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Diverse Bodies: Challenges and Opportunities in the Claim of Sexual Rights for People with Physical Functional Diversity

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Abstract

Is the population of people with physical functional diversity the most invisible among invisible populations? This question persists when examining the state of sexual rights exercise among acquaintances, colleagues, family members, friends, and strangers living with physical functional diversity. This paper forms part of the theoretical framework of an ongoing research project on the sexuality of individuals with physical functional diversity conducted at the University of Puerto Rico, Cayey Campus. Collaborating with students from various academic disciplines, the primary investigator aims to shed light on this crucial issue within a social, human rights, and intersectional framework. This effort seeks to raise awareness and actively include individuals from this population in the everyday processes of life in Puerto Rico.

Keywords: Physical functional diversity, Disability, Sexual rights, Intersectionality, Sexual health, Advocacy, Social inclusion, Diversity, Access to sexuality

While significant variation exists in the scientific literature regarding the definition of disability, common elements refer to a condition that restricts a person's ability to function to some degree (relative to a standard, personal or group norm), whether physical, intellectual, or psychiatric, whether congenital or resulting from injury or illness.¹ Due to its political relationship with the United States, Puerto Rico adheres to the ADA of 1990 for defining disability. According to the Americans with Disabilities Act (ADA), the term "physical or mental impairment" refers to a person who has a physical or mental impairment that substantially limits one or more major life activities, a person with a history of such impairment, or a person perceived by others as having such an impairment (U.S. Department of Justice).2 Activists within this population, however, express a preference for terms such as "physical functional diversity" or "differing abilities" to describe themselves.

Since 2007, Javier Romañach Cabrero, a leader in the Independent Living Movement and a humanist advocate for human rights, introduced the term "functional diversity" with the intention

that the expression itself would refer to individuals with varied capabilities rather than implying a lack thereof.³ Regardless, "the most important aspect regarding the terms used to name us is that they always place the word 'person' first" (I. Figueroa-Rodríguez, Office of Persons with Disabilities, personal communication, October 17, 2022).⁴ Thus, terms like "person with impairments," "person with physical functional diversity," or "person with disabilities" are preferred over characterizing individuals solely by an adjective (such as "impaired" or "disabled"). The term "disability" continues to be justified within healthcare sectors for categorizing medical service needs. Indeed, the term "person with physical functional diversity" (PPFD) is more suitable for emphasizing the abilities and possibilities of individuals within this population.

How citizenship perceives PPFD often depends on the prevailing societal approach at a given historical moment. Currently, four distinct approaches coexist in the perception of disability. The charity approach considers PPFD as incapable of self-sufficiency, necessitating only social assistance. In contrast, the medical model prioritizes disease diagnosis and treatment of the "damaged"

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body. These two perspectives emphasize individual responsibility for one's condition and persist today, even within human rights communities (United Nations).⁵

A third approach, the social model, introduces an interactive perspective of shared responsibility between PPFD and society, facilitated by technological resources to enhance functionality.⁶ In this model, "disability is not an 'error' of society but a part of its diversity." Finally, based on the social model, the human rights approach recognizes PPFD as rights holders, holding the State accountable for discriminatory social barriers. According to the United Nations Guide to the Convention on the Rights of Persons with Disabilities (2014), these latter two modern approaches conceptualize disability differently:

"... it consists of an interaction between an individual's personal circumstances (e.g., being in a wheelchair or having a visual impairment) and environmental factors (such as negative attitudes or inaccessible buildings) that together create disability and affect that individual's participation in society (p.7)."

However, it is crucial to note that these international rights and policy frameworks do not explicitly mention sex and sexuality. While gender issues and violence are recognized, broader issues of sexuality and sexual rights are omitted. This suggests that even within a discourse on human rights, there is a risk that the gender and sexuality of people living with disabilities may easily become invisible or subordinated to seemingly more pressing concerns.¹

Puerto Rico is no exception among societies where a charity perspective and medical model of care still prevail. In fact, it currently falls far short of fulfilling its social and human rights responsibilities towards PPFD. De la Cruz⁷ explains that some societies are more disabling than others, each forming its own structural dynamics. Societies transitioning to more advanced models incorporate inclusive adaptations in public services (e.g., audible signals at pedestrian crossings, ground grooves indicating the end of sidewalks for the visually impaired), but the Island is not there yet. In Puerto Rico, individuals with functional diversity are consistently excluded from social discussions, public policy development, social planning, and of course, the creation and budget allocation for service programs of all kinds.

A simple search of news events on the Island reveals that the Office of Persons with Disabilities is located in a place inaccessible to the population it serves,⁸ government agencies fail to uphold the rights of PPFD and contribute to the lack of access to essential services such as transportation,⁹ and drivers display poor attitudes towards visually impaired individuals taking mobility classes on the streets to promote their independence, leading to dangerous incidents and even the death of a blind pedestrian last year.¹⁰

Fortunately, there are voices, albeit at times solitary, calling for legislation from the state to ensure that individuals with functional diversity have dignified, timely, and continuous access to medical services in the country. A senator from the Puerto Rican Independence Party denounced and introduced a measure to address the lack of protocols and knowledge among many specialists in receiving and treating PPFD, who sometimes deny requested treatment because they do not know how to handle their special needs. There have also been reports of a shortage of sign language interpreters and information provided in braille, lack of access to prescribed medications, minimal specific training on chronic functional diversity received by healthcare professionals in their formal medical education, and the need for interdisciplinary teams to coordinate comprehensive treatments. 11,12

Likewise, undoubtedly, the most significant voices advocating for the rights of PPFD are their own. In the country, there are private individuals, non-profit organizations composed of PPFD and other allied individuals who daily fight for more adequate services and observance of their rights. An example is Dr. José Manolo Álvarez, a visually impaired professor at the University of Puerto Rico, Río Piedras Campus, who provides training on using technology as an assistive tool, enabling him to be productive and independent in the absence of necessary services and adaptations by the state. "I wake up to the sound of the cell phone alarm, issue a voice command to the virtual assistant, and it reads aloud the weather forecast to see if it's a day to use the umbrella," recounts Professor Álvarez. He then explains how he carries out his daily routine using his cell phone's screen reader, a smart speaker, his white cane, and GPS to travel from home to work. Initiatives like these drive equity from within the PPFD community itself.

The Sexuality

Since 2006, the World Health Organization had established a definition of sexuality that is widely used today. Sexuality is:

"An integral aspect of being human, encompassing sex, gender identities and roles, eroticism, pleasure, intimacy, reproduction, and sexual orientation. It is experienced and expressed through thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles, and interpersonal relationships. Sexuality can encompass all these dimensions, although not all are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious, and spiritual factors" (WHO, n.d.).

This definition of sexuality applies to all individuals. Sexuality is a fundamental part of what it means to be human, encompassing all sexual diversity, including diversity related to gender identity, sexual orientation (self-identity; desires/fantasies), sexual behavior, and sexual expression. The sexual and reproductive rights outlined in the Charter of Sexual and Reproductive Rights and the Declaration of Sexual Rights, both documents of the International

Planned Parenthood Federation, IPPF since 1995, also apply to all individuals. 13 Sexual rights stem from the rights to freedom, equality, privacy, autonomy, integrity, and dignity of all people. These sexual rights include, among others, the right to exercise sexuality free from violence or coercion, the right to privacy essential for exercising sexual autonomy, and the right to choose sexual partners and experience sexual potential and pleasure to the fullest within a framework of non-discrimination. They also incorporate the right to access sexual health care, the right to comprehensive sexuality education, the right to choose whether or not to marry, to form and plan a family or not to do so. The right to effective and accessible educational, legislative, judicial, and other measures to ensure and demand that those responsible for guaranteeing sexual rights are fully accountable for enforcing them, are also part of those outlined by this International Federation (International Planned Parenthood Federation, 1995).

These are supposed to be rights and considerations that equally shelter all individuals, so PFD should be included, not excluded. If there are still endless demands for medical services, transportation, accessibility, and other basic services, one can imagine where sexual rights and the discussion about the sexuality of PPFD and the establishment of relationships stand. The sexuality of people living with a disability can easily become invisible or subordinate to other seemingly "higher-order" issues.¹ Attention often focuses on issues of equity, access to employment, transportation, and physical health services. Cattaneo, Leone, Musacchio, and Wasylyk-Fedyszak¹⁴ argue that the sexual health and reproductive health of people with disabilities have a long history of invisibility, ignorance, and prejudiced ways of thinking and doing, rather than health criteria.

Sexuality itself is often a topic that modern societies and their cultures consider inappropriate, unacceptable, or prohibited to openly discuss. These prohibitions are upheld by social and cultural norms, by conservative sectors of power, and transgressing them can result in disapproval or social sanctions. Therefore, the topic of sexuality, as expressed in culture, is laden with myths that persist in social imprint and psychological perception. Some common myths about sexuality include: that sexuality can only be experienced in partnership, that sexual organs are the genital organs, that pleasure depends on societal standards of beauty or age, and that reproduction is the ultimate expression of sexuality. These myths cover all individuals in society, with and without physical disabilities.

These general myths can be compounded by societal beliefs about PPFD and their sexualities. The dominant sexual discourse portrays people with disabilities as asexual or, at best, sexually inadequate. By not conforming to normative and ableist body standards, society attributes to PPFD an incapacity to have an erotic life and experience pleasure. This assumption implies that bodies with physical limitations hinder individuals from experiencing

sexual attraction, desires, and behaviors. If it is widely accepted from Abraham Maslow's hierarchy of human needs¹⁶ to the present day that sex is a basic human need, why is it difficult to conceive that all individuals with functional diversity experience desires, sexual attraction, and eroticism? "All people are sexual from birth, ...it is not possible not to have sexuality". This general premise of sexuality encounters an insurmountable barrier that excludes individuals with functional diversity.

Prominent sociomedical discourses in most societies construct individuals with physical disabilities or sensory impairments as incapable of experiencing sex, romantic love, or partnerships. Chappell¹⁷ explains that these dominant discourses on disabled sexuality have created the illusion of a homogeneous group that fails to recognize the individuality and diverse functionalities and unique characteristics of each PPFD. The medical model has focused exclusively on treating and rehabilitating the bodies of PPFD, in terms of addressing health or preserving life, but has not included guidance on how those bodies can achieve pleasure, nor information on which sexual practices may be appropriate for each individual case, on risky practices, or on existing adaptations to facilitate the sexual experience of the person.18 The sexual response of a person with a disability may be more variable and adaptable to their needs and circumstances than the sexual response in people without disabilities. For example, individuals with disabilities may engage in activities other than intercourse, or focus on different erogenous areas of the body, to achieve pleasure, 19 which is typically not taught.

It should be noted that, as Focault²⁰ warned individuals do not construct their subjectivities autonomously, but are subject to hegemonic sociocultural truths related to power, social order, and interaction with their own consciousness or self-awareness of these truths. The medical model and its cultural practices have contributed to the widespread exclusion of PPFD from sexual topics.¹⁴ Consequently, individuals with functional diversity also judge themselves in light of these dominant sets of truths and transform their thinking, identity, and behavior accordingly.²¹⁻²³ In this sense, many heterosexual women with physical functional diversity have reported feeling invisible when near potential male partners, perhaps because societal standards of beauty are in direct conflict with the reality of their physical appearance.¹⁵

The resulting exclusions permeate the field of sexual education, where PPFD also do not receive necessary information about sexual health, and when offered, it usually does not go beyond learning about body parts or addressing a problem that has already occurred with the person's sexuality.²⁴ PPFD are often deprived of sexual education that includes knowledge about consent, bodily autonomy, sexual safety, which are necessary for all individuals. "I did not receive sexual education from health professionals, the sexual education received was self-sought," affirms one of the activists from the PPFD community, interviewed as part of

ongoing research at the University of Puerto Rico, Cayey Campus (M Rodríguez-Morales, personal communication, 2022). The leader continues her statement when asked if individuals with physical functional diversity in Puerto Rico receive sexual education, and how they obtain information about their sexuality:

"The information I have identified is what they cover in health and responsible parenthood classes in schools. However, I have always wondered what information is provided to students who are part of the Special Education Program, and in the schedule of elective health classes they are in the resource room. Is the material provided to them, how is it provided, what accessibility is there in that information? On the other hand, the information that their family wishes to provide them. I have had experiences from providing information to not providing any information 'this topic is not discussed.' I understand that access to the Internet has increased access to information, the question is what information is accessed?" (M. Rodríguez-Morales, personal communication, 2022).

This community activist even experienced denial of sexual orientation services at an institution dedicated to such purposes on the Island, where it was explained that the information was only for sexually active individuals, highlighting the lack of knowledge of sexual health professionals about the sexuality of PPFD in that facility. As in the medical field, they have used the ableist, normative, and hegemonic model of healthy, white, Western, and cisgender persons to design their programs and interventions. 17,24

In their 2022 study in Japan, Kasai and colleagues advocate for increased sexual education for PPFD, specifically in this case for those living with spina bifida. Most participants in their research wanted education on romantic relationships, violence, and how to stay safe. Participants under 30 wanted education on human anatomy and development. Other participants preferred education on values, rights, culture, sexuality, and gender understanding, and those who had been in a relationship preferred education on gender understanding, health and well-being skills, and sexual and reproductive health. These researchers advocate for comprehensive sexual education covering a range of important topics that PPFD need to know about sex, including topics that are challenging in some social and cultural contexts.

In these different contexts, despite the differences in sexual capabilities and desirability of each person, hegemonic constructions of sexuality question the suitability of all disabled individuals as potential partners.¹⁷ According to this premise, people with disabilities face societal attitudinal barriers that include prejudices, stereotypes, and low expectations about their sexuality.²⁵ In their survey of 403 male and female subjects, Zewude and Habtegiorgis²⁶ found that many young people without disabilities may doubt that people with disabilities can be satisfactory partners in any adult romantic relationship. The result showed that the majority (85.5%)

of young people without disabilities were unwilling to have any kind of personal relationship with PPFD. The main reason for the respondents' determination in this study was fear of their families' reactions (44.2%), and was not influenced by the socioeconomic status of individuals with disabilities.

Stereotypes towards PPFD extend to assuming them as incapable of performing roles arising from love or marital relationships, or as asexual individuals who simply lack interest in sexuality. ^{26,27} In fact, asexuality was previously discussed as a natural part of disability. ²⁴ Asexuality is a sexual identity characterized by a person who does not feel sexually attracted to others or is not interested in engaging in sexual activities. ²⁸ This category can be found within all identity communities—lesbian, gay, bisexual, transgender, queer, questioning, intersex, heterosexual—and certainly among people with functional diversity. Although there is an asexual community within the disability community, these two communities are not synonymous. ¹⁵ Of course, asexuality is a legitimate, empowered choice.

In reality, many PPFD are sexually active and desire to become sexually expressive and fulfilled in that sense.²⁹ Contrary to sociomedical constructions of disabled sexuality, young PPFD participating in Chappell's¹⁷ study clearly perceived themselves as capable of experiencing romantic relationships, love, and forming romantic relationships, both with disabled and non-disabled partners. Additionally, the participants did not see disability playing a decisive role in their understanding of love and relationships. The young people in this research embodied perceptions similar to their non-disabled peers regarding sexuality and romantic relationships.

On the other hand, Rohleder²³ found that the perception of asexuality is primarily held by other non-disabled people, including family and friends, and not by PPFD themselves. They explain in their writing:

"An underlying assumption in this construction is that sex equals penis-vaginal intercourse, where the 'ability' to have sex in these terms ('can you still have sex'?) is questioned and assumed impossible... Asexuality generally was not a script our participants endorsed themselves. Participants saw themselves as sexual human beings, and the imposed idea of asexuality seemed foreign and excluding... (Rohleder).²³

This author emphasizes an important finding: the perception regarding the inability to have a sexual life in PPFD is echoed in research results across multiple countries, both in the Global North and the Global South, suggesting that some of these experiences translate across contexts and cultures and therefore present some universal characteristics.²³

The Intersections

In 1989, Kimberlé W. Crenshaw introduced the concept of

intersectionality to designate "the phenomenon whereby an individual experiences oppression or privilege based on the simultaneous belonging to multiple social categories". The American activist had noted that African-American women had been excluded from feminist and antiracist policies, as neither had taken into account the intersection between race and gender. In the case of the intersection between sexuality and functional diversity, it confronts the series of myths mentioned, which lead to the perception of the subject with functional diversity as inferior, dependent, and bound to their impairment.

While from the intersections of diversity with other categories such as identity, culture, race, social or economic condition, and sexuality emerge the identities of young people with disabilities, the most important aspect of sexuality intersecting with disability in terms of vulnerability is gender. In the study by Pebdani, indicated that while both men and women with physical disabilities were considered less likely to date, men were slightly more likely than women to date. It was also indicated that men with disabilities were likely to date other people with disabilities, whereas it was assumed that women with disabilities had no chance of dating anyone, and people with traditional beliefs about gender roles had more negative attitudes towards the sexuality of women with physical disabilities than towards men's sexuality.

Scientific literature identifies multiple challenges faced by women with physical functional diversity, including low self-esteem related to negative public attitudes, lack of family support, and problematic experiences with transportation and other social systems for health care during pregnancy, besides little acceptance by the community in this regard.^{33,34} Additionally, as suggested in other research, disabled women are more likely to be victims of sexual assault precisely because they are not educated to be aware of these dangers, and when they are, their rape reports are not taken seriously.³⁵

Some of the issues identified by marginalized voices point to intersections with sexual identity, where people with disabilities must challenge heterosexist assumptions and "come out of the closet" twice, not only as part of the LGBTQIA+ community, but also as disabled individuals. Individuals must recognize and confront multiple layers of discrimination. Being part of two minority communities is stressful and stigmatizing. In this scenario, disabled women who identify as queer experience triple discrimination within each minority. Queer women with disabilities are rejected by the queer community because they have disabilities and are rejected from disability communities because they are homosexual. ¹⁵

The situation of women with functional diversity in these contexts makes them an isolated and invisible social group facing all kinds of restrictions and limitations. This group has been the subject of a long history of unequal treatment, undermining their ability to participate in society.³⁶

The Possibilities

Adding a diversity framework provides an alternative yet complementary lens through which to address sexual diversity and the sexuality of PPFD. Like everyone else, PPFD construct their sexual identities around the discourses available to them. Viewing disability as a discursive construction, as an evolving concept resulting from the interaction between people with functional diversity and the attitudinal and environmental barriers imposed on them by their historical moment, is encouraging. Therefore, it is important to raise awareness among people about the diverse sexuality, and to educate on the topic that physical disability has nothing to do with incapacity for sexuality and for forming emotional and romantic relationships. A diversity perspective goes beyond seeing difference in that other minority and promotes recognition and celebration of diversity, considering the issue of sexuality not only independently of disability, but as part of it.

At a sociopolitical level, collective liberation strategies are beginning to expand, and PPFD are starting to explore the need to make themselves visible and demand recognition. Organizations formed by PWD, family members, and allies are currently forums for demands that are part of a collective struggle, to denounce the multiple forms of discrimination they are being subjected to, and also as a means to create networks and share strategies of mutual assistance. Corona-Aguilar²⁵ narrate how PPFD in their study, in this case women, expressed that discovering a world of participation and political activism was like opening a window to do something different from what gender socialization has assigned them. Through the activism of PPFD, the goal is to construct a collective sense, a "we," a political organism, which turns their physical presence into an act of empowerment and overcoming stereotypes, thus developing spaces and mechanisms of participation.²⁵

Authors like Dr. Teresa Milbrodt³⁷ and Dr. Leah Tidey²⁴ advocate for the use of theater as a subversive tool to showcase the bodies of PWD and discuss the barriers society presents to them. Milbrodt³⁷ uses burlesque theater performance to demystify the sexuality of PPFD and propose that other types of bodies can be considered "sexy" and sensual. This university professor and the actors promote the reframing of symbols that present disability as shameful and something to hide, recontextualizing them as erotic objects that a lover should display. Tidey²² on the other hand, creates meaning in PPFD as subjects and objects of research, developing research-based theater as a way for self-expression, exploration, and resolution of sexual prejudices and stigmas. This other university professor and her workgroup promote sexual agency and self-defense of PWD, while aiming to destabilize ableist and heteronormative sexual health education practices.

On the other hand, García Ramos³¹ agree with the appreciation of this work, noting that in recent years there have been numerous proposals in popular cinematography specifically addressing the

intersection between sexuality and functional diversity. Among these, we can mention "Crip Camp: A Disability Revolution", 38 which presents the story of a camp for young people, where they appropriated the adjective "crippled" to redefine it in their favor; and the Spanish documentary "Yes, We Fuck!", 39 a proposal of the post-porn genre that revolutionarily showcases real non-normative sexual and erotic practices of PPFD. It is also interesting that García Ramos 31 mention the original Netflix series "Sex Education" 40 in this line of cinematographic proposals contributing to the normalization of PPFD sexuality, and we could add series like "Atypical" and "Special" 42 also on Netflix. It is possible to establish that, as argued by Alonso Sánchez regarding "Yes we fuck!", these film productions manage to rise against hegemonic models of corporeality, with which many people do not identify anyway.

The subject of sexual assistance has also gained interest in recent years. Sexual assistance refers to when PPFD can rely on another person to assist with sexual activities they cannot access themselves, primarily due to movement limitations. For some, sexual assistance borders on sex work, which remains illegal in many countries, yet for others, it may signify reclaiming self-erotic encounters as an expression of resistance against social oppression. It is a controversial topic that some PPFD view as a means to regain control over their bodies and progress towards full sexual citizenship affirming their sexuality.

Among organizations offering these services is "White hands," a Japanese company founded in 2008, which provides "ejaculation assistance" solely for men with severe physical disabilities who cannot ejaculate independently due to conditions like paralysis or limb contracture Greene. Another organization, "Noir," a nonprofit founded in 2004 by a man with cerebral palsy, focuses on developing a specific plan with an occupational therapist for PPFD to explore self-masturbation methods and offers masturbation assistance to those unable to do so independently.

In Puerto Rico, a conversation has only recently begun on sexual assistance, as evidenced by research conducted at the University of Puerto Rico, Cayey Campus, and others, yet state public policies remain far from enabling these services for PPFD. "Sexgnosis" is a sexual education program founded by a Puerto Rican sex educator and social researcher, who has collaborated extensively on this research. Its educational goal is to pursue responsible and liberating sexual education tailored to the needs of PPFD, proposing the use of sexual instrumentology among other methods.⁴³

Beyond sexual assistance, still a nascent topic in PR's official discourse, other initiatives on the island supporting PPFD and sowing the seeds of activism deserve mention: Puerto Rico Abilities Fair (https://www.facebook.com/PRabilitiesfair/), which held its first edition in 2019; the Symposium of Entrepreneurs with Functional Diversity, held annually since 2022; the celebration of Disability Pride Month by the PWD community in July each year;

the Broad Coalition for Functional Diversity Equality (CADFI), founded by PPFD rights activist Dr. David Figueroa; "Madre Fajona, Fostering Inclusion," a Facebook channel (https://www.facebook.com/madrefajona/) founded by a mother of a PPFD, offering guidance on disability diversity issues; and Functional Diversity in Action, a YouTube channel founded by a counselor on functional diversity issues at the University of Puerto Rico in Cayey (https://www.facebook.com/diversidadfuncionalenaccion/). These are examples of activism demonstrating the beginnings of a population in Puerto Rico awakening to its human and sexual rights within civil society.

Based on these reflections and theoretical models, the present research at the University of Puerto Rico, Cayey Campus, aims to conduct in-depth interviews with PPFD who are advocates for human and sexual rights within their population, under a framework of participatory research/action. This effort aims to shed further light on the state of sexual rights exercise among this population in Puerto Rico, aiming to increase visibility of PPFD rights and collaborate with them towards the normalization of diverse sexuality, inclusion, and affirmation of responsible and liberated sexual life options for all. Equality of opportunities does not exist; it is no longer relevant in this case.³⁶ To challenge social exclusion and constructions of disability and sexuality, private matters need to be brought into the public sphere.²³ Essential is the visibility of PPFD in all social situations, and advocacy for human rights for all. Awareness can be gained that accessibility benefits everyone equally. The current social paradigm of disability is in transition, and PPFD communities, alongside other allied groups in Puerto Rico and globally, have already begun to act inspired by ideas of critical emancipation and social transformation.44-47

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Regarding the publication of this article, the author declares that he has no conflict of interest.

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