

# An Adoptive Parental Perspective on Personal Genomic Screening

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Parenthood changes one's perspective and focus. Myriad things that previously seemed benign, such as escalators, shopping carts, and even forks, now represent imminent danger. Like biological parent-child relationships, adoptive parent-child relationships come in many forms, sometimes good and sometimes bad. I am lucky: My bond with my daughter is strong. I see her light up when I enter the room, and I feel myself light up over something as simple as someone turning the conversation to how she is doing. My world now revolves around her. The focus of my life has become her happiness and well-being and protecting her from harm and sadness. I want to shape the world in her favor: Where I perceive her to lack something that might benefit her, the urge to fill that gap for her benefit is among the strongest influences I have ever felt.

One gap that is constantly present for many adoptive parents (especially for parents of children, like my daughter, who are adopted internationally) is the inability to provide sophisticated genetic heritage information. In my own experience, we were provided with little more than a photograph, and a vague statement that the child appears healthy, as the "medical" portion of our information packet (the rest of the packet focused on personality, temperament, and behavioral traits). We were told that she received basic vaccinations, but lack of verifiable documentation and concerns about reliability resulted in pediatricians in the United States providing vaccinations as if she had not received them before. We are unaware of any newborn screening as might be done in the United States, nor do we believe such screening occurred. Indeed, we have no information about illnesses that run in her biological family from either side. I can relate, then, to the emotions behind adoptive parents' advocacy of genetic testing as a way to fill a gap in their child's biological heritage, be it for information about medical conditions they may be prone to or for facts about where their child came from. Although the emotions underlying the desire to fill informational gaps are definitely not unique to adoptive parents, their manifestation in the potential uptake of genetic testing relates, at least for some adoptive parents (like me), to the circumstances of genetic unrelatedness.

I believe that many, if not most, adoptive parents are aware of the 23andMe genetic testing service. 23andMe has offered 2 distinct types of testing services: testing related to ancestry and a personal genomic

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screening service (PGS), formerly offered as a means to identify medical risk profiles. Ancestry testing is offered exclusively as a way to identify heritage information and possibly connect to other biological relatives. It carries with it little (if any) medical information and therefore is less controversial than PGS because it poses fewer potential harms and little sense of threat to a child's right to an "open future" (although it does raise some concerns about the adopted child's control over his or her "adoption journey," which I discuss later). However, the PGS service has become embroiled in controversy, being temporarily suspended because of a US Food and Drug Administration (FDA) order to discontinue the service until sufficient information is supplied for FDA review, although 23andMe has indicated a "firm commitment" to resolve this controversy and once again offer the PGS service.<sup>1,2</sup> Both the continued availability of PGS in other countries and 23andMe's stated intention to offer this service in the United States again necessitate the availability of reasoned, unbiased information both for and against undergoing such testing.

Before the FDA controversy, there were a number of media testimonials from adoptive parents about the benefits of these emerging technologies for their adoptive children. Two, I am familiar with either explicitly or indirectly identify such testing as an adoptive parental obligation. For many adoptive parents, the costs of PGS testing (available for as little as \$99) are negligible and likely to be overshadowed by other costs associated with adopting through an agency. For other parents, the costs of testing might be challenging, but they may see testing as desirable because of its promised benefit or a perceived obligation, as described by testimonials. Because these tests have been and are likely to soon become available directly to the consumer, I worry how well-considered these

calls for testing are and how many hidden factors may miss the radar of even the most conscientious adoptive parents.

For example, a call from an adoptive father for adoptive parents to undergo direct-to-consumer genetic testing is illustrative: "I don't recommend waiting for your child to be old enough to choose to request a DNA kit. . . . It's our job as parents to lead the way, to get comfortable with the facts, and to have answers ready for them."<sup>3</sup> But the more telling story is one that I believe illustrates the emotional pull of perceiving "an obligation" to provide this information: science writer Elizabeth Murphy's description of her and her husband's use of genetic testing for their 5-year-old adopted daughter.<sup>4</sup> Beginning with a discussion of the awkwardness of having so little information with which to answer their daughter's heritage-related questions, Murphy refers to advocates of genetic testing, such as the aforementioned adoptive father, despite recognizing that testing is not an uncomplicated decision. She acknowledges that her husband did not want predictive genetic testing for himself, believing it would only "saddle him with a sense of helpless anxiety." Yet he agreed that they owed their daughter as much information about herself as they could find. Though anecdotal and not necessarily representative of adoptive parental attitudes, both cases speak to the potential for adoptive parents' evaluation of genetic testing being influenced by a sense of obligation tied to a recognized lack of information about their children's adoptive circumstances.

Again, I identify with the feelings of wanting to fill whatever perceived gap may exist in my own daughter's life and relate to the idea that this feels like an obligation to nurture. But I also worry that part of this sense of obligation is tied to my own insecurities in being unable to

provide to my daughter what nonadoptive parents can provide through the simple act of observation: a sense of genetic heritage. Yes, my daughter does ask questions, but she seems less concerned with the paucity of information I am able to provide than I am with my own inability to provide heritage-related information. Given the factual risks that accompany genetic testing, I do not believe my own insecurities should usurp my daughter's broader interests. Certainly I acknowledge there are times when consideration of parental interests and emotions is legitimate. I simply do not consider these present insecurities to be sufficient to justify the risks for my daughter at this time. Moreover, in my professional capacity I have come to appreciate that the value placed on control over one's life is complex, in some contexts actually increased by delayed information.

I am fortunate to work at an institution at the forefront of clinical sequencing, the first to use these technologies to successfully diagnose and treat a life-threatening condition in a pediatric patient. As a bioethicist, I was tapped early on to advise an oversight committee about the appropriate use of this emerging technology in a pediatric context. In this capacity, I became familiar with a litany of complex issues relating to future insurability (although the Genetic Information Nondiscrimination Act protects against genetic discrimination in some areas, it does not apply to others, such as life or long-term care insurance, nor to smaller companies or potential employers), the uncertain significance of many results, the indeterminacy of disease manifestation even where gene-disease associations are identifiable, and, perhaps most relevant here, the question of a child's right to an open future. This latter concern in particular has led the American Academy of Pediatrics, the American College of Medical Genetics

and Genomics, and the American Society for Human Genetics to recommend that genetic testing not be performed on children absent some identifiable medical need.<sup>5-7</sup> Instead, these bodies recommend that, absent medical indications, genetic testing be delayed until a child is old enough to decide for herself or himself when to receive information, and of what type. More recent recommendations have opened the door to a greater role for parental interests to factor into decision making, but even this recommendation is limited and meant to apply only in cases such as that of “debilitating anxiety.”

These recommendations run counter to the calls for genetic testing as an obligation of adoptive parents, as described earlier. The question that arises is this: Do the special circumstances of adopted children create a different context for judging the desirability of genetic testing? Studies have shown that adopted children, as a population, tend to experience more health problems than nonadopted children as a population.<sup>8,9</sup> Given recent emphases by respected medical bodies such as the US Centers for Disease Control and Prevention on the importance of family medical history, one might argue that because adopted children often lack access to reliable family medical history, the balance of benefits and risks is different. Certainly, the American Academy of Pediatrics has taken a position to the contrary, explicitly recommending that genetic testing for adopted children be approached in the same way as it is for nonadopted children.<sup>6</sup> But several working groups issuing these and related recommendations have cited a dearth of empirical information on the lived experiences of benefits and harms from this very new technology.<sup>10</sup>

Knowing these facts and circumstances (and motivated by my relationship with my daughter), our

team secured funding to conduct a series of focus groups investigating the attitudes and concerns of adoptees toward clinical sequencing (data from these focus groups are being analyzed). Although all involved in these focus groups were adults, many of the statements were profoundly influential on my own thinking, both as a researcher and as an adoptive parent, about the appropriateness of clinical sequencing for adopted children. For example, 1 person expressed concern that adoptive parents would “take over” what she described as the “adoption journey,” a phrase used to describe an adopted person’s lived experience of being adopted. Traditionally, the decision of when and whether to pursue birth family and heritage information is one of the few aspects of being adopted that is directly under the adopted person’s control. Another expressed interest in sequencing for the purpose of disease risk profiling, but again in terms of control, making a reunion with biological relatives optional rather than necessary if she wanted to gain genetic medical history information.

For my own part, I worry about the role that genetic testing might eventually come to play in the adoption process. Although assignment of parents to a specific child is a somewhat random pairing of parents and attributes, adoptive parents are routinely given a right of refusal based on medical information. It is true that nonadoptive parents are also able to exercise a degree of this right prenatally (eg, based on an amniocentesis) and even through the emerging ability to select for traits from among embryos. However, neither of these processes threatens direct harm to an already born child in the way that genetic screening of potential adoptive children could stigmatize and make “unadoptable” children with undesirable health dispositions. This possibility is especially problematic given the very

indeterminate nature of most disease-gene risk associations.

Geneticists I am familiar with would be appalled by the idea that genetic testing would be used to disadvantage a child. At the same time, we seldom can control how technologies are used or not used once they are made available. The same is true of information, even when laws are put in place to protect against misuse of that information. For example, the Genetic Information Nondiscrimination Act places the burden on the person wronged to demonstrate misuse of genetic information. Perhaps my identification with the role of protector usurps my sense of nurturer, but I worry about subjecting my daughter to risks for reasons that may reflect more my own sense of wanting to provide what I cannot: genetic heritage information. The irony is that, given the strong emotional pull of these insecurities, I am less comfortable with genetic testing on my daughter than I would be for some other parents, because of the strong emotional pull of insecurities related to my inability to provide heritage information. I worry that rational decision making might be usurped.

For these reasons, and our team’s focus group research with adoptees, I believe that genetic testing of adopted children for purposes of disease risk profiling should proceed with deliberate caution. I strongly believe that genomic sequencing offers tremendous promise of benefit to adults who were adopted as children, in the context of disease risk profiling, and for other genetic heritage purposes. However, children present different contexts. Each parent will need to assess in the context of his or her own child’s circumstances the balance of risks and benefits. In making this assessment, it is imperative that adoptive parents not neglect risks in focusing on the information gap surrounding genetic

heritage. Unfortunately, little information is known about actual experiences of harm and benefits from genomic sequencing performed for the purposes described herein. Studies of actual experiences in this regard are vital.

For my own circumstances, until much more is known about risks and benefits, the decision of when to seek this information, and exactly what types of information should be sought, seems best left for when my adopted daughter is able to fully participate in the assessment of desirability and drawbacks. In the meantime, far more research is needed into the benefits that emerging genomic technologies might offer to adoptees and the potential drawbacks that might be experienced by this specific population.

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