they purport to serve. This
  includes establishing an accessible location within the community, going beyond
  minimum ADA requirements to ensure the accessibility of the facility for each
  person, working with the community to ensure there is accessible transportation,
  and expanding telehealth<sup>§</sup> in a way that gives meaningful access to care, and
  specifically to abortion and reproductive health care.
- Entities in charge of medical schooling, continuing medical education, and hospital standards, among others, must ensure provider education and training to properly meet the needs of people with disabilities. Health care providers and staff must receive education and information about the health care needs of people with disabilities so that they are able to provide care that is medically appropriate in each situation. Furthermore, all providers should understand present-day concerns about eugenics and the historical context so that they can adequately present the comprehensive spectrum of reproductive health care options, including abortion, without shaming, stigmatizing, or stereotyping people with disabilities who are or want to become pregnant.
- Congress must pass the Home and Community Based Services Access Act, which would ensure that all people with disabilities have access to needed long-term services and supports, including transportation and assistance with scheduling and attending medical appointments. These supports may be necessary in order to access health care.

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

 Providers and the medical establishment must build trust with the disability community. It is not enough for facilities to educate providers and ensure physical building compliance, because the medical establishment has done years of lasting damage to the trust between doctors, in particular, and the disability community. This trust is even further eroded for BIPOC people with disabilities. It is the responsibility of the medical community to reach out and build trust with the disability community, and to demonstrate their commitment to providing culturally appropriate and equitable care, including comprehensive reproductive health care.

<sup>§</sup> Learn more about telehealth in <u>Delivering on the Promise of Telehealth: How to Advance Health</u> <u>Care Access and Equity for Women</u> • 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 ensuring meaningful reproductive autonomy and justice for all people.

## Enact laws and policies that support reproductive health access, as well as equity and justice, for people with disabilities.

- State legislators and other decision-makers must push back against harmful state laws and enact policies that protect and expand abortion access, including explicitly for people with disabilities. This includes repealing reason bans along with other abortion restrictions that push care out of reach for people with disabilities, such as TRAP laws, biased counseling laws, ultrasound requirements, mandatory delays, medication abortion restrictions, and gestational bans.
- Federal policymakers must pass legislation and enact policies that will protect and expand abortion access, as well as laws and policies that better meet the health care needs of people with disabilities.
  - Congress must pass the Equal Access to Abortion Coverage in Health Insurance (EACH) Act, which would end the Hyde Amendment and related abortion funding restrictions in government health insurance plans, such as Medicaid and Medicare.
  - Congress must pass the Women's Health Protection Act (WHPA), which would create a national safeguard against state abortion bans and medically unnecessary restrictions. WHPA would ensure that the right to abortion is a reality in every state.
  - Congress and federal agencies must repeal religious refusals laws that enable health care providers and religious organizations who run and staff group homes or caregiver services to deny access to reproductive health care, including abortion care.
  - Congress and federal agencies must ensure there is more data collection and analysis to disaggregate different communities' needs and barriers to accessing abortion care, including at the intersection of race and disability.
- Policymakers must support people with disabilities' decision-making.
  - They must recognize supported decision-making as an alternative to guardianship and other forms of substituted decision-making in the context of all health care, including abortion care. States may wish to implement additional safeguards against coercion and abuse.

- They must revisit laws that require court approval for an abortion when a person has a disability, even in cases when the person with a disability is actively seeking an abortion, as opposed to the decision being made by surrogates. They must consult with the disability community to find a balance between interests in preventing coerced abortions and creating artificial and discriminatory barriers to abortion.
- They must reform laws that require consent of a legal guardian to abortion, even when the person under guardianship is seeking an abortion. They must ensure that guardians and substitute decision-makers cannot consent over the objection of the person with a disability, or without consultation with the person with a disability.
- 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

<sup>1</sup> SisterSong. "Reproductive Justice," accessed July 17, 2021, <u>https://www.sistersong.net/reproductive-justice</u>

<sup>2</sup> K. K. Rebecca Lai and Jugal L. Patel. "For Millions of American Women, Abortion Access Is Out of Reach," The New York Times, May 31, 2019, <u>https://www.nytimes.com/interactive/2019/05/31/us/abortion-clinics-map.</u> <u>html</u>

<sup>3</sup> Kimberlé W. Crenshaw. On Intersectionality: Essential Writings (New York: The New Press, 2017), <u>https://scholarship.law.columbia.edu/books/255/</u>; Jane Coaston. "The Intersectionality Wars," Vox, May 28, 2019, <u>https://www.vox.com/the-highlight/2019/5/20/18542843/intersectionality-conservatism-law-race-gender-discrimination</u>

<sup>4</sup> Karin Willison. "What 'My Body, My Choice' Means to Me as a Woman With a Disability," Free Wheelin', accessed July 17, 2021, <u>https://www.freewheelintravel.org/my-body-my-choice-as-woman-disability/</u>

<sup>5</sup> Ibid.

<sup>6</sup> Doe ex rel. Tarlow v. D.C., 489 F.3d 376, 382 (D.C. Cir. 2007), <u>https://www.leagle.com/</u> <u>decision/2007865489f3d3761863</u>

<sup>7</sup> Durrenda Ojanuga. "The Medical Ethics of the 'Father of Gynaecology,' Dr. J. Marion Sims," Journal of Medical Ethics, March 1, 1993, <u>https://jme.bmj.com/content/medethics/19/1/28.full.pdf</u>

<sup>8</sup> Theresa Vargas. "Guinea Pigs or Pioneers? How Puerto Rican Women Were Used to Test the Birth Control Pill," The Washington Post, May 9, 2017, <u>https://www.washingtonpost.com/news/retropolis/wp/2017/05/09/guinea-pigs-or-pioneers-how-puerto-rican-women-were-used-to-test-the-birth-control-pill/</u>

<sup>9</sup> Fresh Air. "The Supreme Court Ruling That Led to 70,000 Forced Sterilizations," March 7, 2016, <u>https://www.npr.org/sections/health-shots/2016/03/07/469478098/the-supreme-court-ruling-that-led-to-70-000-forced-sterilizations</u>

<sup>10</sup> Rachel K. Jones and Jenna Jerman. "Population Group Abortion Rates and Lifetime Incidence of Abortion: United States, 2008–2014," American Journal of Public Health, November 8, 2017, <u>https://ajph.aphapublications.org/doi/10.2105/AJPH.2017.304042</u>

<sup>11</sup> Corinne H. Rocca, Katrina Kimport, Sarah C. M. Roberts, Heather Gould, John Neuhaus, et al. "Decision Rightness and Emotional Responses to Abortion in the United States: A Longitudinal Study," PLoS One, July 8, 2015, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4496083/

<sup>12</sup> Lauren J. Ralph, Eleanor Bimla Schwarz, Daniel Grossman, and Diana Greene Foster. "Self-Reported Physical Health of Women Who Did and Did Not Terminate Pregnancy After Seeking Abortion Services: A Cohort Study," Annals of Internal Medicine, August 20, 2019, DOI: <u>10.7326/M18-1666</u>

<sup>13</sup> Advancing New Standards in Reproductive Health. "The Turnaway Study," accessed July 17, 2021, <u>https://www.ansirh.org/research/turnaway-study</u>

<sup>14</sup> Cornell University. "Disability Statistics," accessed July 17, 2021, <u>https://www.disabilitystatistics.org/reports/</u> <u>acs.cfm?statistic=11</u> <sup>15</sup> Elham Mahmoudi and Michelle A. Meade. "Disparities in Access to Health Care Among Adults with Physical Disabilities: Analysis of a Representative National Sample for a Ten-Year Period," Disability and Health Journal, April 2015, <u>https://www.sciencedirect.com/science/article/abs/pii/S193665741400106X?via%3Dihub</u>

<sup>16</sup> Michael Karpman and Sharon K. Long. "QuickTake: Even with Coverage, Many Adults Have Problems Getting Health Care, with Problems Most Prevalent among Adults with Disabilities," Urban Institute Health Policy Center, September 24, 2015, <u>http://hrms.urban.org/quicktakes/Many-Adults-Have-Problems-Getting-Health-Care.html</u>

<sup>17</sup> Monika Mitra, Susan L. Parish, Karen Clements, Jianying Zhang, and Tiffany A. Moore Simas. "Antenatal Hospitalization Among U.S. Women With Intellectual and Developmental Disabilities: A Retrospective Cohort Study," American Journal on Intellectual and Developmental Disabilities, September 2018, <u>https://www.</u> <u>researchgate.net/publication/327562657 Antenatal Hospitalization Among US Women With Intellectual</u> <u>and Developmental Disabilities A Retrospective Cohort Study</u>

<sup>18</sup> Emily E. Petersen, Nicole L. Davis, David Goodman, Shanna Cox, Carla Syverson, et al. "Racial/Ethnic Disparities in Pregnancy-Related Deaths: United States, 2007–2016," Morbidity and Mortality Weekly Report, September 6, 2019, <u>http://dx.doi.org/10.15585/mmwr.mm6835a3</u>

<sup>19</sup> Advancing New Standards in Reproductive Health. "Socioeconomic Outcomes of Women Who Receive and Women Who Are Denied Wanted Abortions," August 2018, <u>https://www.ansirh.org/sites/default/files/ publications/files/turnaway\_socioeconomic\_outcomes\_issue\_brief\_8-20-2018.pdf</u>

<sup>20</sup> Ibid.

<sup>21</sup> Diana Greene Foster, Sarah E. Raifman, Jessica D. Gipson, Corinne H. Rocca, and M. Antonia Biggs. "Effects of Carrying an Unwanted Pregnancy to Term on Women's Existing Children," The Journal of Pediatrics, February 1, 2019, <u>https://doi.org/10.1016/j.jpeds.2018.09.026</u>

<sup>22</sup> U.S. Census Bureau. "Selected Economic Characteristics for the Civilian Noninstitutionalized Population by Disability Status," accessed July 17, 2021, <u>https://data.census.gov/cedsci/table?q=ACSST1Y2019.</u> <u>S1811&tid=ACSST1Y2019.S1811&hidePreview=true</u>

<sup>23</sup> Ibid.

<sup>24</sup> Nanette Goodman, Michael Morris, and Kelvin Boston. Financial Inequality: Disability, Race, and Poverty in America, National Disability Institute, February 2019, <u>https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf</u>

<sup>25</sup> U.S. Bureau of Labor Statistics. "Employment Status of the Civilian Noninstitutional Population by Disability Status and Selected Characteristics, 2020 Annual Averages," February 24, 2021, <u>https://www.bls.gov/news.release/disabl.t01.htm</u>

<sup>26</sup> Roe v. Wade, 410 U.S. 113 (1973), <u>https://supreme.justia.com/cases/federal/us/410/113/;</u> Planned Parenthood of Southeastern Pa. v. Casey, 505 U.S. 833 (1992), <u>https://www.oyez.org/cases/1991/91-744</u>; Whole Woman's Health v. Hellerstedt, 579 U.S. \_\_\_\_ (2016), <u>https://www.oyez.org/cases/2015/15-274</u>; June Medical Services L.L.C. v. Russo, 591 U.S. \_\_\_\_ (2020), <u>https://www.oyez.org/cases/2019/18-1323</u> <sup>27</sup> Anna North. "What Amy Coney Barrett on the Supreme Court Means for Abortion Rights," October 26, 2020, <u>https://www.vox.com/21456044/amy-coney-barrett-supreme-court-roe-abortion</u>

<sup>28</sup> Diana M. Pearce. Disability and Self-Sufficiency: Estimating the Extra Costs of Disability Required to Achieve a Self-Sufficiency Standard of Living, Legal Services of New Jersey, December 2011, <u>http://selfsufficiencystandard.org/sites/default/files/selfsuff/docs/NJ2011-disability.pdf</u>

<sup>29</sup> Azza Altiraifi. "A Deadly Poverty Trap: Asset Limits in the Time of the Coronavirus," Center for American Progress, April 7, 2020, <u>https://www.americanprogress.org/issues/disability/news/2020/04/07/482736/</u> <u>deadly-poverty-trap-asset-limits-time-coronavirus/</u>; Andrea Louise Campbell. "How Medicaid Forces Families Like Mine to Stay Poor," Vox, July 28, 2015, <u>https://www.vox.com/2014/12/9/7319477/medicaiddisability</u>

<sup>30</sup> Megan Kirshbaum. "Parenting with a Disability: A New Frontier of Disability Rights," U.S. Administration for Community Living, June 17, 2016,

https://acl.gov/news-and-events/acl-blog/parenting-disability-new-frontier-disability-rights

<sup>31</sup> Elizabeth Nash. "State Abortion Policy Landscape: From Hostile to Supportive," Guttmacher Institute, August 29, 2019, <u>https://www.guttmacher.org/article/2019/08/state-abortion-policy-landscape-hostile-supportive</u>

<sup>32</sup> Elizabeth Nash and Sophia Naide. "State Policy Trends at Midyear 2021: Already the Worst Legislative Year Ever for U.S. Abortion Rights," Guttmacher Institute, July 1, 2021, https://www.guttmacher.org/article/2021/07/ state-policy-trends-midyear-2021-already-worst-legislative-year-ever-us-abortion

<sup>33</sup> Ibid.; Elizabeth Nash, Lizamarie Mohammed, Olivia Cappello, and Sophia Naide. "State Policy Trends 2020: Reproductive Health and Rights in a Year Like No Other," Guttmacher Institute, December 15, 2020, <u>https://www.guttmacher.org/article/2020/12/state-policy-trends-2020-reproductive-health-and-rights-year-no-other</u>

<sup>34</sup> Alice F. Cartwright, Mihiri Karunaratne, Jill Barr-Walker, Nicole E. Johns, and Ushma D. Upadhyay. "Identifying National Availability of Abortion Care and Distance from Major U.S. Cities: Systematic Online Search," Journal of Medical Internet Research, May 2018, DOI: <u>10.2196/jmir.9717</u>

<sup>35</sup> Jennifer Tolbert, Kendal Orgera, and Anthony Damico. "Key Facts about the Uninsured Population," Kaiser Family Foundation, November 6, 2020, <u>https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/</u>

<sup>36</sup> Jenna Jerman and Rachel K. Jones. "Secondary Measures of Access to Abortion Services in the United States, 2011 and 2012: Gestational Age Limits, Cost, and Harassment," Womens' Health Issues, July-August 2014, DOI: <u>10.1016/j.whi.2014.05.002</u>

<sup>37</sup> Rachel K. Jones, Ushma D. Upadhyay, and Tracy A. Weitz. "At What Cost? Payment for Abortion Care by U.S. Women," Women's Health Issues, March 4, 2013, <u>https://www.guttmacher.org/sites/default/files/pdfs/pubs/journals/j.whi.2013.03.001.pdf</u>

<sup>38</sup> Jae Kennedy, Elizabeth Geneva Wood, and Lex Frieden. "Disparities in Insurance Coverage, Health

Services Use, and Access Following Implementation of the Affordable Care Act: A Comparison of Disabled and Nondisabled Working-Age Adults," Inquiry: The Journal of Health Care Organization, Provision, and Financing, November 22, 2017, DOI: <u>10.1177/0046958017734031</u>

<sup>39</sup> National Partnership for Women & Families. "Quantifying America's Gender Wage Gap by Race/Ethnicity," March 2021, <u>https://www.nationalpartnership.org/our-work/resources/economic-justice/fair-pay/</u> <u>quantifying-americas-gender-wage-gap.pdf</u>

<sup>40</sup> Kaiser Family Foundation. "Medicaid Coverage Rates for the Nonelderly by Race/Ethnicity," accessed July 17, 2021, <u>https://www.kff.org/medicaid/state-indicator/nonelderly-medicaid-rate-by-raceethnicity/?currentTi</u> <u>meframe=0&sortModel=%7B%22colld%22:%22Location%22,%22sort%22:%22asc%22%7D</u>

<sup>41</sup> James W. Fossett and Courtney E. Burke. Medicaid and Faith Organizations: Participation and Potential, Rockefeller Institute of Government, July 2004, <u>https://www.pewtrusts.org/-/media/legacy/uploadedfiles/</u> wwwpewtrustsorg/reports/religion\_in\_public\_life/medicaidandfaithorgs080904pdf.pdf

<sup>42</sup> Natalie Hamilton, Oluwatoyin Olumolade, Madelyn Aittama, Olivia Samoray, Maham Khan, et al. "Access Barriers to Healthcare for People Living with Disabilities," Journal of Public Health, October 10, 2020, DOI: <u>10.1007/s10389-020-01383-z</u>

<sup>43</sup> Liz Moore. "How Can I Convince Doctors I'm an Informed Patient?" Healthline, February 26, 2019, <u>https://</u><u>www.healthline.com/health/doctors-listen-to-patients</u>; Astha Singhal, Yu-Yu Tien, and Renee Y. Hsia. "Racial-Ethnic Disparities in Opioid Prescriptions at Emergency Department Visits for Conditions Commonly Associated with Prescription Drug Abuse," PLoS One, August 8, 2016, DOI: <u>10.1371/journal.pone.0159224</u>; Joanne Spataro. "Doctors Don't Always Believe You When You're a Black Woman," Vice, February 2, 2018, <u>https://www.vice.com/en/article/qvedxd/doctors-dont-always-believe-you-when-youre-a-black-woman</u>

<sup>44</sup> The Intersections of Our Lives. "Reproductive Justice for Women of Color," October 2017, <u>https://</u> intersectionsofourlives.org/wp-content/uploads/2019/03/Reproductive-Justice-for-Women-of-Color.pdf; National Asian Pacific American Women's Forum. "Sex-Selective Abortion Bans," January 11, 2021, <u>https://</u> www.napawf.org/reproductive-health-and-rights/sex-selective-abortion-bans

<sup>45</sup> Guttmacher Institute. "Abortion Bans in Cases of Sex or Race Selection or Genetic Anomaly," July 1, 2021,

https://www.guttmacher.org/state-policy/explore/abortion-bans-cases-sex-or-race-selection-or-geneticanomaly

<sup>46</sup> —. "State Legislation Tracker: Major Developments in Sexual & Reproductive Health," July 1, 2021, <u>https://</u> www.guttmacher.org/state-policy

<sup>47</sup> U.S. Centers for Medicare & Medicaid Services. Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources, December 2020, <u>https://www.cms.gov/files/document/</u> <u>federaldatadisability508.pdf;</u> Emily Johnson. "Disability, Medicine, and Ethics," AMA Journal of Ethics, April 2016, DOI: <u>10.1001/journalofethics.2016.18.4.fred1-1604</u>

<sup>48</sup> Eva Sweeney. "Finding Sexual Health Care Shouldn't Be So Difficult for Disabled People," Rooted in Rights, September 24, 2019, <u>https://rootedinrights.org/finding-sexual-health-care-shouldnt-be-so-difficult-for-</u> <u>disabled-people/</u> <sup>49</sup> Nicole Lee. "As a Disabled Woman, My Abortion Wasn't Questioned – but My Pregnancy Was," Quartz, September 18, 2019, <u>https://qz.com/1710043/being-disabled-my-abortion-wasnt-questioned-but-my-pregnancy-was/</u>

<sup>50</sup> See notes 7 and 8; Hudaisa Hafeez, Muhammad Zeshan, Muhammad A. Tahir, Nusrat Jahan, and Sadiq Naveed. "Health Care Disparities Among Lesbian, Gay, Bisexual, and Transgender Youth: A Literature Review," Cureus, April 20, 2017, DOI: <u>0.7759/cureus.1184;</u> Nyia O. Garrison, and Gladys E. Ibañez. "Attitudes of Health Care Providers Toward LGBT Patients: The Need for Cultural Sensitivity Training," American Journal of Public Health, March 2016, DOI: <u>10.2105/AJPH.2015.303010</u>

<sup>51</sup> American Civil Liberties Union. "Supported Decision Making & the Problems of Guardianship," accessed July 17, 2021, <u>https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/</u> <u>supported-decision-making</u>

<sup>52</sup> Elizabeth Ann McCaman. "Limitations on Choice: Abortion for Women with Diminished Capacity," Hastings Women's Law Journal, Winter 2013, <u>https://repository.uchastings.edu/hwlj/vol24/iss1/7/</u>

<sup>53</sup> Religious Freedom Restoration Act, Public Law 141, 103rd Cong., 1st sess. (November 16, 1993), <u>https://www.govinfo.gov/content/pkg/STATUTE-107/pdf/STATUTE-107-Pg1488.pdf</u>

<sup>54</sup> Emily London and Maggie Siddiqi. "Religious Liberty Should Do No Harm," Center for American Progress, April 11, 2019, <u>https://www.americanprogress.org/issues/religion/reports/2019/04/11/468041/religious-liberty-no-harm/</u>

<sup>55</sup> Erika Harrell. "Crime against Persons with Disabilities, 2009–2015: Statistical Tables," U.S. Bureau of Justice Statistics, July 2017, <u>https://www.bjs.gov/content/pub/pdf/capd0915st.pdf</u>

<sup>56</sup> Joseph Shapiro. "The Sexual Assault Epidemic No One Talks About," All Things Considered, January 8, 2018, <u>https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about</u>

57 Ibid.

<sup>58</sup> For example, in Virginia, a person who has been legally adjudicated to be "incapacitated" cannot access abortion without the consent of "parent, guardian, committee, or other person standing in loco parentis to the woman" (Va. Code § 18.2-76). Furthermore, in many states, guardians are authorized to seek abortion over the objection of the pregnant person. (See, e.g., Guardianship of Mary Moe, 81 Mass. App. Ct. 136 [2012], applying "substituted judgment" standard to determine whether a woman could be subjected to an abortion over her objection).

<sup>59</sup> Matthew J. Breiding and Brian S. Armour. "The Association Between Disability and Intimate Partner Violence in the United States," Annals of Epidemiology, June 1, 2016, DOI: <u>10.1016/j.annepidem.2015.03.017</u>



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.

Learn more: NationalPartnership.org



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: <u>AutisticAdvocacy.org</u>

#### About the authors

This resource was authored by Nikita Mhatre, Health Justice Policy Associate at the National Partnership.

The following people also contributed:

- Sam Crane, Legal Director, ASAN
- Shaina Goodman, Director of Reproductive Health and Rights, National Partnership
  - Sinsi Hernández-Cancio, Vice President for Health Justice, National Partnership
- Jessi Leigh Swenson, Director of Congressional Relations for Health Justice, National Partnership
  - Lauren Paulk
  - Sarah Lipton-Lubet
    - Jorge Morales

