

ADOPTION ADVOCATE

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Advocating for Adoption in Personal Genetics Testing

BY KIT MITCHELL

In 2003, the completion of the Human Genome Project opened the way for a large-scale private sector investment in genetic technologies.¹ As synthesizing genes became less costly, companies like 23andMe, Ancestry, and others, were able to market home testing kits to the general public. Anyone can spit into a tube, send it off to the company, and receive a personalized report in less than a month. Companies that perform genetic testing for a nominal fee outside of a medical facility are referred to as direct-to-consumer companies, or DTC companies. DTC companies offer the chance to find out ancestral roots, disease risks for a variety of conditions from serious to commonplace, and—perhaps most significantly in the world of adoption—the option to connect with extended family members.

As DTC testing has grown commercially and become more socially widespread, it is not surprising that adopted individuals and birth families have begun to use these services. In the last two years, social workers have reported seeing a dramatic increase in the number of adopted individuals and birth parents who report using DTC testing to find members of their birth family. While using DTC technologies instead of traditional search and reunion procedures is typically less expensive, more personally driven, and more in tune with younger adult adoptees' strategies for independently seeking information, DTC genetic testing has significant

¹ All About the Human Genome Project [Web]. Retrieved from <https://www.genome.gov/10001772/all-about-the--human-genome-project-hgp/>



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implications for the adoption community. These implications can be sorted largely into two categories: understanding and contextualizing the information in a report, and search and reunion efforts. These categories disproportionately impact the adoption community. Therefore, it is imperative that both those who were adopted and their adoptive families, birth families, and agencies are informed about such issues and able to react appropriately.

There are clear benefits and concerns that result from adopted individuals accessing DTC genetic testing services. This article lays out the potential concerns regarding information about medical conditions or health risks; then it considers the concerns around using genetic testing for search and reunion, the potential implications of this at present and in the future, and what adoption advocates can consider doing to support those who were adopted in using genetic testing services.

Medical Implications for Adopted Persons Seeking Genetic Testing

Prior to genetic testing options, people who were adopted had less direct access to family medical history information. In confidential infant adoptions, adoptees might have a birth family's medical history if the birth parent had disclosed anything in the file created at the time the child was placed for adoption. Conversely, they may have very little information available to them. In open adoptions, they might have information that is more updated or a relationship where they may ask the birth family, depending on how open the relationship is. Still, they typically lack the close relationships that allow them to know nuanced information about the details of their medical history or that of their biological family in the same way a more direct relationship might allow. For internationally adopted individuals information varies, but is often very limited. Even for those adopted from U.S. foster care, the information they have may be out of date, inaccurate, or incomplete. It can vary significantly depending on the age of the child at removal and the level of continuity of relationships with the biological family.

It is crucial to note that DTC genetic testing is *not* a medical process. Genetic testing done in a medical setting usually involves sequencing a specific part of a person's genome multiple times to confirm that there are no errors. DTC genetic testing sequences certain specific points on the entire genome about half as many times as a medical genetic test. Medical-grade testing is much more expensive at sticker price than DTC testing, which usually costs somewhere between \$100 and \$400. DTC companies offer a summary of the full genome, rather like a book report, whereas medical genetic testing offers a more in-depth analysis. Some companies

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have marketed disease-risk analyses in the past, but more recently the Food and Drug Administration (FDA) has intervened and halted tests because they were out of compliance with federal regulations regarding medical laboratories. This is a rapidly changing area of biotechnology; however, in May of this year, the FDA re-authorized 23andMe, one of the largest DTC genetic testing companies in the U.S., to offer several of their disease-related tests. More re-authorizations will likely follow.

These DTC disease-related tests frequently offer an assessment of the consumer's risk of developing a certain disease. A common example is the BRCA1 and BRCA2 genes, which are linked to breast and ovarian cancer. Carrying the gene increases the lifetime risk of developing breast cancer to between 45 and 65 percent.² Environmental and other genetic factors may decrease a person's risk, but because DTC companies are not physicians, they are not licensed to provide information about what to *do* with this new knowledge and how it affects one's chance of developing breast cancer. For individuals who have been adopted, this becomes particularly challenging when placed alongside a potential dearth of family medical history. In less strongly linked genetic diseases, such as diabetes or heart conditions, a risk percentage without the context of family history seems to carry more meaning than it should, and it is clear that family history cannot be replaced through genetic analysis alone.^{3, 4}

DTC companies often have significant disparities in the population makeup of their customer bases. Data from some of the largest companies in the U.S. indicate that a majority of customers have self-reported their race/ethnicity as white.⁵ Companies do not share their customer databases between one another, but the results they provide customers with are based in part on the aggregated data of previous customers' profiles. Thus, customers who self-report as white will receive a profile based on a larger pool of customers than a customer who self-reports their ethnicity as Asian, for example. These proportional differences do impact the precision of results as a larger pool of data provides more precise results.⁶ While there have been companies in the past that specifically marketed to African-Americans, as well as other smaller companies with similar targeted interests, the aggregated data cannot be transferred to companies that possess most of the market share. For intercountry adoptees who

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² National Cancer Institute. BRCA1 and BRCA2: Cancer Risk and Genetic Testing. Retrieved from <https://www.cancer.gov/about-cancer/causes-prevention/genetics/brca-fact-sheet>

³ Ashley, E. A., Butte, A. J., et. al. (2010) Clinical Assessment Incorporating a Personal Genome *The Lancet*, 375(9725), 1525-1535.

⁴ Guttmacher, A. E., (2004) The Family History – More Important than Ever, *The New England Journal of Medicine*, 351, 2333.

⁵ Wagner, J. K., (2010), Interpreting the Implications of DNA Ancestry Tests, *Perspectives in Biology and Medicine*, 53(2), 231-248.

⁶ Rapp, R. (2013), Commentary: Thinking Through Public Health Genomics *Medical Anthropology Quarterly*, 27(4), 573-576.

were adopted from countries outside of Eastern Europe, or domestically adopted people of color, a genetic profile from DTC companies may be affected by this customer disparity.⁷ Diversity in customers and in the data they contribute matters as studies continue to indicate that social, environmental, and genetic causes are responsible for major public health concerns such as asthma, and DTC companies contribute research findings to the wider scholarly community.⁸

These concerns do not and should not discredit a customer profile, but they are worth taking into account when adoptees, agencies, and advocacy groups are discussing genetic testing in adoption. Particularly because the issues surrounding risk assessment and family health history are so specific to the adoptive context, it is important that adoptees and adoption professionals are aware of both the positive and negative technical aspects of commercial genetic testing.

Search and Reunion

After learning she was adopted at age 42, Khrys Vaughn began searching for birth family members. Finding herself unable to access her closed adoption records, Mrs. Vaughn decided to try genetic testing services. Within minutes of receiving her results, she had found connections not only to her ancestry in North Africa, Eastern Europe, and France, but to potential members of her extended family. After exchanging a series of emails, she met with a third cousin, and discovered she had four sisters. Mrs. Vaughn was welcomed into her extended birth family, and attributes her reunion to helping her to find her place in the world.⁹

This story isn't uncommon. Many adopted persons also choose to access DTC testing services to look for birth family members. Birth families and birth siblings may also seek out contact through DTC services, but the vast majority of individuals who are adopted and use DTC testing do so to search for information about their birth family. Genetic testing as a method to find birth relatives has skyrocketed in the last two years. Social shifts, word of mouth, and company marketing programs have made it an alternative (or an addition) to traditional search and reunion procedures, but genetic testing offers a new set of risks as well.

One of the benefits of using genetic testing technologies is the opportunity to expand a search for identifying information beyond the borders of the U.S. In countries such as China, where intercountry adoption is frequent

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⁷ Rapp, R. (2013)

⁸ Konkel, L. (2015), Racial and Ethnic Disparities in Research Studies, *Environmental Health Perspectives* 123(12), A298-A302.

⁹ Swarns, R. L. (2012), With DNA Testing, Suddenly They Are Family, *The New York Times*, web. 24 January 2012, Accessed 23 August 2017.

but information about birth parents is sparse, genetic testing offers a new route for search and reunion that was not possible before. Given the improved affordability and access to genetic testing in countries from which children may be adopted by U.S. parents, the opportunity to reconnect with birth parents half a world away increases with each new customer.

The reasons for conducting search and reunion efforts through genetic testing are as numerous and varied as the people who choose this path. Adopted individuals may choose to use genetic testing to find birth relatives, for easier access to information, to start the process independently and without needing a court order or state permission, lower associated costs, or closed adoption agencies. Individuals who are adopted and birth parents may search for each other outside of an adoption system because they may feel disenfranchised by the system and wish to have more control over the search process. It is also possible to find extended family members or members of the birth father's family using DTC testing. Unlike many states, DTC companies do not require a court order to provide identifying information about the birth family. Finally, while a search and reunion process through a social worker or adoption agency may take many weeks or months, genetic testing may offer a shorter turnaround time.

There are some concerns that come with using genetic testing for search and reunion purposes. First and foremost, using DTC genetic testing to search for birth family members may create privacy issues for people who do not wish to be 'found'. Most companies will offer connections with other customers as genetically distant as potential fourth or sixth cousins, meaning that those seeking to connect with birth family will often find cousins even if their immediate family is not in the company's database. Unlike traditional (indirect) search and reunion, where a social worker reaches out to the party wishing to be contacted and determines whether they are interested, first contact in these 'direct' reunions is not always with the birth parent or sibling, but may be with a cousin or more distant relative—as it was in the case of Mrs. Vaughan. In this case, many individuals will explain that they are adopted and looking to connect with their birth family. They may have non-identifying information they can provide a relative with to help determine the identity of a birth parent. While this process of connecting with a cousin or other family member is understandably empowering for adopted persons, it may inadvertently deny a birth parent the choice to inform extended family of a placement. Birth parents (or the person who was adopted in a reverse search) may feel their privacy was violated. Caught off guard and with no time to emotionally prepare for contact, birth families may at times respond

with less warmth than the adopted individual anticipated. However, many adopted individuals who reconnect with birth family through DTC testing, such as Mrs. Vaughan, have fulfilling and meaningful reunions.

Search for birth family through DTC companies often means that adopted persons undergoing the search and reunion process do so without the experience and aid of an adoption professional. While this may be preferable for some searchers—as previously discussed, many adoptees may feel empowered by searching through DTC or do not want to engage with a system they may feel disenfranchised them—some may ultimately feel they could have benefitted from more support from adoption (or adoption-aware) professionals during the process. In a direct reunion, social workers usually are not involved until a mental health or emotional crisis occurs and one party reaches out. At this point, a social worker must first help the individual (or group) reach a stable place before working to create a long-term reunion plan. Adoption professionals who work in search and reunion can utilize their experience gained through working on other reunions to help support individuals currently going through the process. They provide pre-search consultation and continuing services throughout the process to help individuals process emotions around connecting with birth family, in addition to their work as intermediaries for initial contact.

Advocating for Adoption-Aware Genetic Testing

Direct-to-consumer genetic testing offers the option to find out so much more about oneself and one's family through genetics. For persons who were adopted and who may not have much information about their birth family, their origins and heritage, or who seek to connect with their birth relatives, genetic testing through DTC companies offers a new and relatively inexpensive option. That said, there are potential issues that may arise when those who were adopted choose to seek DTC services:

- Uncertainty when comparing genetic risk assessments for diseases with a family medical history.
- A less diverse sample pool for non-white adoptees, in some cases.
- Contact with birth family members other than birth parents, which may result in emotional turmoil or previously unknown knowledge of the circumstances surrounding adoption.

Genetic testing companies could create more adoption-sensitive services by offering a screening question such as “are you adopted?” in their initial survey; and then presenting resources for individuals who were adopted and for birth parents, if the customer responds in the affirmative.

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Offering lists of free resources, including adoption professionals, support groups, websites with more information, and other accessible materials, would allow adopted persons to access resources typically made available during the search and reunion process through an adoption agency or professional.

In addition to working with DTC genetics companies to compile resource lists and offer this screening question, advocates can work to inform the adoption community about the concerns and benefits of DTC services. As technology becomes more accessible and more global, the use of DTC services is unlikely to decrease in the short term. By creating information campaigns designed to reach those who were adopted who choose to search without agency help, advocates are more likely to reach those who would benefit from knowing the risks, benefits, and resources.

It is also important to consider the impact of DTC genetic testing on birth parents and adoptive parents. The accessibility of genetic technologies significantly decreases the likelihood that a confidential adoption will remain so. While an agency may maintain records appropriately, in an age where information is shared around the world on social media, confidential adoptions become less likely. In the vast majority of cases, some level of openness in adoption is beneficial to all involved. As openness in adoption continues to increase, this issue of DTC genetics invading privacy will become less of a concern. Still, adoptive parents may need to be prepared to answer questions about their child's adoption earlier than they might have previously. Providing age-appropriate, honest answers is the best way for all involved. For particularly sensitive information, it may be valuable for adoptive parents to reach out to adoption professionals to get support on how to have these conversations. Likewise, birth parents should be aware that they may be contacted, regardless of their preferences. They should know what kinds of resources are available to them as well, from birth parent-specific groups online and in person, to reading materials and local counseling services.

Search and reunion processes independent of the adoption agency or other adoption professionals do not necessarily remain so. As discussed earlier, post-adoption professionals are contacted in independent search and reunions, but often only after contact between the adoptee and the birth family. It is important for agencies and adoption professionals to support adoptees and birth families at all points in the search process, regardless of whether they use "official" channels for reunion. Adoption professionals can—and do—provide opportunities for search-related counseling and assistance to all individuals involved in the process. It is vital that this work continue to be expanded upon in order to accommodate the growing

number of people choosing to seek birth family members through DTC genetic testing.

The opportunities to know more about oneself, one's history, and one's family through genetic testing are growing daily. It is undeniable that genetic testing and adoption will continue to intersect. In embracing this future, agencies, advocates, adoptive and birth families can increase awareness and access to relevant resources in order to preserve the health and wellbeing of every member of the search and reunion process. In doing so, we empower adopted individuals and families to make the decisions they feel are best for them, and create a model for adoption in the genetic age.

Recommendations

Advocacy! For any adoption advocates, professionals, policymakers, or those searching, you can advocate to ensure:

- DTC companies offer resources that are adoption-supportive and sensitive.
- Adopted people and birth parents know the risks and benefits of using DTC genetic testing.
- Quality resources exist to support all those who may be involved in a search process, including: adopted people, birth parents, adoptive parents, and adoption or mental health professionals who may provide support.

For adopted persons or birth parents considering DTC genetic testing:

- Educate yourself on DTC testing so that you understand the strengths and limitations of pursuing and interpreting DTC genetic results, and using the service for search and reunion.
- If possible, consult with a medical professional or licensed genetic counselor regarding results you have concerns about.
- Pursue support resources before search and reunion. Resources might include:
 - Speaking to an adoption professional for support.
 - Consulting with someone who has been through the search and reunion process.
 - Reading materials to educate yourself on search and reunion.
 - Discussing the impact of this process on you and others with a mental health professional.

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For adoption professionals:

- Educate yourself on DTC testing's strengths and weaknesses.
- Consider offering support services that can come alongside those using DTC testing and making your services known so that the process can be done with the sensitivity and expertise of a professional.
- Offer support to clients at any point in the independent search and reunion process without judgement.
- Create resources that provide information on DTC testing and adoption and where to find further support.

ABOUT THE AUTHOR

Kit Mitchell is a senior at Wellesley College studying anthropology and biology, and is writing an undergraduate honors thesis focusing on intercountry adoption, genetics, and personal narratives of family history and origin. As a 2017 NCFA public policy and education intern, Kit was responsible for helping plan and prepare for the annual conference, and working to promote policy issues related to adoption and child welfare.



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