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Commentary

# Looking back while moving forward: a justice-based, intersectional approach to research on contraception and disability

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ABSTRACT

For the first time in the 21st century, we have an emerging body of research regarding contraceptive use among adult women with disabilities in the United States.
We highlight key findings from population-based analyses that found higher odds of female sterilization and lower odds of long-acting reversible contraception use among women with disabilities compared to their peers without disabilities. We consider potential reasons underlying these differences, including discriminatory attitudes and policies that restrict the sexual and reproductive autonomy of people with disabilities. We advocate for a justice-based, intersectional approach to research on contraception and disability with the aim of promoting the reproductive autonomy of people with disabilities.

## 1. Introduction

It is estimated that 12% of US reproductive-age women have one or more disabilities, which include those with physical, sensory or cognitive disabilities that are associated with difficulty in self-care and independent living [1]. This heterogeneous population is comprised of individuals across a wide spectrum of functional ability. While individual variations based upon genetic and medical history exist, most women with disabilities are fertile and as likely to experience pregnancy as women without disabilities [2]. Based upon 12 reproductive health questions from the 2013 Behavioral Risk Factor Surveillance System in 7 states, Haynes and colleagues recently reported that the overall prevalence of sexual activity was similar for women with and without physical or cognitive disabilities [3]. Women with disabilities who do not desire pregnancy should receive counseling regarding and access to all available contraceptive methods.

In this commentary, we highlight recent US population-based analyses reporting that women who report having sex with men and have a disability are more likely to undergo female sterilization and less likely to use long-acting reversible contraception (LARC) than women without disabilities even after adjusting for age and other confounders. We summarize potential reasons for these differences and limitations of these analyses. To inform future research, we advocate for the application of intersectionality, a paradigm rooted in black feminist scholarship, to understand discrimination and inequities that arise from the intersection of multiple social and cultural identities [4].

## 2. An intersectional framework: stratified reproduction and ableism

We first propose an intersectional framework that blends the concepts of stratified reproduction and ableism, which are derived from a

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reproductive justice framework and disability theory, respectively. The reproductive justice framework originally developed by women of color is based upon the premise that women's reproductive rights extend beyond the right to abortion only and should include the equally paramount right to pursue pregnancy and parenthood [5]. Stratified reproduction, as conceptualized by anthropologist Shellee Colen, refers to the differential experience, value and rewards of reproductive work (pregnancy, parenting, maintaining the household) based upon social and material inequities [6]. Stratified reproduction ultimately manifests as the preferential valuing of the fertility of white women of higher socioeconomic status over that of poor women of color [7]. While stratified reproduction has been primarily conceptualized in relation to race and class, there is a need to understand its contribution to reproductive injustices in the context of disability theory and ableism. Disability theory asserts that social inequities and health disparities related to disabilities are not biological in nature but rather created by structural barriers that render much of the world inaccessible for people with disabilities [8]. Ableism refers to systems of social power that devalue the bodies and lives of disabled people; furthermore, disability is viewed as something that needs to be ameliorated, corrected or erased in order to come closer to the ideal able-bodied state [9]. When the forces of stratified reproduction and ableism interact, the fertility of people with disabilities is further devalued based not only on ability but also other intersecting identities, including race and class.

## 3. The United Nations Convention on the Rights of Persons with Disabilities

Although this commentary is focused on US studies, it is critical to appreciate the global scope and impact of disability-based disparities on all spheres of life. Individuals with disabilities represent one in every six people worldwide [10] and constitute a population whose human rights — including equal rights and access to health, education, work and due process under the law — have been systematically neglected and violated [11]. Ratified in 2008, the United Nations Convention on the Rights of Persons with Disabilities — the CRPD — catalyzed international efforts to promote "full and effective participation in society on an equal basis with others" [12] for people with disabilities, including issues related to reproductive health. To date, the United States has signed but has yet to join 164 other nations in ratifying the CRPD [13].

Reflecting the CRPD's broad definition of disability [12], we acknowledge the diversity of people with disabilities who may have one or a combination of physical, cognitive and sensory (vision- or hearing-related) disabilities. For the purposes of this commentary, we refer to women with disabilities collectively and consider, when possible, variations in contraceptive experiences based upon the type(s) and severity of disability and impact on functional status.

## 4. Female sterilization and LARC trends in the United States

Female sterilization and LARC (the implant and intrauterine devices) are important options for women who desire highly efficacious and long-term contraception. From 2008 to 2014, LARC use among the general US population of reproductive-age women increased significantly, from 6% to 15% of all contraceptive users [14]. During the same period, there was a significant decrease in the percentage of contraceptive users who relied upon female sterilization, from 27% to 22% [14]. These changes in contraceptive mix appeared to reflect a preferential shift from female sterilization to LARC use among women who desired long-acting contraception rather than the result of users switching from less effective methods (e.g., condoms) to more effective methods [14].

## 5. Female sterilization and LARC use differs by disability status

Several recent population-based analyses from the National Survey of Family Growth (NSFG) have identified differences in LARC and female sterilization based upon disability status. Wu and colleagues reported that after adjusting for confounders including age, parity, smoking status and body mass index, the odds of LARC use were lower among women with physical and/or sensory disabilities than women without these disabilities [adjusted odds ratio (aOR) 0.55, 95% confidence interval (CI) 0.33–0.92] [15]. In contrast, the adjusted odds of female sterilization were higher among women with physical and/or sensory disabilities (aOR 1.36, 95% CI 1.03–1.79) [16], even higher for women with cognitive disabilities (aOR 1.54, 95% CI 1.19–1.98), and the highest for those with both physical *and* cognitive disabilities (aOR 2.67, 95% CI 1.71–4.51) compared to women without any disabilities [17]. Alarmingly, Li and colleagues found that women with cognitive disabilities also had significantly higher odds of undergoing hysterectomy for female sterilization and without any clear medical indication (e.g., fibroids) than women without disabilities (aOR 2.64, 95% CI 1.53–4.56) [18].

A noted limitation of these studies is that women with disabilities who depend on others to access health services and/or make medical decisions were likely underrepresented. The NSFG samples people who live in civilian households but not institutions like long-term care facilities or group homes. Women with more severe disabilities who require assistance with physical and/or cognitive tasks are more likely to reside in institutions than women with less severe disabilities and women in the general population. NSFG respondents must be able to listen to survey questions with headphones and type on a computer [19] and are not allowed to have another person in the room at the time of the survey [20]; therefore, women who need special communication equipment (e.g., large font type for visually impaired) or one-on-one assistance with survey items (e.g., sign language interpreter, support person) would also not be included in the survey. Because of these methodological limitations, we hypothesize that current estimates of contraceptive use among US women with disabilities represent those with greater independence with daily activities and/or autonomy with decision making and, in essence, the "tip of the iceberg." We suspect that differences in LARC and female sterilization prevalence would be even greater if survey procedures were fully accessible to people who need accommodations and if women living in institutions were included.

## 6. Potential reasons for differences in female sterilization and LARC use by disability status

### *6.1. Patient-related factors*

It is possible that women with disabilities and/or their advocates (e.g., family members, legal guardians, caseworkers) are simply more familiar with female sterilization than with LARC, leading to more requests for female sterilization. Unfortunately, population-based studies that assess contraceptive knowledge among US adult women with disabilities and their advocates are limited. However, one nationally representative study of adolescents [21], along with qualitative and small cross-sectional studies, indicates that women with disabilities in general, and more so for those with intellectual disabilities, have less sexual and reproductive health knowledge compared to their nondisabled peers [22–24]. However, knowledge gaps may not solely be explained by cognitive differences. Pownall and colleagues compared health knowledge among three groups of young people (physical disabilities only, cognitive disabilities only or no disability) and found no differences in knowledge about healthy eating and only modest variations in knowledge about alcohol use [25]. However, those with physical or cognitive disabilities had significantly poorer understanding of sex and contraception [25]. The authors hypothesized that the social exclusion of people with disabilities from discussions about sex and reproductive health, rather than cognitive deficits alone, may underlie disparities in contraceptive knowledge [25].

Assuming that women receive contraceptive counseling tailored to their fertility desires, there will be, of course, women who simply prefer the permanence of female sterilization over LARC. We advocate for the right to female sterilization and measures to avoid unfulfilled requests for female sterilization, which disproportionately affect women on Medicaid because of the mandatory waiting period from consent to operation [26]. At the same time, we are concerned about findings from mostly older studies that document the strong influence of family members, health care providers and long-term care facilities on requests for female sterilization, especially for those with intellectual disabilities. Reasons cited for these requests include parental intent to protect their daughters from pregnancy in the event of sexual assault [27], provider and caregiver beliefs that hysterectomy is a reasonable option to manage menstrual hygiene and menstrual-related behavioral changes [28], and institutional policies requiring that female residents use contraception [29,30].

### *6.2. Health care providers' skills and interactions*

Women with disabilities may avoid gynecologic exams and procedures in the office setting because of fear, embarrassment or lack of confidence in their providers' skills. For example, women with spasticity from physical disabilities have observed that their providers did not perform pelvic exams in a manner that protected them from accidental falls or minimized discomfort during speculum placement [31,32]. These findings are not surprising given the absence of standardized and mandatory medical training in disability health. A 2017 survey of US medical schools revealed that only half of schools had any disability awareness curricula, which typically consisted of presentations regarding physical disabilities only and did not include hands-on clinical skills training [33]. Even providers who are otherwise skilled in IUD provision may be reluctant to offer IUDs to certain patients, such as those with mobility limitations, without training in how to safely perform gynecologic exams while maximizing patient comfort (e.g., safe transfers, alternative pelvic exam positions).

Unfriendly and even hostile interactions with health care providers reinforce negative stereotypes that women with disabilities cannot and should not engage in sexual activity and romantic relationships or become parents. Examples include medical staff making insensitive and judgmental comments about the sexuality of women with disabilities or refusing to assist pregnant women with disabilities during labor and delivery [31,34–36]. Through life-long acculturation, negative stereotypes are internalized and lead to shame and self-hatred among people with disabilities regarding their value as reproductive beings [9]. We raise the question of whether accumulative exposure to reproductive discrimination from health care providers (and society) systematically discourages women with disabilities from ever considering parenthood, which in turn leads to requests for permanent sterilization over reversible methods.

### *6.3. Health care facilities are not fully accessible*

The 1990 Americans with Disabilities Act mandates equal access to health care services and that health facilities make reasonable accommodations for individuals with disabilities [37]. While health care facilities typically support external accessibility such as wide building entrances and ramps, the availability of accessible medical equipment is more variable, with a notable need for improved internal accessibility in gynecology clinics [37]. Office administrators often oversee the purchase of medical equipment; however, research suggests that office staff may not be familiar with the necessity for and types of accessible equipment [38]. Without accommodations such as height-adjustable tables, padded leg supports, transfer boards and staff trained in safe patient transfers, LARC provision for women with mobility impairments will appear daunting for patients, which could contribute to reluctance to request LARC. Providers have reported concerns about insurance reimbursement for the extra time and resources needed for physical accommodations [32], which may contribute to reluctance to recommend LARC.

In contrast, patients and providers may be more comfortable with female sterilization partially because it takes place in the operating room (OR) with anesthesia, which provides more physical accessibility and pain control than most outpatient settings. However, LARC placement in the OR setting should be an option for those who desire it but cannot tolerate the procedure in the outpatient setting (even in fully accessible offices) because of medical or psychological factors (e.g., severe spasticity not ameliorated by muscle relaxants, severe anxiety regarding pelvic exams). We do not know the extent to which providers are willing to provide or refer for LARC insertion in the OR setting or if patients and their advocates are aware of this option.

Full accessibility extends beyond physical accessibility. It also requires aids and services that promote effective health communication such as sign language interpreters for deaf and hard of hearing people; written information in large print or electronic format for those with limited vision; and communication in simple, nontechnical language for those with cognitive disabilities [39]. In the absence of high-quality data, we suspect that most contraceptive education materials are not fully accessible and that information about LARC is even scarcer given its relatively recent resurgence in use among US women [14].

### *6.4. Social norms and policies that perpetuate ableism and stratified reproduction*

We hypothesize that social norms and policies that perpetuate ableism and stratified reproduction shape the fertility desires, the ability to fulfill these desires and consequently contraceptive patterns among women with disabilities. Ableist-derived values include beliefs that people with disabilities are not sexual, are undesirable romantic partners and are unfit to parent [9]. Structural forms of ableism that prevent emotional and sexual intimacy between people with disabilities abound, including the lack of physically accessible private homes and the denial of consensual sexual activity among people with disabilities who reside in institutions [9]. Low-income couples with disabilities who depend upon Medicaid, Medicare and social security income to cover high medical costs are disincentivized from marriage in order to maintain their benefits [40].

Women with disabilities are disproportionately poor, racial and ethnic minorities, and publicly insured [2,15–17]. As described earlier, the concept of stratified reproduction helps in understanding the intersection of race, poverty, gender and disability and its impact on fulfilling one's reproductive desires. Stratified reproduction can be traced back to colonial times and persists in the present. Among the most well-known examples is the compulsory sterilization of over 60,000 people, predominately low-income men and women of color, as well as people with disabilities, throughout the 20th century [26]. However, stratified reproduction continues to be embedded in social policies that devalue the reproduction of marginalized women; examples include the "welfare queen" narrative used to denigrate poor Black single mothers and the fact that fertility treatments are not covered for poor women and/or women with disabilities who rely upon Medicaid [41]. What remains unknown is the extent to which ableism and stratified reproduction inform the internalized beliefs of patients, their advocates and their clinicians and how these beliefs subsequently influence contraceptive recommendations and requests.

## 7. A call for a justice-based, intersectional approach to contraception and disability research

The new body of research described in this commentary is a necessary but insufficient step towards understanding how to provide equitable contraceptive counseling and care for women with disabilities. First, a more robust body of evidence is necessary to understand *why and how* differences in contraceptive patterns between women with and without disabilities occur, and to what extent these differences reflect fully informed decisions and preferences versus inequities in contraceptive care. Second, we need population-based studies that assess contraceptive use among women with disabilities who reside in institutions and thus were excluded from prior national studies. Furthermore, direct assessments of women's contraceptive knowledge and preferences, provider knowledge and skills, and provider-patient interactions are critically needed. Many questions remain: What do women and their advocates know about reversible and permanent contraceptive methods? What and who are the sources of this information, and does this knowledge reflect positive or negative social constructs of disability? What assumptions and knowledge underlie the questions providers ask and the way that reproductive and contraceptive choices are framed? For women who have advocates involved in their medical care, to what extent do providers engage women themselves in contraceptive counseling and uphold their sexual and reproductive agency? What provider and staff training gaps must be addressed to provide fully accessible contraceptive care? How do providers currently approach counseling and consent for women who cannot communicate their needs and wishes because of severe intellectual disability?

We call for investigators to apply the intersectional concepts of stratified reproduction and ableism to their empirical research. Conducting contraceptive research through an intersectional lens provides a natural vantage point to understand and mitigate the relational and magnified impact of disability, social class, race/ethnicity, sex, gender identity and sexual orientation on reproductive autonomy. As an example, the vast majority of studies to date, including the studies cited in this paper, are focused on the sexual and reproductive health behavior of cisgender and heterosexual women. The overlapping identities of people with disabilities who are also sexual and/or gender minorities must be understood to fully appreciate and correct the devaluation of their reproductive rights. Indeed, focusing on the most marginalized of a given population catalyzes policy and practices that are the most inclusive and as nuanced as the clients and patients served.

Because reproductive health is a personal and sensitive topic for many, qualitative and mixed methods (qualitative and quantitative data collection and integration) are well suited to elicit candid and complex narratives from those with lived experience with disability (i.e., experts by experience). For example, in-depth interviews of women with disabilities who have chosen, contemplated or decided against sterilization can begin to disentangle how pregnancy desires and contraceptive decision making were shaped by socialization regarding their agency as sexual beings, potential partners and parents in the context not only of their disabilities but also their race/ethnicity, gender and socioeconomic status. Observations or audio recordings of clinical interactions among patients, their advocates and providers can consider if and how ableism and stratified reproduction may influence contraceptive discussions and recommendations. These data can then identify knowledge, attitudes and skills that are modifiable targets for future interventions. Investigators should strongly consider adapting methods and principles from participatory action research (PAR) into their work. PAR intentionally includes study participants as partners in research to empower them to challenge conventional forms of knowledge construction and systems of power and address inequities through action, particularly those rooted in racism and gender discrimination [42].

## 8. Conclusions

The higher odds of sterilization among US women with disabilities relative to LARC use are a finding that demands further investigation. Factors that may contribute to these contraceptive patterns include incomplete contraceptive knowledge among patients and their advocates, inadequate provider training and lack of fully accessible health care facilities. We also posit that ableism and stratified reproduction are interrelated forms of discrimination that discourage and prevent people with disabilities from engaging in full sexual and reproductive expression, and that the cumulative impact of these experiences shapes clinician recommendations and patient/advocate requests for female sterilization over reversible contraceptive methods. A justice-based, intersectional approach to future research will put the voices and experiences of people with disabilities front and center, and uphold principles of full inclusion and participation in society as codified by the United Nations Convention on the Rights of Persons with Disabilities and in the spirit of the Americans with Disabilities Act.

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