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The Effects of Forcible Separation and the Ramifications Involved in Using Genetic Testing to Reunite Immigrants at the Border

*Thameshwarie Ghamandi**

I. INTRODUCTION

One-year-old Mateo and father, Jose Fuentes, arrived at the United States border following a month-plus journey from El Salvador.¹ The asylum seekers were fleeing gang violence and extortion.² With a weak and dehydrated Mateo, Jose was happy to finally reach their destination.³ However, to his dismay, despite presenting officials with a genuine copy of his son's birth certificate, Mateo was forcibly removed from his father and shipped to an Office of Refugee Resettlement (ORR) more than 1500 miles away.⁴

The United States of America is a nation built by immigrants. Granted, protecting the borders of the United States is a top priority. However, this scenario of having one's child ripped away from their caregiver definitely raises many questions. The trauma involved in this forcible separation will leave scars not only on the adults but especially on the innocent children involved.

Part I of this article discusses the background events leading up to the passage of the "zero-tolerance" policy regarding illegal entry across the United States border. Part II of this article illustrates the potential psychological ramifications involved during a forcible separation of loved ones. Part III of this article addresses the current use of genetic testing and the laws that currently govern its use. Part IV of this article delves into the privacy and consent risks involved in utilizing genetic testing as a means of reuniting families separated due to the enforcement of the "zero-tolerance" policy. Part V

* J.D. Barry University School of Law (2019).

¹*Migrant Seeking Asylum Says His Toddler Was Taken Away At The U.S. Border*, PBS (Dec. 22, 2017), <https://www.pbs.org/newshour/show/migrant-seeking-asylum-says-his-toddler-was-taken-away-at-the-u-s-border>.

²*Id.*

³*Id.*

⁴*Id.*

discusses the potential solutions to decrease the risks associated with reuniting families at the border. Part VI is the conclusion of this article.

II. BACKGROUND

There has been an on-going problem of illegal entry into the United States. Previously, if families arriving at the border claimed a credible fear of returning home, they were permitted to enter and apply for asylum.⁵ In 1997, the court in *Flores v. Reno*, required the government to release children from immigration detention without unnecessary delay to parents, close relatives, or legal guardians.⁶ If the children could not be released, the government was required to hold them in the least restrictive setting available.⁷

In response to the on-going problem at the borders, on May 7, 2018, the Attorney General of the United States announced a “zero-tolerance” policy regarding illegal entry across the United States border.⁸ The policy states that all adults illegally entering the United States would face criminal prosecution and if a child accompanied the adult that the child would be separated from the detained parent and placed with relatives, foster parents, or shelters.⁹

As a result of the “zero-tolerance” policy, approximately 70 children per day were being sent to federal shelters as their parents were being prosecuted.¹⁰ In fact, within the first five weeks of the program, more than 2300 children were removed from their parents.¹¹ Parents were being transferred from the Border Patrol to the US Marshals Service and then were being tried in court for the misdemeanor of illegal entry or the felony charge of illegal re-

⁵Chris Cillizza, *The Remarkable History of the Family Separation Crisis*, CNN (June 18, 2018), <https://www.cnn.com/2018/06/18/politics/donald-trump-immigration-policies-q-and-a/index.html>

⁶*Reno v. Flores*, 507 U.S. 292 (1993).

⁷*Id.* at 297.

⁸*Attorney General Sessions Delivers Remarks Discussing the Immigration Enforcement Actions of the Trump Administration*, JUSTICE.GOV (May 7, 2018), <https://www.justice.gov/opa/speech/attorney-general-sessions-delivers-remarks-discussing-immigration-enforcement-actions>

⁹*Id.*

¹⁰John Burnett, *The Last “Zero Tolerance” Border Policy Didn’t Work*, NPR (June 19, 2018), <https://www.npr.org/2018/06/19/621578860/how-prior-zero-tolerance-policies-at-the-border-worked>.

¹¹*Id.*

entry.¹² Their children were subsequently being turned over to the Department of Health Human Services' Office of Refugee Resettlement.¹³ Although the federal care shelter can hold approximately 3,800 children, the conditions reported were unsettling. In addition, the children are supposed to spend as little time in these shelters as possible but the average length of stay in these shelters has increased from 34 days to 59 days.¹⁴

Despite the court-ordered reunification of July 26, 2018, approximately 350 out of the 2,654 children separated remained to be reunified with their families as of October 2018.¹⁵ Of those 350 children, 141 of them had their parents waive their rights to reunification or indicated they did not immediately intend to reunite with their children; most likely because they believed their children would have a better chance of an asylum claim if they stayed in the United States. In addition, in 29 of those cases the parents were found unfit for reunification because the U.S. Department of Homeland Security recognized "red flags" ranging from criminal histories to abuse allegations to pending DNA results.¹⁶ These 170 children were slated to remain in shelters indefinitely, especially since 41 relatives were deported after undergoing a background check and fingerprinting to sponsor their separated family member.¹⁷

The separated child's journey began at the Customs and Border Protection (CBP) facilities.¹⁸ These places were often depicted as "[i]nside an old warehouse in South Texas, [with] hundreds of children wait[ing] in a series of cages created by metal fencing. One cage had 20 children inside. Scattered about are bottles of water,

¹²Chris Cillizza, *The Remarkable History of the Family Separation Crisis*, CNN (June 18, 2018), <https://www.cnn.com/2018/06/18/politics/donald-trump-immigration-policies-q-and-a/index.html>

¹³*Id.*

¹⁴Hannah Wiley, *Hundreds of Migrant Kids Haven't Been Reunited With Their Parents. What's Taking So Long?*, TEXAS TRIBUNE (October 2018), <https://www.texastribune.org/2018/10/04/zero-tolerance-policy-reunite-separated-immigrant-families/>

¹⁵*Id.*

¹⁶Hannah Wiley, *Hundreds of Migrant Kids Haven't Been Reunited With Their Parents. What's Taking So Long?*, TEXAS TRIBUNE (October 2018), <https://www.texastribune.org/2018/10/04/zero-tolerance-policy-reunite-separated-immigrant-families/>

¹⁷*Id.*

¹⁸Camila Domonoske & Richard Gonzales, *What We Know: Family Separation and "Zero Tolerance" at the Border*, NPR (June 19, 2018), <https://www.npr.org/2018/06/19/621065383/what-we-know-family-separation-and-zero-tolerance-at-the-border>

bags of chips and large foil sheets intended to serve as blankets.” Children are only supposed to remain at the CBP center for a maximum of 3 days and then sent to the ORR, which is under the Department of Health and Human Services.¹⁹ Tender-aged children, less than five (5) years old, up to 17-year-old children were placed at those non-profit centers.²⁰ Temporary “tent camps” also popped up and were typically used for teenage minors.²¹

On June 26, 2018, a federal judge in California issued an order requiring federal officials to stop detaining parents and minor children separately and called for the reunification of all parents and minor children previously separated.²² The order called for children of tender ages, below five years old, to be reunited within fourteen days and for all other minors older than five years to be reunited within thirty days.²³ The ORR’s job includes reuniting unaccompanied minors with relatives already in the United States.²⁴

Despite the previous description of a child’s journey through the system, it has been discovered that there is actually no formal process or protocol for tracking the separated parent(s) and child(ren).²⁵ In addition, parents have been deported, against their will, without their children, making reunification much harder as they return to their homeland.²⁶

Typically, documents such as birth certificates are used to verify kinship claims.²⁷ However, in order to comply with the previously mentioned court order, DNA verification is also being used.²⁸ In late June, Jackie Speier (D-Calif.) asked the DNA

¹⁹*Id.*

²⁰*Id.*

²¹*Id.*

²²Laura Jarrett, *Federal Judge Orders Reunification of Parents, and Children, end to Most Family Separations at Border*, CNN (June 27, 2018), <https://www.cnn.com/2018/06/26/politics/federal-court-order-family-separations/index.html>

²³*Id.*

²⁴Chris Cillizza, *The Remarkable History of the Family Separation Crisis*, CNN (June 18, 2018), <https://www.cnn.com/2018/06/18/politics/donald-trump-immigration-policies-q-and-a/index.html>

²⁵Camila Domonoske & Richard Gonzales, *What We Know: Family Separation and “Zero Tolerance” at the Border*, NPR (June 19, 2018), <https://www.npr.org/2018/06/19/621065383/what-we-know-family-separation-and-zero-tolerance-at-the-border>

²⁶*Id.*

²⁷Kristen Brown, *DNA Tests on Separated Migrant Children Raise Privacy Issues* BLOOMBERG (July 5, 2018), <https://www.bloomberg.com/news/articles/2018-07-05/dna-tests-on-separated-migrant-children-raise-privacy-concerns>

²⁸*Id.*

company 23andMe to play a role in reuniting the separated parents and children.²⁹ However, rather than a detailed test, a standard paternity test was suggested to be sufficient.³⁰ In some cases, genetic testing (saliva swab) has been ordered by the government to confirm the identity of parent(s) and child(ren).³¹ Genetic information includes information about an individual's genetic test, genetic tests of an individual's family members, or family medical history including the "manifestation of a disease or disorder."³² The average cost of genetic testing can range from under \$100 to more than \$2000, depending on the nature and complexity of the test; a paternity test, which is the recommended test for reunification, will typically cost \$99,³³ with test results taking a few weeks to several months to receive.³⁴

III. BIOLOGICAL RESPONSES TO FORCED SEPARATION

Forcible separation of children from parents and caregivers can cause a cascade of biological responses.³⁵ Their heart rate increases; stress hormones are released, which can start destroying brain cells ultimately causing long-term damage to both the physical and psychological structure of the brain.³⁶ According to Charles Nelson, a pediatrics professor at Harvard Medical School, "the effect is

²⁹Karen Weintraub, *Genetic Testing to Reunite Immigrant Families Raises Issues of Privacy and Consent*, SCIENTIFICAMERICAN (June 26, 2018), <https://www.scientificamerican.com/article/genetic-testing-to-reunite-immigrant-families-raises-issues-of-privacy-and-consent/>

³⁰Karen Weintraub, *Genetic Testing to Reunite Immigrant Families Raises Issues of Privacy and Consent*, SCIENTIFICAMERICAN (June 26, 2018), <https://www.scientificamerican.com/article/genetic-testing-to-reunite-immigrant-families-raises-issues-of-privacy-and-consent/>

³¹*L. v. United States Immigration & Customs Enf't ("ICE")*, 310 F. Supp. 3d 1133 (2018).

³²220 OTHER TYPES OF RESTRICTED PERSONAL DATA, 2006 WL 2053654.

³³Genetics Home Reference, *What is the Cost of Genetic Testing, and How Long Does It Take To Get The Results*, NIH (Mar. 19, 2019), <https://ghr.nlm.nih.gov/primer/testing/costresults>

³⁴*Id.*

³⁵William Wan, *What Separation From Parents Does To Children: The Effect Is Catastrophic; Trump's Border Policy Could Cause Long-Term Damage to Children's Brains, Experts Warn* https://www.washingtonpost.com/national/health-science/what-separation-from-parents-does-to-children-the-effect-is-catastrophic/2018/06/18/c00c30ec-732c-11e8-805c-4b67019fcfe4_story.html?utm_term=.981c7273de6e

³⁶*Id.*

catastrophic.” Likewise, Chandra Ghosh Ippen, associate director and dissemination director of the Child Trauma Research Program at the University of California, San Francisco and the Earth Trauma Treatment Network, considers the zero-tolerance policy to be a “traumatic experience with long-term consequences.”³⁷

Adverse experiences, like forcible separation from parents, can have long-term negative impacts on a child’s health.³⁸ As mentioned previously, when a child is separated from his or her parent, the stressed body is flooded with a multitude of chemicals, including cortisol, in an effort to help the child cope with the short-term stress. However, in situations of prolonged stress, the continuously elevated levels of stress hormones can lead to increased risks of lasting, destructive complications such as heart disease, diabetes, and cancers.³⁹ In addition, repetitive stressful instances in early life can lead to mental health problems including depression, anxiety, and post-traumatic stress disorder (PTSD).⁴⁰

Depending on the length of time the body is stressed, stress hormones can be beneficial or destructive. During periods of short-term stress, the elevated levels of hormones are protective and even essential for survival.⁴¹ However, prolonged levels of these hormones can be toxic to the body and can lead to “wear and tear” of the organ systems.⁴²

In addition, young children believe that parents can protect them from anything and that is what allows them to feel safe enough to explore the world.⁴³ John Bowlby, a British scientist, explains this attachment theory as an explanation of how children understand the world around them and why children need their primary caregiver’s support.⁴⁴ The forcible separation may therefore, hinder the affected

³⁷Allison Eck, *Psychological Damage Inflicted By Parent-Child Separation is Deep, Long-Lasting*, PBS (June 20, 2018), <https://www.pbs.org/wgbh/nova/article/psychological-damage-inflicted-by-parent-child-separation-is-deep-long-lasting/>

³⁸*Id.*

³⁹*Id.*

⁴⁰*Id.*

⁴¹Jack Shonkoff et. al, *The Lifelong Effects of Early Childhood Adversity and Toxic Stress*, 129 AMERICAN ACADEMY OF PEDIATRICS 232, 235 (Jan. 2012).

⁴²*Id.*

⁴³Allison Eck, *Psychological Damage Inflicted By Parent-Child Separation is Deep, Long-Lasting*, PBS (June 20, 2018), <https://www.pbs.org/wgbh/nova/article/psychological-damage-inflicted-by-parent-child-separation-is-deep-long-lasting/>

⁴⁴Allison Eck, *Psychological Damage Inflicted By Parent-Child Separation is Deep, Long-Lasting*, PBS (June 20, 2018),

children's ability to relate to the world around them especially since there did not seem to be enough supportive care after they were separated.

There are three types of stress responses that occur in response to stressful situations: a positive stress response, a tolerable stress response, and a toxic stress response.⁴⁵ A positive stress response occurs when a child encounters a situation where he/she is frustrated, getting an immunization, or anxiety associated with the first day at a child care center.⁴⁶ When buffered by an environment of stable and supportive relationships, the positive stress responses are a growth-promoting element of normal development.⁴⁷

A tolerable stress response occurs with exposure to non-normative experiences that present a greater magnitude of adversity or threat, such as the death of a family member, a serious illness or injury, or an act of terrorism.⁴⁸ When these types of experiences are buffered by supportive adults, the risk of producing excessive stress hormones that damages health and learning is significantly reduced.⁴⁹

The third and most dangerous form of stress response is toxic stress, such as forceful removal from a parent, which can result from strong, frequent, or prolonged activation of the body's stress response in the absence of the buffering protection of a supportive adult.⁵⁰ This disruption can lead to learning impairments and behavior issues relating to stress-related mental illnesses.⁵¹ The brain, especially during infancy and early childhood, is highly sensitive to chemical changes, especially persistently high stress levels.⁵²

Therefore, it is not surprising that in response to the separation of families at the border that organizations including the American Academy of Pediatrics, the American Psychiatric Association, and

<https://www.pbs.org/wgbh/nova/article/psychological-damage-inflicted-by-parent-child-separation-is-deep-long-lasting/>

⁴⁵*Id.*

⁴⁶*Id.*

⁴⁷*Id.*

⁴⁸*Id.*

⁴⁹Jack Shonkoff et. al, *The Lifelong Effects of Early Childhood Adversity and Toxic Stress*, 129 AMERICAN ACADEMY OF PEDIATRICS 232, 235-6 (Jan. 2012).

⁵⁰Jack Shonkoff et. al, *The Lifelong Effects of Early Childhood Adversity and Toxic Stress*, 129 AMERICAN ACADEMY OF PEDIATRICS 232, 236 (Jan. 2012).

⁵¹*Id.*

⁵²*Id.*

various other mental-health professions signed a petition⁵³ urging the government to stop border separation from parents.⁵⁴ It has been shown that children separated early in the first two years of life scored significantly lower on IQ tests later in life.⁵⁵ In addition, their fight and flight response system seemed to be irreparably broken as these children remained unresponsive in stressful situations that would typically illicit physiological responses in other people.⁵⁶ In fact, many of these children often develop PTSD later in life due to the inability to sort safe and dangerous situations accordingly.⁵⁷ Studies on the lasting effects of children who were removed from their families showed that they were nearly twice as likely to be arrested or criminally charged as adults as well as struggle with alcohol abuse problems and gambling.⁵⁸ Additionally, studies in China has shown that these children have higher rates of anxiety and depression.⁵⁹ All in all, forcible separation can have highly negative consequences.

IV. SHOULD GENETIC TESTING BE USED TO REUNITE SEPARATED IMMIGRANTS AT THE BORDER

In order to decrease the lasting psychological and medical harm that these children may experience due to the toxic stress of this inhumane separation, should the government be able to use genetic testing to reunite immigrants at the border? There are several issues regarding utilizing genetic testing for reunifications. First, minors, especially children of tender ages, lack the capacity to consent to a

⁵³Dr. Dana Sinopoli & Stephen Soldz, *Stop Border Separation of Children From Parents*, *CHILDSWORLDAMERICA* (<https://childsworldamerica.org/stop-border-separation/stop-border-separation-text-preview/>)

⁵⁴William Wan, *What Separation From Parents Does To Children: The Effect Is Catastrophic; Trump's Border Policy Could Cause Long-Term Damage to Children's Brains, Experts Warn*, *WASH. POST* (June 18, 2018), https://www.washingtonpost.com/national/health-science/what-separation-from-parents-does-to-children-the-effect-is-catastrophic/2018/06/18/c00c30ec-732c-11e8-805c-4b67019fcfe4_story.html?utm_term=.981c7273de6e

⁵⁵*Id.*

⁵⁶*Id.*

⁵⁷*Id.*

⁵⁸William Wan, *What Separation From Parents Does To Children: The Effect Is Catastrophic; Trump's Border Policy Could Cause Long-Term Damage to Children's Brains, Experts Warn*, *WASH. POST* (June 18, 2018), https://www.washingtonpost.com/national/health-science/what-separation-from-parents-does-to-children-the-effect-is-catastrophic/2018/06/18/c00c30ec-732c-11e8-805c-4b67019fcfe4_story.html?utm_term=.981c7273de6e

⁵⁹*Id.*

test regarding how their medical information may be used in the future.⁶⁰ In addition, the Children's Act of 1989 considers harm, best interests, and paternalism to the child.⁶¹ For example, the Children's Act allows courts to find that a child's "expressed" wishes are not his true wishes and do not serve his best interests. The question of whether children can "expressly" consent to genetic testing for the purpose of reunification cannot be answered without first understanding the elements of consent.

The process of educating the child/parent about the test and obtaining their permission for the test is called informed consent.⁶² Usually adults make choices based on informed consent and in the cases of children then the parents, guardians, or person that is legally responsible for the child is entrusted with that decision.⁶³ There are various factors that need to be considered whether the consent provided was informed:

- a general description of the test to be performed;
- the process of how the test will be carried out;
- the meaning of any test results;
- the physical or emotional risks associated with the test;
- whether the results can be used for research purposes;
- whether the results might provide information about other family members' health;
- how and to whom test results will be reported and under what circumstances results can be disclosed;
- what will happen to the test specimen after the test is complete;
- acknowledgement that the person requesting testing has had the opportunity to discuss the test with a healthcare professional; and
- the individual's signature, and possibly that of a witness.⁶⁴

However, when considering the separated families at the border, in many cases there are children of tender ages involved who do not have the capacity to consent. Also, since the minors are

⁶⁰Karen Weintraub, *Genetic Testing to Reunite Immigrant Families Raises Issues of Privacy and Consent*, *SCIENTIFICAMERICAN* (June 26, 2018), <https://www.scientificamerican.com/article/genetic-testing-to-reunite-immigrant-families-raises-issues-of-privacy-and-consent/>

⁶¹*Id.*

⁶²Genetics Home Reference, *What is Informed Consent*, NIH (Mar. 19, 2019), <https://ghr.nlm.nih.gov/primer/testing/informedconsent>

⁶³*Id.*

⁶⁴*Id.*

separated from their families, there is no one to consent on their behalf on whether to use genetic testing. In addition, the right for a minor to consent to genetic testing is dependent on the age of the minor. Although the age of majority is 18 years, the Family Law Reform Act of 1979 allows minors above 16 years of age to give legally valid consent.⁶⁵

Under the Health Information Portability and Accountability Act (HIPAA) privacy laws, parents of minor children are often recognized as their personal representative.⁶⁶ As the child's personal representative, the parent typically has the right to consent to the use and disclosure of the child's Personal Health Information (PHI).⁶⁷ However, HIPAA only applies to an organization if it is a "covered entity" or a "business associate" of one.⁶⁸ Therefore, many non-covered genetic testing companies, like 23andMe and genealogy websites like Ancestry.com, are self-regulated.⁶⁹

In May 2008, Congress enacted special protections for genetic information by enacting the Genetic Information Nondiscrimination Act, "GINA," which defined a "genetic test" as "an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes."⁷⁰ However, GINA does not deal directly with privacy issues, but rather preventing discrimination based on genetic information.⁷¹

Also, according to the 1998 World Health Organization's *Proposed International Guidelines on Ethical Issues in Medical Genetics and the Provision of Genetic Services*, "[c]hildren should only be tested when it is for the purpose of better medical care." Therefore, using genetic testing to reunite families poses a multitude of issues ranging from capacity to consent to privacy issues.

⁶⁵Donna Dickenson, *Can Children and Young People Consent To Be Tested For Adult Onset Genetic Disorders*, 318 *BMJ* 1063, 1064 (Apr. 17, 1999), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1115457/>

⁶⁶PHI re 220 Other Types of Restricted Personal Data, 2006 WL 2053654.

⁶⁷Angela L. Morrison, *A Research Revolution: Genetic Testing Consumers Become Research (and Privacy) Guinea Pigs*, 9 *J. on TELECOMM. & HIGH TECH. L.* 573, 578 (2011).

⁶⁸*Genetic Information Privacy*, ELECTRONICFRONTIERFOUNDATION (last visited Mar. 24, 2019), <https://www.eff.org/issues/genetic-information-privacy>

⁶⁹*Id.*

⁷⁰Genetic Information Nondiscrimination Act, GINAHELP (June 2010), <http://www.ginahelp.org/GINAhelp.pdf>

⁷¹*Genetic Information Privacy*, ELECTRONICFRONTIERFOUNDATION (last visited Mar. 24, 2019), <https://www.eff.org/issues/genetic-information-privacy>

V. PRIVACY RISKS ASSOCIATED WITH USING GENETIC TESTING

In addition, privacy issues are an important consideration when considering using genetic testing to reunite families at the border. American constitutional law has called privacy the “right to be let alone.”⁷² Several privacy risks for sharing DNA, either voluntarily or forcibly, include the risk of hacking, third-parties profiting from your information, inadequate legal protection, use by law enforcement agencies, and change in the company’s business model.⁷³

Data in the digital form is far easier to obtain illegally or without a patient’s knowledge than in paper form.⁷⁴ This issue of hacking is not limited to only the genetic-testing industry, however the information these companies receive is so unique to each person that the effects of hacking could be disastrous. In fact, over 92 million account details from genealogy and DNA testing service were found on a private server on October 26, 2017.⁷⁵ Luckily the DNA data section was not specifically breached; however, the mere fact that hackers were able to access that space is concerning.⁷⁶

In addition, many DNA companies are contracting with drug companies in an effort to help find a cure for diseases.⁷⁷ Many people, with a wish to help others, consent to their DNA being used to help others.⁷⁸ However, that does not translate to pharmaceutical companies acting in the best interests of the people that could be helped by these future medical advancements.⁷⁹ In the context of the “zero-tolerance” policy, there is no guarantee that the samples

⁷²*Katz v. United States*, 389 U.S. 347, 350 (1967).

⁷³Eric Rosenbaum, *5 Biggest Risk of Sharing Your DNA With Consumer Genetic-Testing Companies*, CNBC (Jun 16, 2018), <https://www.cnbc.com/2018/06/16/5-biggest-risks-of-sharing-dna-with-consumer-genetic-testing-companies.html>.

⁷⁴Louise Slaughter, *Genetic Information Non-Discrimination Act*, 50 HARV. J. ON LEGIS. 41, 63 (2013).

⁷⁵Reuters, *Hackers Leak Data From 92 Million MyHeritage Users*, NY POST (June 6, 2018), <https://nypost.com/2018/06/06/hackers-leak-data-from-92-million-myheritage-users/>.

⁷⁶*Id.*

⁷⁷Eric Rosenbaum, *5 Biggest Risk of Sharing Your DNA With Consumer Genetic-Testing Companies*, CNBC (Jun 16, 2018), <https://www.cnbc.com/2018/06/16/5-biggest-risks-of-sharing-dna-with-consumer-genetic-testing-companies.html>.

⁷⁸*Id.*

⁷⁹*Id.*

obtained through mandate will not be utilized by third parties for-profit.

Currently, the only law governing genetic privacy, GINA, focuses only on banning employers or insurance companies from discrimination based on using a person's genetic information.⁸⁰ Additional regulations need to be in place to safeguard the interests of those whose genetic information may be used.

For example, the laws regulating the use of genetic information by law enforcement officials are still in flux.⁸¹ Although genetic testing companies, like 23andMe, state that "we have never given customer information to law enforcement officials," their transparency report states "under certain circumstances Personal Information may be subject to disclosure pursuant to judicial or other government subpoenas, warrants, or orders, or in coordination with regulatory authorities."⁸² Thus, the legal relevance of how the courts can demand disclosure of genetic information is new, uncharted territory.

Another problem regarding privacy issues with genetic testing, is evidenced by the Golden State Killer. On April 24, 2018, nearly 32 years after the Golden State Killer's rampage ended, he was finally arrested.⁸³ The arrest was made on the basis of genetic information made with DNA sample from the killer's home compared to an open-source database, GEDmatch.⁸⁴ Even though in

⁸⁰Louise Slaughter, *Genetic Information Non-Discrimination Act*, 50 HARV. J. ON LEGIS. 41 (2013). GINA was passed in 2008 in an effort to encourage participation in genetic testing and genetic research by protecting Americans from employer and insurance discrimination based on genetic information. For example, before GINA, Title VII of the Civil Rights Act of 1964 makes it illegal for an employer, labor organization, employment agency or training program to "discriminate against any individual...because such individual's race, color, religion, sex or national origin." It makes no mention, however, of genetic information, or even any kind of health information.

In order to address this gap in protections against discrimination, a patchwork of state laws were implemented to address genetic information discrimination before GINA was enacted in 2008.

Critics of GINA have argued that its language is too narrow in scope. GINA does not protect against genetic discrimination in life, long term care, or disability insurance or discrimination by creditors.

⁸¹Susan Scutti, *What the Golden State Killer Case Means For Your Genetic Privacy*, CNN (May 1, 2018), <https://www.cnn.com/2018/04/27/health/golden-state-killer-genetic-privacy/index.html>.

⁸²Susan Scutti, *What the Golden State Killer Case Means For Your Genetic Privacy*, CNN (May 1, 2018), <https://www.cnn.com/2018/04/27/health/golden-state-killer-genetic-privacy/index.html>.

⁸³*Id.*

⁸⁴*Id.*

the previous case it may seem as a public benefit to be able to use genetic information to catch criminals, that information can also be used to investigate non-criminals.

Once genetic information is given to a testing center, the results are used not only in regards to the individual, but also their un-consenting relatives.⁸⁵ For example, if one of the separated child's genetic information is stored, it is possible for that information to be accessed by a third party (i.e. law enforcement) and an extended family may be subsequently harassed because they are thought to be linked to the child's illegal status.

The issue regarding whether a sample will remain private and thereby destroyed upon successful reunification is also still up in the air;⁸⁶ however, at this stage, immediate destruction of the sample would mean that the government will need to have complete faith and trust in the company it has outsourced to perform the testing has destroyed the sample, since there are no current regulations in place to monitor destruction of samples.⁸⁷ Although genetic companies are only supposed to use the information to determine parentage, there is no guarantee that the genetic information is destroyed.⁸⁸ In fact, the information is commonly given to pharmaceutical companies for testing.⁸⁹ In this event, the child's genetic information can be used without both parental and the child's wishes.

If stored, the genetic information can pose a risk to both the tested person as well as their families themselves.⁹⁰ The reason being that once stored, law enforcement agencies, including immigration enforcement, could have access to their information

⁸⁵Susan Scutti, *What the Golden State Killer Case Means For Your Genetic Privacy*, CNN (May 1, 2018), <https://www.cnn.com/2018/04/27/health/golden-state-killer-genetic-privacy/index.html>.

⁸⁶Elizabeth Weise, Ryan Suppe, & Alan Gomez, *DNA Tests Used to Reunite Migrant Families Spark Worries They'll Be Used For Much More*, USA TODAY (July 9, 2018), <https://www.usatoday.com/story/tech/2018/07/09/how-dna-testing-work-reunited-families-separated-border/761810002/>

⁸⁷*Id.*

⁸⁸Kristen Brown, *Deleting Your Online DNA Data Is Brutally Difficult*, BLOOMBERG (June 15, 2018), <https://www.bloomberg.com/news/articles/2018-06-15/deleting-your-online-dna-data-is-brutally-difficult>

⁸⁹Maggie Fox, *Drug Giant Glaxo Teams Up With DNA Testing Company 23andMe*, NBCNEWS (July 25, 2018), <https://www.nbcnews.com/health/health-news/drug-giant-glaxo-teams-dna-testing-company-23andme-n894531>

⁹⁰Ryan Suppe, *Using DNA Tests To Reunite Migrant Families On the Border Raises Privacy Concerns*, USA TODAY (July 23, 2018) <https://www.usatoday.com/story/tech/2018/06/23/using-dna-tests-reunite-immigrant-children-parents-poses-privacy-risk/727424002/>

and could potentially use it to target that individual's family.⁹¹ This fear of law enforcement officials using genetic information is not unfounded as illustrated by the Golden State Killer scenario mentioned above.

Also, although the genetic testing centers claim that the information received are de-identified, there are means through which a person can be re-identified.⁹² This is relevant in context of reuniting families via genetic testing because currently the national standard is to require the maintenance of records for at least five years.⁹³ Thus, if that sample is not destroyed or has been shunted to third parties, then it is possible that it can be used in the future to re-identify an individual.

If DNA, either voluntarily or involuntarily obtained, has been sent off to a DNA ancestry or health-screening company, there is a likelihood that the obtained DNA data will be shared for medical research or even crime-solving; unless the company has been specifically requested not to do so.⁹⁴ For example, DNA samples from genetic genealogy company FamilyTreeDNA were subsequently provided to the FBI to be used in the identification of perpetrators of violent crimes. Whereas DNA testing company, 23andMe, has signed a \$300m deal with pharmaceuticals giant GSK to help it develop new drugs. The genetic information of immigrants that have been forcibly separated and are now being strong-armed into genetic testing are at risk for potential misuse of their information in the future.

If DNA samples are taken in order to reunite families, many questions remain unanswered. Primarily, who has legal control of the samples?⁹⁵ Would it be the FBI (since DHS does not have its own DNA database) or would it be the private genetic testing

⁹¹Id.

⁹²Zachary Shapiro, *Big Data, Genetics, and Re-Identification*, HARVARD.EDU (Sept. 24, 2015), <http://blog.petrieflom.law.harvard.edu/2015/09/24/big-data-genetics-and-re-identification/>

⁹³George Maha & James Mason, *Genetic Privacy and Paternity Testing*, 18 DEL. LAW. 14, 15 (2000).

⁹⁴Manuela Saragosa, *Who's Monetising Your DNA?*, BBC (Mar. 2, 2019), <http://www.bbc.com/capital/story/20190301-how-screening-companies-are-monetising-your-dna>.

⁹⁵Jennifer Lynch, *DNA Collection is Not the Answer to Reuniting Families Split Apart by Trump's "Zero Tolerance" Program*, ELECTRONIC FRONTIER FOUNDATION (July 10, 2018), <https://www.eff.org/deeplinks/2018/07/dna-collection-not-answer-reuniting-families-split-apart-trumps-zero-tolerance>

company?⁹⁶ More importantly, using genetic testing to reunite children bears the significant pitfall when encountering children that have been adopted or have been traveling with a step-parent or legal guardian. How will these children be reunited when a genetic test is inadequate and the child may be of tender ages?⁹⁷

VI. SOLUTION

Reuniting separated families at the border as quickly as possible is the ultimate goal in order to decrease the lasting effects of this trauma. However, using genetic testing companies to collect samples to promote reunification may not be in the best interest of the child (or parent). Since genetic testing is relatively new territory, in the legal context, until proper protective legislation is in place to protect immigrants, this avenue to reunification should be avoided or saved as a last resort.

In fact, usually when people are detained, they are fingerprinted.⁹⁸ Therefore, if the proper intake process was followed when they were detained then there should be no issue as to which child belongs to which parent.⁹⁹ Mandatory DNA tests should be case-specific and only utilized when there is a genuine reason to doubt parentage, parentage cannot be determined by any other means, and the parent agrees to the test.¹⁰⁰

In response to the privacy concerns with genetic testing, one solution would be to expand legislation to protect the genetic data itself, rather than focusing on “covered entities” possessing that data.¹⁰¹ However, even if the genetic information itself was protected, another major ethical hurdle remains.¹⁰² Unlike many other tests and procedures, where the results of a test only directly affects that specific person; in genetic testing, the results of the test can provide information regarding not only that specific person, but

⁹⁶*Id.*

⁹⁷*Id.*

⁹⁸Daniella Silva, *DNA Tests for Separated Families Slammed by Immigration Advocates*, NBCNEWS (July 5, 2018).

⁹⁹*Id.*

¹⁰⁰*Id.*

¹⁰¹Jennifer Lynch, *DNA Collection is Not the Answer to Reuniting Families Split Apart by Trump’s “Zero Tolerance” Program*, ELECTRONICFRONTIERFOUNDATION (July 10, 2018), <https://www.eff.org/deeplinks/2018/07/dna-collection-not-answer-reuniting-families-split-apart-trumps-zero-tolerance>

¹⁰²*Id.*

also immediate and extended relatives of that person.¹⁰³ The courts will have to deal with this ethical issue in the near future.

VII. CONCLUSION

Prompt reunification is best in this situation where children, including those of tender ages, have been separated from their primary caregivers. To minimize the psychological damage that occurs during separation, prompt reunification would be ideal to reestablish a stable, nurturing environment. Since the federal government still has not reunified separated parents and children from their previously enacted zero policy protocol, it serves to show that additional steps are needed to complete this process.

However, using genetic testing to facilitate this process poses both privacy concerns and consent problems. If the government guarantees that the collected genetic information will only be used to establish paternity and then destroyed, then the privacy issue will be abated. However, realistically, the government cannot guarantee that the genetic information will be subsequently destroyed because regulations are not currently in place to do so; hence, the privacy reservations held by many remains a valid concern.

¹⁰³Daniella Silva, *DNA Tests for Separated Families Slammed by Immigration Advocates*, NBCNEWS (July 5, 2018).