

## Disabled by Design: Justifying and Limiting Parental Authority to Choose Future Children with Pre-Implantation Genetic Diagnosis

ABSTRACT. Often, ethical analysis of Pre-Implantation Genetic Diagnosis occupies one of two positions in a moral dichotomy. On the one hand, we have a deep suspicion of the technology as directly leading to eugenics, which is assumed to be a negative consequence; and on the other, we have a vigorous enthusiasm for the technology as a means toward creating better offspring, where “better” is assumed to mean, at minimum, non-disabled. For my part, I eschew both of these positions and attempt to break this dichotomy wide open by maintaining that future parents are not morally required to use PGD to select some vision of an objectively “best” child, but should be permitted to use PGD to select embryos according to their own conception of the good life, even if that conception of the good life includes disability. Yet, I still would not argue that *any* use of PGD to select a future child to correspond with a particular view of the good life is morally permissible and so we need some way to identify which conceptions of the good life ought to be allowed to motivate prenatal selection without defaulting to a flawed concept of disability as a convenient measuring stick. To achieve this, I will invite moral judgments regarding a future child’s likely range of life opportunity that would result from her parents’ acting according to their conception of the good life in the context within which she will be raised. However, I reject the notion that this opportunity range should itself be defined only in terms of a socially decontextualized, purely medicalized conception of disability that is so often defined in terms of species normal functioning, so as to be considered *equal* or *normal*. Instead, an *acceptable* opportunity range should include a variety of modes of functioning that can contribute to a broad enough opportunity range if they are *reasonably accommodated*. In summary, this paper attempts to carve out a position that acknowledges the danger of PGD encouraging simplistic, stigma-based reproductive decision making while also justifying parents’ use of PGD to choose embryos that will develop into children with and without disabilities who will flourish in the context in which they are raised.

## INTRODUCTION

Like any philosophically interesting health care practice, ethical analysis of Pre-implantation Genetic Diagnosis (PGD) has produced a wide range of moral positions. For example, one might contrast David King's view that warns PGD should be strictly limited and regulated because it will soon result in the expansion of a troubling "laissez-faire eugenics" (1999, 176–82) with Julian Savulescu's argument for the "principle of procreative beneficence" morally requiring parents to use information attained through PGD to select the "best child" (2001, 415). That is, these authors represent two poles of a sort of moral spectrum regarding PGD. At one end, we have a deep suspicion of the technology as directly leading to eugenics, which is assumed to be a negative consequence; and at the other, we have a vigorous enthusiasm for the technology as a means toward creating better offspring, where "better" is assumed to mean non-disabled. For my part, I eschew both of these positions and attempt to break this dichotomy wide open by maintaining that future parents are not morally required to use PGD to select some vision of an objectively "best" child, but should be permitted to use PGD to select embryos according to their own conception of the good life, even if that conception of the good life includes disability. Yet, I still would not argue that *any* use of PGD to select a future child to correspond with a particular view of the good life is morally permissible and so we need some way to identify which conceptions of the good life ought to be allowed to motivate prenatal selection without defaulting to a flawed concept of disability<sup>1</sup> as a convenient measuring stick.

To achieve this, I will invite moral judgments regarding a future child's likely range of life opportunity that would result from her parents' acting according to their conception of the good life in the context within which she will be raised. However, I reject the notion that this opportunity range should itself be defined only in terms of a socially decontextualized, purely medicalized conception of disability that is so often defined in terms of species normal functioning, so as to be considered *equal* or *normal*. Instead, an *acceptable* opportunity range should include a variety of modes of functioning that can contribute to a broad enough opportunity range if they are *reasonably accommodated*. This notion of reasonable accommodation, as it has been developed in the Americans with Disabilities Act, will help parse between uses of PGD that ought to be accepted and those that should be outside the scope of parental decision-making authority. Further,

deploying the notion of reasonable accommodation to provide boundaries to the acceptable usage of PGD would not inevitably sanction the sort of “laissez-faire eugenics” King is worried about because it would leave room for policy interventions suggested by disability advocates looking to challenge reproductive decisions premised on harmful stigma and stereotype. Likewise, my position acknowledges that some disabilities in some contexts can offer a future child an acceptable opportunity range; and so it would expand the range of reproductive choice beyond what is typical for those who are most enthusiastic about genetic selection by providing parents much more flexibility in defining which embryos are suitable for said selection. In summary, this paper attempts to carve out a position that acknowledges the danger of PGD encouraging simplistic, stigma-based reproductive decision making while also justifying parents’ use of PGD to choose embryos that will develop into children with and without disabilities who will flourish in the context in which they are raised.

I will begin by philosophically grounding a presumption of parental decision-making authority regarding PGD by extending arguments for parental surrogate decision making in general. Then, I will offer an argument for limiting this *prima facie* parental decision-making authority by evaluating a future possible child’s opportunity range with the standard of reasonable accommodation rather than conflating the notion of an acceptable opportunity range with normal species functioning. I will conclude by arguing that my position is entirely compatible with *both* the goals of preventing unreflective reproductive decisions based on harmful social stigmas *and* permitting the thoughtful use of PGD by potential parents to improve their future child’s well-being, while not requiring they do so.

#### GROUNDING THE PRIMA FACIE PARENTAL AUTHORITY TO MAKE PGD DECISIONS

Currently, there is a widespread philosophical and popular consensus that, other things being equal, parents<sup>2</sup> ought to enjoy broad decision-making authority to make major life decisions for their incompetent<sup>3</sup> children. In this section, I will summarize what I take to be a series of common, powerful arguments grounding this authority and then extend these arguments to applications affecting the fates of potential children created via in-vitro fertilization (IVF) and PGD.

As a starting point, I will draw on what I believe is an appropriately rigorous and sophisticated justification of parental decision-making

authority that has been developed in the health care ethics literature on surrogate decision making by Allen Buchanan and Dan Brock's classic *Deciding for Others*. Buchanan and Brock contend surrogate decision making that is shared by all interested parties, including family members and health care professionals, is the ideal in cases of incompetence. However, an incompetent person's family should be the default *principal* decision maker regarding medical choices (Buchanan and Brock 1989, 135–6). This is because, they argue, a person's family has the strongest concern for the individual's good as well as the most accurate knowledge of what is required to achieve that good—including knowledge about the incompetent patient's previously held values and preferences that give content to that good (136).

Of course, only part of this justification retains its full force for young children, who are incompetent to decide for themselves in no small part because they have not yet developed their own coherent values and preferences by which they might decide. So, it is unintelligible to argue that an incompetent minor's family ought to be their presumptive surrogate because they have the best knowledge of that child's values and preferences and are, hence, best prepared to offer a substituted judgment (Buchanan and Brock 1989, 246–7). Yet, even without specific knowledge of a child's unique values and preferences, these reasons can still justify a presumption of parental decision-making authority, as well as a third reason that is somewhat particular to minors: the parents' interests in the outcome of the decision made (233–4). So, for, Buchanan and Brock, when it comes to making important health care decisions for minors, parents ought to be presumptive surrogates because they tend to 1) feel great concern toward a child's well-being, 2) have the most accurate knowledge of what is required for a child's well-being, and 3) hold an important stake in the consequences of such a decision.

The first of these reasons seems obvious enough. To be sure, some parents have knowingly committed horrific abuses against their children and so a parent's desire to promote the well-being of their child is far from an a priori truth. However, it is safe to assume most parents do have a particularly powerful sort of concern for the interests of their children because of the intimacy that is engendered by the child rearing process. In fact, this is a special sort of concern that may be characterized as a form of justifiable or even laudable partiality that would not be exhibited by other benevolent, but objective third parties. For example, if the well-being of a person's child was seriously threatened, it would seem morally

suspect for a parent to think through the utilitarian benefits or harms of protecting her child or not. A precise calculation of the overall utility of protecting her child from harm would and should not be a parent's reaction to a serious threat. This is *her* child and she very rightly shows special concern for it rather than for other persons who may have a stake in the situation. Similarly, future parents also show special concern for the well-being of any future child they plan to have. When potential parents try to conceive an embryo, with or without the use of reproductive technology, they typically exhibit behaviors that display serious consideration for the well-being of that future child. Hopeful future parents prepare themselves and their home in all sorts of ways in anticipation of their future child and these preparations indicate the sort of special concern Buchanan and Brock use to ground *prima facie* parental decisional authority more generally.

It may be objected that mere *potential* children have no interests to be cared for. While they are not referring to embryos, Buchanan and Brock provide a response to this criticism parsing between a being's current interests and "future or forward looking interests" (1989, 247). They take infants themselves to be potential rather than actual persons and describe some forward-looking interests they have that seem to apply equally well to embryos.<sup>4</sup> These are interests that may not be exercised by newborns at the present time, but still must be protected so that they can be satisfied later. Such conditional future interests are of key importance to newborns, but also carry weight for embryos that are likely to survive to the point that they can be satisfied. It might be argued that the protection of these sorts of future-oriented interests makes it coherent to talk about a potential parent having strong concern for the well-being of an embryo that is regarded as a potential person.

Perhaps, it might still be objected that any particular embryo in the PGD stage is so early in its development, with all the variability that entails, that it is not even coherent to regard it with future-oriented interests as we would a newborn. It might be metaphysically suspect to argue that an embryo has any interests at all, future or current, because of the great uncertainty that exists about its future. However, a weaker claim may suffice for establishing a parent's partiality toward her embryo. Namely, it might be argued that a parent has a concern for the well-being of *any* child that they may have in the future and this concern does not turn on the existence of a particular embryo as an entity. For example, even before she is pregnant, a potential mother may try to do away with an unhealthy habit like smoking tobacco for the sake of any future child she

may conceive in the future.<sup>5</sup> So, rather than claim that a parent ought to have prima facie surrogate decisional authority for their embryo because of a concern for that particular embryo's current or future interests, I would argue that this can be established with a particular sort of parental concern for any future child's *potential* interests.

The second reason why parents should be the default deciders for their children also enjoys a sort of obvious appeal. In almost all segments of society, a child's parents are also her default caretakers. Of course, there are exceptions to this generalization, but in the vast majority of cases, a child's most intimate relationship is with her parents and so they have the most thorough knowledge of that particular child's specific needs. These needs are determined by the particular anatomical and psychological characteristics of the child herself, as well as the various facets of *context* in which the child is being raised. This justification for a prima facie parental decisional authority needs a slight reframing if it is to apply equally well to the future children produced by PGD because intimacy does not yet exist between a parent and a potential child, so it can not establish a parent's special knowledge of that child's specific needs.<sup>6</sup> So, it is not obvious that parents would have special knowledge of the projected needs of their future children.

In some sense, the choices parents make via technologies like PGD themselves give parents some specific knowledge of what the characteristics of that particular future child will be. However, this knowledge is still quite vague given the limits of genetics to predict or determine the full range of human characteristics that are relevant to parenting decisions. Yet, it doesn't seem that specific, accurate knowledge of what a child needs to flourish is limited to knowledge of that particular child herself. In fact, knowledge of what a child needs is also constituted by knowledge of the social, cultural, and environmental context in which that child exists. There are some needs a potential child will also have that are determined by these contexts and they can be more accurately predicted by a parent who will be raising it in that context than any outsider point of view. For example, the broad, sophisticated knowledge of a child psychologist would tell him nothing of how likely it is a potential child will need to learn how to ice fish or navigate a complex subway system. This need has little to do with the characteristics of the child but is determined by the context of whether one is growing up in Nunavut or Manhattan. In this way, the second justification for parental decisional authority can be understood to apply to potential as well as existing children, coming to bear on the PGD question.

Finally, Buchanan and Brock make the more controversial claim that parents ought to be the default decision makers because of the stake they themselves have in the decision at hand. Here, they are not arguing parents have unlimited authority to make any decision they like that serves their own interests at their child's great expense. Rather, it is maintained that parents ought to have at least some latitude to make decisions that take into consideration their self-interest and the interests of their other children.

One reason for this is that parents are responsible for dealing with the consequences of such decisions and so "it may be unfair to force them to bear the consequences of the treatment choice while denying them any input into it" (1989, 233). Correspondingly, a potential parent has to deal with the emotional and material consequences of any major decision regarding a potential child in his care just as an actual parent would have to contend with these same consequences regarding an actual child. By its very nature, this sort of reasoning hinges on the prediction and valuation of various decisional outcomes. Such predictions and valuations are always future oriented in that they are always judgments of potential rather than actual outcomes. So, it doesn't seem to diminish the strength of this argument in any way to apply it to the decisional authority of potential parents considering choices about their potential child via PGD.

None of these arguments should be taken as reasons to grant parents absolute authority in making decisions for their children. However, I do think that these arguments work as a *prima facie* justification for locating decisional authority with parents rather than someone else. If these are good reasons to assume parents are the best decision makers when it comes to their children's well-being, then we must try to construct coherent ethical boundaries to that decisional authority. The remainder of this essay will attempt to establish such boundaries for potential parents making decisions about the well-being of their future children with PGD technology.

#### REDEFINING THE LIMITS OF PARENTAL DECISIONAL AUTHORITY OVER FUTURE CHILDREN

The above arguments are for a presumption of parental authority to make important decisions for their future children, some of whom will be conceived through IVF and PGD, but there are surely some such decisions parents might make that are outside acceptable moral boundaries. The boundaries of parental decisional authority over actual children have been drawn by statute and case law and we recognize deviance from those boundaries as abusive. Nonetheless, it is not nearly as clear where those boundaries are regarding future, potential children.

Perhaps the limit of parental decisional authority over future children should be understood as a matter of balancing benefit and harm. Derek Parfit famously problematizes this question of harm to potential persons via genetic traits as the “non-identity problem.” He argues, in cases where technology allows us to avoid an impairment for a potential person only by eliminating the existence of that potential person, it cannot be said that the resulting actual person is harmed by their impairment unless their existence itself is a harm (Parfit 1984). In other words, the non-identity problem points out that, so long as a person’s life with a genetic impairment is worth living on balance, even if other people without that impairment have an easier time of it, the so-impaired person cannot claim that *they* are harmed by the impairment because the only way such harm could have been avoided would have also precluded their existence. Thus, if we were to rely on the concept of harm to future potential persons to set the boundaries of parental authority, the non-identity problem would find any choice acceptable so long as the resulting life is not so burdened by suffering that it is not worth living.

Of course, this is an incredibly low bar for parents to meet with their reproductive choices. It would seem counter-intuitive to argue that, all else being equal, this parental decisional authority to use PGD is justified in part because parents care so deeply for their future children and have knowledge of what they will need to have a good life, but then allow for any such decision resulting in any amount of suffering to a future child up to the point that their life is not worth living.

Instead, I would suggest that we jettison an overly crude concept of *harm*<sup>7</sup> to a specific future person as useful for this boundary setting portion of the project and instead turn to the concept of *life opportunity*.<sup>8</sup> This is because I believe there is likely a category of future children that could not complain that they had been *harmed* by being brought into existence, but maybe could claim that they had not been given a fair shot at a life that included enough in the way of opportunity to attain well-being and were thus, frustrated with that life. To develop this analysis, I now look to the thought of Norman Daniels, along with some guidance from the Americans with Disabilities Act (ADA), to equip us for this task. That is to say, Daniels’s philosophical notion of a normal opportunity range has been applied to future persons in the enormously influential book *From Chance to Choice* (Buchanan, Brock, Daniels, and Wikler 2000) and it can be amended and improved with the disability rights legal concept of reasonable accommodation so that it provides a viable alternative to

relying merely on a concept of equality of opportunity that is defined by normal function.

While Daniels is not usually explicitly drawing a moral boundary for PGD when he lays out his theory of health care justice, his theory is a good starting point for crafting such a boundary because of the important connections he highlights between an individual's health and their access to social goods. These are just the sort of future-oriented interests that should be preserved when making PGD decisions. In *Just Health* (2008), Daniels argues that health has special moral importance because it preserves an individual's normal opportunity range. Drawing on Rawls's notion of fair equality of opportunity, Daniels reasons that "if we believe that individuals should enjoy a *fair share* of the normal opportunity range, we will want to correct for special disadvantages that have led to the misdevelopment or underdevelopment of talents or skills" (2008, 44). Daniels goes on to extend Rawls's argument by asserting inequality in health is one of these special disadvantages we should correct to protect individual fair equality of opportunity (2008, 29–79). For Daniels, health is a necessary condition for a normal opportunity range, which he takes as the practical content of a fair equality of opportunity. Daniels further clarifies his position by following Boorse in defining health as "normal functioning for our species" (2008, 37). Thus, Daniels inextricably binds normal function for our species<sup>9</sup> to his notion of normal opportunity range. His argument is simply that we have a responsibility to maintain the normal functioning of individuals in order to maintain their fair share of the normal opportunity range.

I would argue that a modified version of Daniels's notion of the normal opportunity range should limit parental authority to decide the characteristics of their children with PGD. That is, deliberately selecting embryos that will not develop into persons that have an acceptable range of life opportunities should be outside the range of morally acceptable uses of PGD. However, it does not follow that PGD can be used only to implant embryos with normal species function.

This is because Daniels makes a mistake by positing a "normal" opportunity range and defining it exclusively in terms of normal species functioning. In his chapter "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics," Ron Amundson argues that, even if Boorse correctly defines health as statistically normal species function,<sup>10</sup> it does not follow that normal species function is either necessary or sufficient for accessing an acceptable range of opportunities (2005, 107–08). Instead,

Amundson argues “the opportunities lost to impaired people come from environmental design, not from biology itself . . . [and so] the notion that discriminatory barriers to opportunity are unavoidable facts of nature is no more justified in the case of disability than it would be in the case of racial or sex discrimination” (107–08). Of course, Amundson admits that disabilities entail a degree of biological impairment, but argues that Daniels is performing an obfuscation by *defining* opportunity in such narrow terms because whether impairments “restrict employment, the freedom to live where one chooses, or one’s social status depends on the social structures in which they are embedded” (108). Opportunity range is not so simply defined by biological function. This is much too crude of a narrative.

Once we thus complicate the relationship between normal opportunity range and normal species functioning, it becomes clear that we cannot merely point to normal species function as a bright line for the boundaries of the morally acceptable use of PGD. It may be that there are many biological variations of function that lead to a normal, or at least an acceptable, opportunity range within various social contexts. Indeed, if we appropriately accommodate people with modifications of the physical and social environment, there are multiple modes of functioning that offer access to similar, important opportunities. However, pluralism is not the same thing as nihilism. My claim that *many* modes of functioning can still allow for a plenty broad compliment of life opportunities should not be conflated with the claim that *any* mode of functioning will do this.

That is, I think it should be acknowledged that there are some disabilities that will not allow for an acceptable range of opportunity within some social and environmental contexts. It is true that the social stigmas perpetuating myths about life with a disability being unavoidably tragic warp most people’s judgment about whether a given disability will allow for an acceptable range of opportunity in any context. There is evidence that such stigmas cause non-disabled people to consistently evaluate life with a disability as much more dismal than how that life is actually experienced by a disabled person (Amundson 2010, 374–92). This is reason for us to be very cautious in making these sorts of judgments and to make them based on the carefully considered lived experiences of people with the disabilities we are evaluating. However, it does not follow that every disability allows for a life in which a person can access a sufficiently broad range of life opportunities in any context.

I believe that we can turn to one of the central concepts of the Americans with Disabilities Act (ADA) to provide a guide that will parse between modes of function that lead to an acceptable range of opportunities if embedded in the appropriate social structures and those modes that should not be deliberately sought with PGD in certain other social contexts because they will severely limit a person's life prospects. This distinction can be drawn with the concept of *reasonable accommodation*.

The reason is that this concept of reasonable accommodation provides us with a procedure that can be used to distinguish between disabilities that will allow for an acceptable range of life opportunities in a given context and those that will not. This is partly the function the concept plays for the ADA itself, as the law addresses employment opportunities and access to public space and services for disabled people. David Wasserman describes reasonable accommodation as “a heuristic for approximating the arrangements that would prevail in a society no more egalitarian than our own, but in which people with disabilities were not stigmatized; as a corrective for the effects of stigmatization on the physical and social organization of our present society” (2000, 159n8). So, according to Wasserman, this feature of the ADA is merely applying our current standards of fairness more evenly across the population, rather than radically revising what individuals are entitled to when pursuing life opportunities.

Moreover, even if we conceptualize reasonable accommodation in this fashion, it still does not call for an *absolute* remediation of *all* the effects of stigmatization in our society. This requirement is limited by what is considered *reasonable*. Indeed, for example, the ADA does not assume that all people with all disabilities will always be capable of performing all jobs, even with accommodations. In fact, even the very term “reasonable accommodation” signifies the rejection of this claim. Employers are not required to provide every accommodation, but rather the reasonable ones. Of course, this raises the thorny question of what sorts of accommodations might be considered reasonable.

This issue is dealt with in the law via a highly contextual, procedural standard rather than any attempt to draw an objective bright line; and this can be informative to my application of the idea to PGD as well. Mark Kelman explains,

“It [an accommodation] must be reasonable first in the sense that it is not unduly costly. Under current law, we evaluate whether the accommodation is too costly in part by reference to the capacity of the particular service

provider or employer to afford the accommodation, rather than inquiring whether, in some more general sense, we believe the benefits of the accommodation outweigh the social resource costs of providing it.” (2000, 99n6)

How this procedure unfolds and where the line of reasonableness is drawn may be ambiguous sometimes, but there are some clear cases. Certainly, employers and service providers aren’t required to provide accommodations that would be impossible to invent. For example, given our current state of technology, the Detroit Pistons are not required to find a way for Stephen Hawking to play as starting center and Yellow Cab isn’t required to accommodate and hire Stevie Wonder as a taxi driver.<sup>11</sup> Likewise, even if an accommodation is available, no particular employer or service provider ought to be forced to provide it if the cost would so high that their business would no longer be solvent.<sup>12</sup>

I would argue that this procedure can be translated into a method for predicting when a future child will or will not have an acceptable range of life opportunities. Since the limits that disability place on life opportunity are so contextual, it would be a mistake to try to create some sort of supposedly objective criteria for determining which disabilities can be “reasonably accommodated” when making reproductive choices.<sup>13</sup> This lack of contextual responsiveness is partly what was wrong with Daniels’s initial conflation of normal function with equal opportunity range. Instead, we might determine when a future disabled child is likely to have an acceptable range of life opportunities by making a judgment about whether the potential parents and surrounding community will be able to provide the accommodations the child will need to access such opportunities. This is a multidimensional question that will depend on features of the future child’s physiology, but, just as importantly, the material, epistemic, and emotional resources of her parents and community.

One might object<sup>14</sup> that it is morally wrong to implant an embryo with any sort of impairment on the grounds that, by definition, there are *some* opportunities that will be closed off from the future being with that impairment. This objection rests on the premise that every person deserves to access the full range of all possible life opportunities, otherwise known as an “open future.” After all, a Deaf person may be accommodated so that their deafness does not diminish their chance of becoming a practicing attorney, but they will never have the opportunity to enjoy Beethoven’s fifth symphony. In response, Jackie Leach Scully observes that no child has access to the full range of all possible life opportunities because “all

parents make decisions about the form and content of a child's life from the moment it is born (and often before), including the education it gets and the company it keeps . . . we understand that no child can survive, let alone flourish, in the absence of a familial and social framework that guides its development and, in doing so, inevitably restricts some choices and behaviors" (Scully 2008, 62). As Scully observes, a large part of the project of parenting is constituted by adjudicating trade-offs between different possible life opportunities your child will have access to. Thus, no child, disabled or otherwise, ever has an open future.

The upshot to Scully's reply to the open future argument is that there is no Archimedean point from which to define a *normal* or *equal* opportunity range because everyone has a limited range of opportunities from which to choose from. The best we can hope for is to delineate an *acceptable* range of opportunity for our future children with the choices we make on their behalf.

At this point, it is important to remember that we have already established a *prima facie* decisional authority for parents over the fate of their future children. The notion of an acceptable opportunity range as adjusted by the concept of reasonable accommodation is meant only to be a limiting concept that restricts the otherwise presumed authority of parents to make decisions about the use of PGD. So, all this boundary really needs to do is help us pick out cases in which parents are making choices that severely diminish the scope and quality a future child's opportunity range, even considering mitigating social or technological remedies.

Some examples would be informative at this point. One might imagine a couple who live in a developed constitutional democracy that has civil rights legislation protecting disabled citizens, both of whom have achondroplasia, the most common form of dwarfism. Let's say this couple needs to use IVF to successfully achieve pregnancy and, thus, decide to take the next small step to use PGD to select an embryo with achondroplasia. These potential parents have presumptive authority to do this because they care about their future child, understand the cultural and physical environment in which it will exist as a person with dwarfism, and have some legitimate interests in how the child will be raised. In their judgment, any restriction to opportunity range posed by achondroplasia will be balanced by improvements in the infant's care resulting from it not quickly outgrowing them and sharing some of the most fundamental aspects of their life experiences. While achondroplasia would inevitably eliminate some opportunities from a potential child's supposedly open future,<sup>15</sup> it

does not seem that this is the sort of disability that inevitably restricts function to the point that many or most important life opportunities will be eliminated after adjustments with readily available reasonable accommodations. Further, given the fact that these parents share this disability with their future child, they are well equipped to understand the complex interaction that will take place between the future child's physiology and their physical and social environment. We can endorse their decision to use PGD to deliberately have a child with achondroplasia in as far as we can be reasonably sure that these parents have a handle on what material, epistemic, and emotional resources will be needed to accommodate the child's modes of functioning and whether or not these resources will be available in the context in which they will raise the child.

In contrast, the standard of reasonable accommodation would restrict that same couple from deliberately implanting an embryo that has two copies of the dominant achondroplasia gene because double dominance leads to a very attenuated life filled with profound physical pain and suffering from start to finish. We can imagine a situation in which this couple ascribes to a religious belief system that posits that suffering is always redemptive and is the only path to a heavenly afterlife. Thus, they wish to have a child who will suffer greatly in the earthly realm to ensure that she will enjoy a heavenly reward. However, even if this is their view of the good life, no plausible—never mind reasonable—accommodations could be used to mitigate the severe impairments that accompany homozygous achondroplasia in a way that would leave such an infant with any prospect of accessing even the most basic sorts of life opportunities because of the certainty of a very early death.

Additionally, this procedure would also preclude this same couple from deliberately implanting an embryo with achondroplasia if they lived in society where the future child's life opportunities would be severely restricted by a lack of mitigating accommodations. That is, imagine that, instead of a constitutional democracy, this couple lived in a totalitarian state that removed children with physical anomalies from their homes so that they could be put on public display for the amusement of the masses for the rest of their lives. In such a society that forced disabled people into such public servitude, no sort of "corrective for the effects of stigmatization on the physical and social organization of our present society" would be forthcoming.

Finally, we might also consider a scenario in which a couple of average height, who have never met a Little Person and do not have even an inkling

of how dwarfism would affect a future child's life opportunities, wants to implant an embryo with achondroplasia because they believe it would be amusing to have a dwarf child. They hope that they may even be able to sell the idea to a television network as a reality TV show and become wealthy and famous. It may be argued that this couple does not even meet the criteria for prima facie decisional authority because it is not clear that they care about their future child, understand the cultural and physical environment in which it will exist as a person with dwarfism, and have any *legitimate* interests in how the child will be raised.

Admittedly, these examples are probably too easy and many cases will challenge our intuitions of what accommodations are reasonable and what range of opportunity is acceptable. We must account for our limited imagination for what is possible when accommodating people with disabilities, usually erring on the side of the judgment of potential parents, especially when they themselves have experienced the sort of life they wish to impart on their future children.<sup>16</sup> Yet, there will be some clear cases that are analogous to the ones highlighted above where parents, disabled or not, may be crossing a moral boundary by implanting an embryo that is very unlikely to have an acceptable range of life opportunities.

Of course, this procedure relies on parents' ability to predict whether they and their community will be able to accommodate the disability of their future child so that they have acceptable opportunities for living life well and such predictions are likely to sometimes be mistaken. After all, both broad social context and individual family circumstances can change drastically over the course of a life and have a profound impact on what life opportunities will be available to a disabled person who may or may not have their disability sufficiently accommodated. However, this problem does not seem to be at all specific to reproductive decisions regarding disability. In some sense, any morally sensitive decision to become a parent relies on a prediction that the social and family circumstances you are bringing this future person into are ones that will offer them adequate opportunity to have a good life. Mistakes can be made regarding this judgment, regardless of whether disability is a contributing factor. This sort of uncertainty is an unavoidable, if somewhat alarming, feature of parenting.

Relatedly, there is a more serious concern that my proposed view contains a bias against the reproductive choices of parents who may *know* what accommodations their future child would need, but do not have the resources to provide those accommodations. Also considering

the fact that access to advanced reproductive technology like IVF and PGD is already tied to socioeconomic status—which is, in turn, correlated with structural racism, ableism, sexism, and other oppressions—my argument could be read as inevitably eugenic. This is because the only people that will be able to access this technology and then have the resources to meet the criteria of providing an acceptable range of life opportunities for their future children will be those with a degree of wealth and power.

Yet, it doesn't seem that this problem either is located in my procedure for thinking through how to ethically use PGD as much as it is with the deep inequalities that are present in our current society. That is, as with the problem predicting the availability of reasonable accommodations that I just addressed, this issue with *supplying* those reasonable accommodations is also not particular to disability. With or without my proposed procedure for thinking about the relationship between disability and opportunity, within our current social structure, this technology will be available only to those above a certain threshold of economic and social power. Likewise, regardless of how we deliberate about the ethics of choosing children with PGD, without radical changes to the current distribution of social power, it will be harder for some parents to provide an acceptable range of life opportunities to their children than it will be for others, irrespective of the presence of a disability in their family. Thus, there are biases against the reproductive freedom of people at the margins of society, but they run much deeper than PGD and resolving them is well beyond the scope of this paper. Short of biting this bullet and eliminating the use of PGD entirely, I believe my procedure would be an improvement toward using the technology in a way that reduces rather than exacerbates existing inequalities in reproductive freedom, even if many remain.

#### ACCOUNTING FOR “LAISSEZ-FAIRE EUGENICS” AND THE DISABILITY CRITIQUE OF EMBRYO SELECTION

It should be clear that my position is not an endorsement of the sort of “laissez-faire eugenics” feared by David King in the article cited above. My argument does not endorse reproductive freedom only in as far as it would reduce the incidence of genetically transmitted disability, as King argues is the motivation and outcome of PGD programs (King 1999, 177). Clearly, in some cases, my position would even justify the permissibility of allowing prospective parents to deliberately produce a disabled child. So, it doesn't seem that the sorts of tight regulation of PGD that King promotes would be justifiably leveled against the expansion of PGD application this paper endorses.

Further, many disability studies scholars and disability rights activists strongly object to the unreflective use of prenatal diagnosis and selection, including PGD, because of the way in which it has the potential to express, reinforce, and encourage harmful social stigmas toward disabled people. At first blush, my position seems to be at odds with some of the most prominent of these arguments.

Most notably, Adrienne Asch developed her sophisticated critique of prenatal diagnosis and selection for more than twenty years. With David Wasserman, Asch argued that prenatal diagnosis and selection against disability are deeply morally troubling because they encourage the discriminatory practice of synecdoche, which is defined as “not the literary device, in which the part stands for the whole, but the characteristic response to a stigmatized trait, in which the part obscures or effaces the whole” (Asch and Wasserman 2005, 173). Asch and Wasserman argue that this cognitive process of synecdoche is at the core of common practices of unjustified discrimination in that every time a person is denied housing, employment, access to a public service, or participation in the political process merely because of a stigmatized characteristic like disability, race, ethnicity, gender, or sexual orientation, they have been judged as a whole based on a single, irrelevant characteristic. They maintain that selecting non-disabled embryos and fetuses with PGD or selective abortion relies on synecdoche and, hence, should be faced with the same sort of moral indignation as these other commonly condemned practices.

However much my position seems to have in common with Asch and Wasserman’s refutation of the idea that equality of opportunity is inevitably contingent on a narrow range of normal functioning, they go on to argue that deliberately selecting a disabled embryo with PGD would also be synecdochal and ought to be rejected. Using the example of a Deaf couple that desires to have a child like themselves, Asch and Wasserman claim “Selecting for deafness is just as synecdochal as selecting against it, in our view, because it assumes that intimacy and community can be achieved only through one shared characteristic” (195). On its face, this seems like a flawed argument because Asch and Wasserman’s definition of synecdoche requires that the trait being chosen against must be one that is *stigmatized*. They seem to highlight this distinction between synecdochal reasoning that is based on stigma and other sorts of preference based choice with an analogy to marriage, “We recognize some moral difference between a Jew who would date or marry only another Jew, and a Jew who would date or marry a white Christian but not a black of any faith; between those

who restrict themselves to ‘their own kind’ and those who exclude only certain other ‘kinds.’ . . . The former attitude may be insular or clannish, but it need not offend in the same way as the latter, because it need not convey disrespect” (186). Being hearing is not a widely stigmatized trait and so it may seem that a Deaf couple selecting a deaf embryo might be understood as “insular and clannish” rather than synecdochal in the strict sense. However, I am inclined to read Asch and Wasserman more charitably on this issue and suggest that selecting against hearing embryos *could* be based on synecdochal reasoning if Deaf parents are making their decision within the context of a Deaf culture that stigmatizes the trait of hearing within the boundaries of that culture. Admittedly, I do not know enough about Deaf culture to know if that could ever be the case, but it seems at least possible.

I do not think there is a way to make my position on PGD and reproductive freedom completely philosophically consistent with Asch and Wasserman’s critique. However, I do not think my arguments categorically reject the fundamental goals of their critique. Asch, Wasserman, and the vast majority of disability activists and scholars are not calling for some sort of legal ban on prenatal diagnosis and selective abortion/implantation. Rather, they are providing a moral analysis of the practice that is meant to “sensitize people to the moral problems of impairment screening” (211). I believe my arguments divorcing the concepts of species normal functioning and acceptable opportunity range and deploying the tool of reasonable accommodation when thinking about a future child’s life chances are very much in line with this goal. This is because my position challenges prospective parents and health care providers to think critically and with nuance about how impairment always exists within a specific social context when disability appears in a person’s lived experience. I hope it is clear that my position is not one that would embrace mechanical reproductive decision making grounded in unexamined stigma and stereotype.

In addition to being compatible with the stated social goals of Asch’s critique, I believe my position is very much congruent with the specific policy suggestions made by Asch and others in the disability community to reduce reproductive decision making grounded in social stigma and stereotype. Namely, Asch has repeatedly argued for changes in the practices of genetic counseling that would improve the quality and accuracy of information about disability delivered to potential mothers through the counseling process. Turning to the influence exerted on reproductive decisions by the ironically named nondirective counseling, Asch and

Geller argued as early as 1996 that “the most important problems with the communication of genetic information stem from the content of the material and the style of disclosure, especially when the material conveys traditional biases about disability, focuses simply on medical characteristics and probabilities, and includes woefully little about the lives of people with the disabilities for which tests are available” (Asch and Geller 1996, 341). The idea is that synecdochal reproductive decision making based on stigma-laden stereotype can be reduced by providing parents with a richer account of life with a disability than what is available in popular stereotypes and medicine’s physiological descriptions.

Specific policies have been developed to achieve this end. The Prenatally and Post-natally Diagnosed Conditions Awareness Act, more widely known as the Kennedy–Brownback Bill for its two original co-sponsors in the U.S. Senate, was passed into United States law in 2008, for instance. The act was intended to reduce what Asch would call synecdochal decision making by improving the breadth and accuracy of information available to parents who are using prenatal diagnosis. Its key components were to: establish a hotline for new or prospective parents of children with genetic disabilities; collect and disseminate evidence-based information about genetic disabilities; expand networks for peer support, outreach, and information from and for parents of children with genetic disabilities; and establish disability awareness educational programs for genetic counselors and other healthcare providers who communicate with potential parents about prenatal diagnosis (Lehman 2008).

I see no reason why my position that justifies parental authority to choose a future child’s mode of function through PGD would be antagonistic toward the provisions of laws such as this. In fact, I would argue that all of components of the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008 would dovetail quite nicely with my suggestion that parents and medical providers should interpret the boundaries of an acceptable opportunity range for their future children by thinking through a given mode of function that has been accommodated reasonably. All of the policy mechanisms mentioned above could be used by parents and providers who are trying to learn more about the lived experience of a given disability and how it might have an impact on one’s opportunity range in different possible contexts and environments.

Thus far, I have argued that prospective parents have the authority to use PGD to select embryos according to their own conception of the good life, so long as that conception is compatible with an acceptable opportunity range for the resulting infant, taking into consideration the plausibility of reasonable accommodations. While my view embraces a broader range of parental choice than what would be encouraged by many disability rights advocates and scholars, it also stands in sharp contrast with enhancement enthusiasts like Julian Savulescu, who would morally *require* parents to use PGD and other technologies to choose what he takes to be the best embryos. By grounding my argument for parental authority to use PGD in an extension of widely accepted arguments for parental surrogate decision making, I maintain that parents have a broad authority to not only choose how to use PGD, but whether to use it at all. Savulescu, on the other hand, has grounded his stance on a principle of *procreative beneficence* that morally requires parents to choose the best possible embryo via PGD (2001, 415). In some sense, my position broadens the scope of parental reproductive freedom while Savulescu narrows it.

Savulescu's principle of procreative beneficence seems simple enough on its face. It argues that a rational morality requires: "couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on relevant, available information" (2001, 415). The upshot of this principle is that if there are no competing reasons that trump it, prospective parents are morally required to use PGD and other prenatal diagnostic technologies to choose children with the best genetic characteristics (415).

I reject the principle of procreative beneficence that drives this idea that parents are morally required to use PGD to choose their future children. This is simply because, unlike Savulescu, I do not support the idea that there is a rational, objective standard of what sorts of traits we should think of as "best." My position is appropriately characterized as permitting parents to make reproductive choices based on a broadly pluralist conception of the good life that can even include disability as contributing to a future child's well-being. I would argue Savulescu's pluralism is strikingly more narrow.

To be sure, one might try to charitably read his principle of procreative beneficence as compatible with a range of judgments on a parent's part about what constitutes "the best life." He could simply be arguing that a

parent has a moral obligation to choose the embryo that they believe will have the best life according to whatever conception of the good life they ascribe to. In fact, he says as much, arguing that his view of the best life is compatible with the values of a liberal democracy that allows “people to form and act on their own conception of the good life” because it is arguing only that parents are *required* to select traits that provide “general purpose means, i.e. those useful to any plan of life” (420) if they are to exhibit procreative beneficence.

However, this is undoubtedly mistaken because Savulescu is not recognizing how very narrowly he has defined “general purpose means” that are supposedly useful to any life plan, immediately expounding upon his view with examples of disability: “Examples of general purpose means are the ability to hear and see” (420). Savulescu is even more explicit in his commitment to eliminating disability from any rational conception of the good life as he makes his case for the principle of procreative beneficence and takes selecting against embryos with “disease genes” to be the simple case that everyone ought to agree is rational if they are seeking the best embryos. Of course, my position would grant parents a much broader authority to select embryos they would determine to be best based on their own conception of the good life, even, in some cases, if that embryo would be considered disabled with “disease genes.”

Ultimately, for Savulescu and others that share his type of enthusiasm for PGD, it would be almost unthinkable that future children with disabilities would be selected *for the benefit of the future child herself*. To be clear, I am not merely arguing parents have the authority to select an embryo that does not have the greatest probability of living a good life as a matter of convenience for themselves, as Savulescu would sometimes allow (424). In my example of the couple with achondroplasia, they are not choosing to implant an embryo with achondroplasia just “because their house is set up for dwarfs” (424) and it would be easier for them, but because they believe having achondroplasia will, on balance, improve that future child’s well-being.

In summary, I argue that choices like that of this couple with achondroplasia are made according to the parents’ particular conception of the good life and fall within the boundaries of their authority if the resulting child’s opportunity range falls within my reshaped boundaries of acceptable. However, parents ought not to make simplistic choices based on stigma and do not have any sort of moral obligation to make any such choice at all.

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## NOTES

1. Of course, the metaphysics of disability is itself notoriously contested and this is not a quagmire I want to enter with this paper. Thus, I am hoping my procedural approach to drawing a line for acceptable opportunity range will be satisfying for those that hold a variety of positions regarding what a disability *is*. For my part, I am clearly assuming that the disadvantages of disabilities are socially mediated and not always inevitable as a matter of biological dysfunction. Yet, for the purposes of this paper, I will remain agnostic about what counts as a disability and the degree to which disabilities are socially constructed.
2. In the context of PGD, the term "parent" is a somewhat vague expression because it can refer to genetic parents, gestational parents, or parents that will be responsible for raising the child. In this paper, I am using the term parent to refer to a person that will raise the child, regardless of whether they are genetically related or carried the pregnancy.
3. This consensus regarding parental authority seems to exist for a wide range of cases that involve offspring who are not competent to make their own medical and other complex life decisions, including: children who are not yet competent because of their young age, but who will likely become competent at some future time; children who are not yet competent, but who are unlikely to ever become competent because of congenital or acquired intellectual disability; adult offspring who never were competent and will not become competent because of congenital or acquired intellectual disability; and adult offspring who were once competent but are no longer because of acquired intellectual disability. Given that this paper is focused on making reproductive decisions that will affect the lives of children that do not yet exist, I am primarily concerned with the philosophical foundations of the first case of parental authority, in which a parent makes decisions for a child who is not yet competent, but who will likely become competent to make her own decisions as she matures.
4. It is important to note that Buchanan and Brock argue that these forward-looking interests are *conditional* in that a potential person "has them only

on the assumption that he or she is likely to survive to the point in the future at which they will either be thwarted or could have been satisfied” (163). That is, these interests cannot be used as justification for a right to life for a potential person because they are conditional on survival and not the other way around.

5. I think this view is distinct from what I take to be the claim that a parent can promote the well-being of “their” child (rather than any child), even if there is no particular child that yet exists to benefit from a reproductive choice. Janet Malek attempts to defend this claim by deploying the concept of narrative identity with her article “Identity, Harm, and the Ethics of Reproductive Technology” (2006). Jeffrey Reiman comes to a similar conclusion using the conceptual tools of Rawls’s original position in “Being Fair to Future People” (2007).
6. Perhaps, one might even claim an expert like a pediatrician or a developmental psychologist would be more able to accurately predict what a potential child will need because they have a broad, sophisticated knowledge of what children need as a type.
7. To be sure, life opportunity is itself related to the concept of well-being, and thus the concept of harm. After all, well-being is an important, if not the only object a person should have the opportunity to pursue throughout their life course. However, I think framing the argument in terms of life opportunity rather than harm allows for greater flexibility when thinking about what we owe future people, as I hope becomes more apparent as my argument unfolds.
8. A parallel analysis might be developed that was grounded in Amartya Sen or Martha Nussbaum’s capabilities approach to human well-being, so long as it was contextual enough to account for the ways in which the capabilities of disabled people are limited by factors other than the physiological features of their bodies. I chose to pursue an argument deploying the concept of opportunity because I thought it offered a clearer path to a procedure that could be used to morally evaluate the range of contexts in which a parent might be making reproductive choices. For a similarly contextualized version of the capabilities approach that may also be useful for thinking about reproductive ethics, see: Nussbaum (2007).
9. This is sometimes referred to in the literature and in this essay as *species typical functioning*.
10. I doubt this very much and so does Ronald Amundson, as he challenges the Boorseian view of normal function both in the chapter cited here (2005) and in his article “Against Normal Function” (2000). However, he grants the definition of normal function for the sake of argument at this point in this chapter in order to show how it is being misapplied by Daniels.

11. I chose these particular, high profile examples to highlight how, via natural talent, personal inclination, and accommodation, a disabled individual can be wildly successful at pursuing and gaining important life opportunities in general without having a right to any particular accommodation that would mitigate a particular disadvantage if such an accommodation were unreasonable.
12. How much cost any particular entity can absorb is going to be different in every case, of course.
13. It is worth noting that, while I am borrowing this concept of reasonable accommodation from the ADA, my use is quite distinct from how it is used legally. In the ADA, the notion of reasonable accommodation is deeply prescriptive, meaning that employers and others are obligated to reasonably accommodate a disability and failing to do so constitute a form of discrimination. In contrast, my use of the concept is descriptive in that it is a mechanism parents might use for thinking about a future person's life possibilities in the social context where they will live, not necessarily a moral imperative for parents to reasonably accommodate the disability of a future child.
14. For variations on this sort of argument, see: Feinberg (1992); Davis (1997); Schmidt (2007).
15. For example, like Stephen Hawking, a dwarf could never be the starting center for the Pistons.
16. To be sure, it won't be the case that parents that have a particular disability they are considering passing on will have infallible judgment about whether that life offers an acceptable range of opportunities. However, it seems that, when evaluating a highly stigmatized identity, knowledge generated by lived experience is less likely to be biased by such stigma than otherwise might be the case. For a more complete defense of this claim, please see Amundson (2005, especially pages 110–13).

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