One Is the Loneliest Number: How the WHO's Redefinition of Infertility Provokes Contestations of the Body and the Body Politic

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Introduction

The argument I wish to advance in this presentation is a simple and straightforward one, yet one I also suspect will invite no small share of skepticism and perhaps even vigorous contestation when subjected to further examination.

In its most succinct and compact compass, my argument is this: the recent decision by the World Health Organization (WHO) to (re)define single people unable to find consenting sexual partners as both infertile and disabled and thus as eligible to receive publically financed artificial reproductive treatments commits two significant errors—one conceptual and the other normative.

Conceptually this definition ignores an intrinsic quality of disability or what Christopher Riddle (2013: 23–40) has rightly referred to as its ontological reality. For while it is certainly true that singleness as a result of unsuccessful sexual coupling invariably renders one physically incapable of reproducing, it is just as true that a proper account of reproductive disability must look beyond a mere inventory of contributing social factors, lest the meaning of reproductive disability be reduced to an exclusive focus on functional limitations. It is thus imperative to recognize that a person unable to reproduce because of unsuccessful sexual coupling is fundamentally different from a person unable to reproduce because of an underlying physiological/biological impediment and that this difference is not merely one of degree but of kind.

Normatively speaking the WHO decision rightly attends to the fact that the capacity to become a parent need not be predicated upon successful and sustained coupling. Nevertheless, it fails to see that the political practice of being a parent is invariably communal in nature and thus an enterprise whose full normative import cannot be adequately realized, let alone discharged, within the exclusive domain of

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exercising an autonomous agent's right. Indeed as Brian Duff has argued in *The Parent as Citizen: A Democratic Dilemma*, if the true goal of a flourishing public order, particularly a liberal democratic one, is not simply the establishment and preservation of a regime of rights but also the "creation of and caring for new members who will carry that tribe into the future," then it follows that the "[c]aring for our children provides the fundamental basis upon which liberal citizenship might be built and extended outward by extending parental sympathies" (2010: 133). Hence while the decision to become a parent may be solitary, the actual practice and lived experience of parenthood is anything but.

Thus taken together, these conceptual and normative errors ultimately erode the integrity of both disability and parenthood. Stated differently and by way of analogy, we can say that just as defining singleness as an infertile disability undermines the latter's conceptual integrity, so too does redefining parenthood as the exercise of autonomous right render it incapable of producing the kind of moral and political goods integral to a flourishing liberal democratic society. I will thus use the remainder of this paper to further flesh out and defend each of these claims.

Before I do so, however, it will be instructive to return to the WHO decision in question in order to further delve into its specifics as well as explore the philosophical and normative assumptions upon which it rests. In so doing, we shall be able to discern not only the *how* of this decision but also more importantly its *why*. That is to say we shall come to see that the WHO's decision to expand the definition of reproductive disability to include singlehood is not a departure nor even an aberration of modern reproductive ethics, but rather its logical, indeed its inevitable, conclusion insofar as parenthood is conceived—so to speak—as a natural liberty right.

Singleness, Infertility, Disability, and the WHO

If one were to consult the WHO's definition of "infertility" prior to October of 2016, one would encounter a complex and multivariate statement. To wit, according to the WHO's website, infertility can simultaneously be defined within three distinct categories—clinically, demographically, and epidemiologically. Clinically infertility is "a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse" (WHO 2017b: 1).[1] Demographically infertility is an "inability to become pregnant with a live birth, within five years of exposure based upon a consistent union status, lack of contraceptive use, non-lactating and maintaining a desire for a child" (WHO 2017b: 2). Lastly, the epidemiological definition holds that infertility occurs when

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[1] "Infertility definitions and terminology," *World Health Organization*, accessed April 5 2017, http://www.who.int/reproductivehealth/topics/infertility/definitions/en/. A second clinical definition of infertility is offered which states, in part, that infertility is "the inability of a sexually active, non-contracepting couple to achieve pregnancy in one year."

"[w]omen of reproductive age (15–49 years) at risk of becoming pregnant (not pregnant, sexually active, not using contraception and not lactating) who report trying unsuccessfully for a pregnancy for two years or more" (WHO 2017b: 3).

In addition to these various definitions, the WHO also classifies infertility as a disability. More specifically it states that "[i]nfertility generates disability (an impairment of function), and thus access to health care falls under the Convention on the Rights of Persons with Disability" (WHO 2017b: 4).

The WHO's definition of "disability" is itself similarly complex and multifaceted. "Disabilities," it states, "is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations" (WHO 2017b: 1).

Furthermore the WHO asserts that disability "is not just a health problem." Rather, it should be viewed as "a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives." Accordingly "the difficulties faced by people with disabilities require interventions to remove environmental and social barriers" (WHO 2017a: 2).

What is noteworthy about both these definitions is the degree to which the WHO sees both infertility and disability as pluriform. That is, both infertility and disability are regarded as complex phenomena whose etiology owes to an intricate interface and synthesis of exogenic and endogenic factors. So while disability can be manifested on account of an immediate physical impairment, it can also be manifested because of the social exclusion and isolation that impairment causes.[2] In the same vein, infertility can be a function of disease, age, and/or sexual activity or some combination thereof. Thus to reduce infertility or disability to any one set of factors at the exclusion of others is to misapprehend their true essence.

As a short but necessary digression, though certainly not a tangential one, it should be noted that while these WHO definitions of infertility and disability demonstrate a concerted effort to preserve their complexity and polygonal nature and etiology, both nevertheless suffuse their meaning with a subtle but noticeable negative valence. That is to say, by viewing infertility as a disability, the WHO is not only providing a descriptive claim but a normative one as well, namely, that infertility is a malady in need of remediation. Such a claim is not without considerable contestation, however, especially as feminist bioethicists have critically deconstructed some of the essentialist and pronatalist presuppositions and discourses that tend to underpin its normative ambit (Parry 2005). Thus, aside from assessing the content of the definitions themselves, one could question upon what normative and political basis the WHO arrogates unto itself the authority to deem infertility as

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[2] This view is consistent with Barbara Altman's assertion that because "disability is a complex social phenomenon," it is therefore "undefinable empirically unless one reduces the focus of the definition to a specific aspect of experience" (117). "Disability Definitions, Models, Classification Schemes, and Applications" in *Handbook of Disability Studies*, eds. Gary Albrect, Katherine Seelman, and Michael Bury (Thousand Oaks: Sage Publications, 2001), 97–117.

disability. While certainly an important and essential question to be asked and explored, it is nonetheless one that falls outside the scope of my ability to adequately address within the confines of this paper. I simply raise it here to illustrate just how complex the nature and relationship between infertility and disability is, even more so than the already complex definitions of the WHO allow for.

Even so given this sensitivity to wanting preserve their complexity and multidimensionality, it should come as little surprise then that the WHO would maintain a certain vigilance in adapting or modifying their definitions of infertility or disability less some heretofore undiscovered or unacknowledged aspect get overlooked and omitted. And so it was that the WHO's international committee on assisted reproductive technology announced in October of 2016 that it would change the WHO's previous definitions of infertility and disability to now include single women and men who are unable to have children not solely because of a medical condition but also because of the "inability to find a suitable sexual partner or the lack of [a] sexual relationship which could achieve conception" (Bodkin 2016). As such, under these new definitions, the WHO would deem single men and women as equally infertile and disabled as gay and lesbian couples or heterosexual couples unable to conceive a child because of a medical condition and thus as equally deserving of publicly funded IVF treatments.

Once again, in the same vein as my discussion of the contestation surrounding the implicit negative normative evaluation of infertility above, it should also be observed how this new definition seemingly conflates the infertility of a heterosexual couple or single person with the infertility of a homosexual couple or gay person and views both as equally disabled. However, this conflation glosses over and obscures an important distinction that has comparably weighty normative import. For while it may be said that the infertility of a heterosexual couple of single person is derivate of an "abnormal" functioning of their reproductive capacities, the infertility experienced by homosexual couple or single person is decidedly quite "normal." In fact, it would be extraordinarily "abnormal" in the case of the homosexual couple at least if they did not experience infertility. Thus we arrive at a similar conclusion as we did above with the WHO labeling infertility as a disability except in this instance it is homosexuality itself that is effectively viewed as a disability. Of course such a view, even if unwittingly assumed, has to be just fiercely contested.

Be that as it may, neither the subtle reinforcement of a pronatalist discourse nor the implicit reification of heteronormativity was what elicited and drove the main outcries of criticism over the WHO's decision to redefine infertility and disability as inclusive of non-coupling singles. Gareth Johnson, a member of the British Parliament and a former chair of the All Parliamentary Group on Infertility, expressed subdued skepticism by stating "I'm in general a supporter of IVF. But I've never regarded infertility as a disability or a disease but rather a medical matter. I'm the first to say you should have more availability of IVF to infertile couples but we need to ensure this whole subject retains credibility" (Bodkin 2016). Josephine Quintavalle, on the other hand, speaking on behalf of Comment on Reproductive Ethics or CORE—a British public interest bioethics organization—registered a decidedly greater level of pique. "This absurd nonsense," Quintavalle stated, "is not simply re-defining infertility but completely side-lining the biological process and significance of natural intercourse between a man and a woman. How long before babies are created and grown on request completely in the lab?"(Perring 2016).

Yet to think these definitional changes effected by the WHO were either a case of blinkered thinking or worse a sinister pretext for legitimizing ectogenesis would overlook their true philosophical and ethical provenance—a provenance that forms the very foundation of much of modern reproductive medicine, namely, the right to reproduce. Indeed as Dr. David Adamson, one of the authors behind the changes in definitions, stated in their defense, "[t]he definition of infertility is now written in such a way that it includes the rights of all individuals to have a family, and that includes single men, single women, gay men, gay women. It puts a stake in the ground and says an individual's got a right to reproduce whether or not they have a partner" (Bodkin 2016).

Adamson's point on how redefining infertility to include uncoupled single men and women is coeval with a right to reproduce tracks closely with John Robertson's conception of procreative liberty. The liberty to procreate, argues Robertson (1994), is the "freedom to decide whether or not to have offspring." Thus "to deny procreative choice," Robertson concludes, "is to deny or impose a crucial self-defining experience, thus denying persons respect and dignity at the most basic level." As Muireann Quigley (2010) rightly observes, in this particular articulation of reproductive liberty, the right to reproduce is conceived as a negative right, that is, a right "against the interference of other individuals (or the State) in one's reproductive decisions." As such when interpreted in its broadest possible terms, it is a "right to non-coital collaborative reproduction, such as involved in the process of gamete donation and surrogacy" (2010).

Thus, as Adamson contends above, there is a logical trajectory that naturally extends the right to reproduce to uncoupled singles. For inasmuch as uncoupled singles have the same decisional capacity to choose to have a family as heterosexual and homosexual couples, then they also possess the same liberty and right to reproduce and become parents. To deny them this right, and thus the material means by which this right can be properly exercised, simply because they are uncoupled would be just as arbitrary and unjust as depriving a medically infertile heterosexual couples or homosexual couples of their reproductive rights on account of the vicissitudes of biology or sexual orientation.

The Integrity of Disability and Parenthood

Does, however, the unfettered choice to simply reproduce—whether one is single or not—adequately capture the reality of what it means to be a parent? That, of course, is a question of description. However, since this is an occasion to reflect on the ethics of reproductive medicine, there is also the prescriptive question, i.e., is this what parenthood *should* mean?

I would like to probe these questions further and make the case that parenthood so conceived, that is, as purely a negative right of reproductive freedom, does not do justice to the lived experience of parenthood either descriptively or prescriptively.

Before I do so though, I would first like to address the conceptual question of whether being an uncoupled single makes one infertile and disabled. Let us return once again to the WHO's definition of disability cited above. In keeping with its operating premise that disability is a complex and multifaceted phenomenon that encompasses physical impairments, activity limitations, and participation restrictions, the WHO maintains that disability reflects "the *interaction between* features of a person's body and features of the society in which he or she lives [emphasis added]" (WHO 2017a: 1). It bears repeating here that the WHO views the phenomenology of disability as intersectional. That is say to be disabled is *both* to possess a physical impairment *and* to endure social isolation and exclusion as result of that impairment. Neither aspect in and of itself is sufficient to be disabled although both are certainly necessary.

The problem therefore with defining uncoupled singles as suffering from an infertility disability is that it decouples the physical from the social. In other words this redefinition of disability ironically severs the very kind of symbiotic interaction between "a person's body and the features of the society in which he or she lives" that the WHO originally argues is integral to maintain. And it does so because like the social model theory of disability, there is a failure to acknowledge what Christopher Riddle calls the ontological reality of disability.

As Riddle explains a proponent of the social model theory would "view the disabling barriers in one's life as resulting from social organization, and not from individual limitations in functioning" (Riddle 2013: 24–25). Thus as Michael Oliver (1996), a leading social model theorist, writes:

> It is not individual limitations, of whatever kind, which are the causes of the problem, but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization.

To be sure, to be disabled is to know all too well the myriad and sundry ways society deprives one of full social recognition and integration. Nevertheless, what social model theorists of disability tend to ignore or even reject, according to Riddle, is the causal link between physical impairment and social depravation. Hence, by rejecting "the argument that there is a causal connection between impairment and disability," the social model "clos[es] the door on the possibility that impairment is bad in-and-of-itself" (Riddle 2013: 26). And in so doing, "the social model does little to address the experience of pain (or welfare deficiency), and tends only to the functional limitations (or resource deficiency)" (Riddle 2013: 29).

In light of this conceptual lacuna in the social model theory, Riddle proposes that a definition of disability must also include the metaphysical or ontological reality of being disabled as well. For while "social circumstances can exacerbate or minimize the effects of impairment," the physical impairment of disability "can negatively impact well-being" as well "even in the complete absence of the effects of social arrangements" (Riddle 2013: 35).

Thus by juxtaposing Riddle's critique of the social model theory of disability with the WHO's redefinition of infertile disability to extend to uncoupled singles, we can see that it is susceptible to the same kind of fallacy and critique. That is, the WHO's redefinition ignores or even rejects the causal connection between physical impairment and social deprivation. An uncoupled single woman and a woman suffering from premature ovarian failure may both be functionally infertile and thus suffer from the same kind of social stigma and isolation that comes with being single and childless. But to maintain that both are equally disabled would be akin to saying that a man who is only a 20% free-throw shooter is just as disabled as a man who is a quadriplegic insofar as both are functionally prohibited from becoming professional basketball players. In both instances the corporeal or metaphysical dimension of disability is denied.

Analogously we can say that to reduce the reality of parenthood to the pure exercise of individual autonomy—i.e., purely as a negative right to reproductive freedom—is similarly harmful to preserving the integrity of the body politic. This is so two ways.

The first concerns a proper conception of not only of rights more generally but also of the right of reproduction in particular. While it is undeniably the case that the provision, enactment, and protection of negative rights—that is, rights whose chief aim is to secure and protect an individual's autonomy from interference—are an integral prerequisite to a flourishing liberal democracy, it is just as undeniable that the exercising of these kinds of rights alone is insufficient to that project, indeed to autonomy itself. For as Cathleen Kaveny argues, "[p]ositive freedom—autonomy—is not merely the capacity to choose, willy-nilly what one want to do here and now. It is also and more fundamentally the capacity to commit oneself to an overarching project that will take years to realize, with each new each new step building upon the last…It is impossible to preserve a political community committed to autonomy unless that commitment is collectively passed down from generation to generation" (Kaveny 2012). Thus the endurance and vitality of a liberal democratic order is just as dependent upon the provision, enactment, and protection of positive rights—that is, rights whose chief aim is to ensure the provision of certain goods and services—as it is on the exercise of negative rights.

If this securing of both negative *and* positive rights is integral to the maintenance and flourishing of a liberal democracy, then how much more so is to maintenance and flourishing of parenthood? To be sure there is a vital and essential component of parenthood that entails a significant notion of negative rights, that is, the freedom to choose whether when and how one becomes a parent or whether one becomes a parent at all and to not have the freedom infringed upon. Such a negative right has been clearly enunciated and codified in American jurisprudence. Yet as Tamar Ezer observes, American jurisprudence has also revealed, although to not as great an extent, the existence of a positive right to parenthood as well. More specifically, it views "the work of parenthood [as] both a right and a duty, endowed with special public value" (Ezer 2014). To be a parent then not only means that I have the negative right to choose to become a parent, but also the recognition that I am now simultaneously the object of the claim of another's positive right, namely, the child whose parent I have chosen to become. Thus, in a sense, I am only truly a parent to the extent that I recognize that my negative right to reproductive freedom is inextricably linked to assuming my child's right to dignity and care. Indeed, the former right is quite literally a dependent. As Ezer explains:

> Recognizing positive rights for children need not undermine either the rights of parents or those of society. Children's rights do not threaten parent's rights, but, in fact underpin them. Parent's rights are empty and meaningless when divorced from the needs of children. Children's rights do not create conflict, but rather translate existing tensions, forcing us to wrestle with openly difficult questions. Not only do positive rights for children not create conflict, but to the contrary, the affirm connections to the community. Bound up with duties and responsibilities between the state and the individuals, rather than contributing to dissolution, they strengthen connections.

Ezer's concluding point about how the positive rights of children strengthens rather than weakens communal bonds speaks to the second way a purely negative right to reproductive freedom can undermine the integrity of the body politic. For while reproduction is essential to becoming a parent, the actual practice of parenthood is, by its very nature, an inherently communal enterprise. This is the case whether one is a single parent or co-parenting. In fact, it is especially the case if one is a single parent. It is precisely because a child has a positive to right to care and dignity that a parent or parents must forge the kind of connections and relationships with not only other parents but by extension all members of their society to ensure that they have access to the necessary communal goods and institutions which make such care and dignity possible. Hence I can no more choose to become a parent in isolation from my child than can I choose to parent in isolation from my community. To pretend otherwise is to deny ourselves of the very moral and communal goods that make parenting a meaningful and worthwhile endeavor.

As such to become a parent is to incur obligations of caring, nurturing, and responsibility that one does not necessarily get to choose. Indeed, there is a great irony in linking parenthood as with a negative liberty right since the actual fulfillment of that right acts as its own negation at the same time. I may well say that I can fulfill my right to become a parent simply by exercising my right to reproduce and leave it at that. In such a situation, there can exist a mother and/or a father of a child. Yet it would be difficult to say that either or both were parents as we have come to think of and define that term short of one or both fundamentally limiting their autonomy. To be a parent then is not only to possess the freedom and right to have a child but also to forego that very same right and freedom such that the child has you. Such a practice and politic is all the more necessary and salutary in a society and culture where one indeed is the loneliest number.

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