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Prenatal Whole Genome Sequencing: An Argument for Professional Self-Regulation

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The prospect of sequencing a fetus's whole genome raises a number of fraught ethical concerns. Critics worry that new genetic techniques will enable parents to select particular traits in their children, undermining unconditional parental love (Sandel 2007) and causing parents to be less accepting of flaws in their children (Asch and Wasserman 2014). Furthermore, as parents are able to learn more and different kinds of information about their fetuses, will that information be useful for reproductive decision making, or will it cause unnecessary anxiety? Before more expansive prenatal testing becomes widely available, we must carefully consider how to guide its implementation (Donley, Hull, and Berkman 2012).

In spite of the many concerns that have been raised about the prospect of prenatal whole genome sequencing (PWGS), Chen and Wasserman (2017) argue against the idea that prenatal testing should be restricted to some set of "'serious' or 'severe ' disabilities or health conditions" (28). Their argument for unrestricted access to information is intuitively appealing, and as we discuss in the following, we agree that state-imposed limitations would be inappropriate. However, we question the Chen/Wasserman assertion that it would also be inappropriate for professional societies to issue guidance about the kinds of prenatal genetic results that should be available to parents.

In our commentary, we distinguish between different types of regulation. Chen and Wasserman assert that both governmental and nongovernmental regulation would be equally problematic, but we believe they are wrong to equate professional society recommendations with public policy. While it is likely true that many people would simply follow their doctor's advice, there are important differences between professional guidance and the use of state power. Most significantly, government power is coercive and compulsory, whereas professional guidance does not actually restrict parents' ability to make autonomous choices. An analysis of the appropriate scope of control over PWGS should therefore treat these two regulatory methods separately.

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WHY LESS IS MORE

Unlike Chen and Wasserman, we believe that there are good reasons to promote access to certain kinds of information and to limit access to other kinds of information. First, as Chen and Wasserman concede, there is a concern about parents' ability to absorb and process the massive amount of information that could be produced by PWGS. They argue that even though unrestricted access would increase anxiety and confusion, a restricted policy would be so complicated that any marginal increase in confusion seen under their proposal would be inconsequential. We disagree. An informed consent paradigm of the complexity that they envision would require intellectual engagement at a level that we do not require for other medical decisions. Even if conditions were grouped into categories, to facilitate the kind of elaborate deliberation they propose would require describing and distinguishing a daunting matrix of categories that triangulates information about type of condition, degree of clinical severity, and relative risk level. They acknowledge that this will be a difficult task, conceding that parents should be given access to a default option if the task is too intellectually or emotionally onerous. In our view, this is backward; since most parents will not want to engage at the level the Chen/Wasserman proposal requires, prospective parents should initially be presented with a default option that has been promulgated by the relevant professional societies. The small set of parents who wish to engage in a more deliberate decision-making process can subsequently choose to do so.

Second, we have concerns about the undue commercial pressure that prospective parents will feel to receive the maximum available set of information. The history of prenatal genetic testing has been characterized by a consistent push toward learning more fetal genetic information. Genetic testing companies have sought to frame prenatal genetic testing as a necessary means of protecting your unborn child, and they will have a strong commercial interest in further expanding their market once PWGS is clinically available (Regalado 2013). Moreover, given the well-documented dearth of genetic counselors, there is reason for concern that doctors will have to rely on genetic counseling services provided by the genetic testing companies themselves (Pollack 2012). This could lead to unavoidable conflicts of interest, resulting in additional pressure for parents to accept unprecedented amounts of information about their fetuses. A clear statement from professional societies about a recommended default set of genetic information would serve as a much-needed counterweight to the anticipated commercial pressure toward more information.

Finally, Chen and Wasserman admit that massive amounts of genetic information could have the "potential to increase anxiety, foster confusion, and complicate decision making" (5). While the target article dismisses this issue, we remain concerned about the effect that a radically increased amount of information could have on the reproductive decision-making processes of prospective parents. Reproductive autonomy is an essential value to uphold, but the immediate challenge of processing large amounts of complex genomic data could cause some parents to make decisions that are ultimately inconsistent with their values and preferences. For example, the affective forecasting literature demonstrates that people are often unable to accurately predict how they will feel in the future about receiving genetic risk information. People routinely overestimate the magnitude and duration of their negative response, when in fact negative responses are generally mild and transient (Peters et al.

2014). More research is needed to learn how difficulty with predicting future emotions might impact decision making in the context of PWGS, but it seems plausible that expansive prenatal genetic testing could cause parents to make decisions that they later come to regret.

GOVERNMENT REGULATION IS INAPPROPRIATE

Though we believe that there should be some default limitations on the kinds of fetal genetic information that is offered to parents, we agree with Chen and Wasserman that it would be inappropriate for government regulators to establish and implement these boundaries. There are a number of arguments that can be made against government intervention in this sphere, but we wish to briefly focus on the fact that the government does not have a sufficiently compelling state interest to justify this kind of regulatory intervention. There are a number of plausible state interests that could be relevant (Fox 2015), but on our analysis, none of them prove to be convincing.

The first plausible state interest would be in preventing harmful, population-level effects caused by the impact of reproductive decision making following PWGS. However, unlike sex-selective abortions in certain countries, which have resulted in significant gender imbalances, PWGS seems unlikely to lead to population-level effects. Given the range of possible conditions and the low incidence of the kinds of harmful conditions for which most parents might consider terminating, it is doubtful that reproductive decisions following PWGS would cause population-level shifts. A second state interest might be in limiting the negative impact that PWGS could have on social mores, such as the parent–child relationship. The direct effect of PWGS on social norms is unlikely to be demonstrably severe, though, and courts may be skeptical about this kind of state intrusion into how children are raised. A third state interest could be in protecting the life of the fetus, but this interest has been extensively litigated. If a woman can terminate a healthy fetus before a certain stage for any reason, it is likely unconstitutional for the state to limit reproductive choices on the basis of genetic information. In fact, an Indiana abortion law proposing to do just that was recently struck down (Smith and Eckhom 2016). Finally, a state might argue that aborting affected fetuses amounts to disability discrimination, but it is unlikely that this argument will be successful; terminating the pregnancy of a fetus that will have a disability is not the same as discriminating against an existing disabled person (de Jong and de Wert 2015). While courts will inevitably be called upon to adjudicate the constitutionality of additional laws designed to limit reproductive decisions on the basis of genetic information, we believe that proponents of this kind of regulation will be hard pressed to present a sufficiently compelling state interest.

PROFESSIONAL SOCIETY GUIDANCE IS THE SOLUTION

With clinical adoption of PWGS on the horizon, we need to think prospectively about what kinds of information parents should routinely be able to access. Although government intervention would be inappropriate, unrestricted access to fetal genetic information could also be problematic for the reasons already discussed. Ultimately, our view is that access to fetal genetic information should not be prohibited, but rather that self-regulation by professional societies should be employed to guide the use of PWGS. Medical professionals

are well situated to advise parents, and their recommendations are ultimately nonbinding, preserving ample room for parental autonomy. We envision a paradigm in which a limited set of highvalue information is offered as a default part of standard care, allowing parents to seek additional information either after discussion with their prenatal care team or through commercial services. Additional work must be carried out to determine which findings are most relevant for reproductive decision making and should be included in the default offer. Although we disagree with the conclusions drawn by Chen and Wasserman, we appreciate that their target article is helping to move this important conversation forward.

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