

Draft: 4/1/08

Necessary Subjects: The Need for a Mandatory National Donor

Gamete Registry

Naomi Cahn¹

INTRODUCTION

Donor eggs, donor sperm, donor embryos -- and adoption -- are each means of creating families in which children are not genetically related to one or both of their parents. Although the offspring in each of the differently-formed families may know of this lack of genetic connection, they may not have access to information about their biological progenitors.

Like the reproductive technology field, adoption law has faced numerous issues concerning children's access to information about their biological progenitors,² even though each field has a different history of confidentiality. It was not until the early twentieth century that adoption records were sealed from a prying public.³ States allowed members of the adoption triad access to these records until the latter half of the twentieth century. While this secret, closed system is a relatively recent phenomenon in adoption, the secrecy of donor sperm dates to its earliest known uses.⁴ On the other

¹ John Theodore Fey Research Professor of Law, George Washington University Law School, and author of *Test Tube Families* (NYU Press, forthcoming 2009). Thanks to Bill Cordray, Nanette Elster, Susan Crockin, Tony Gambino, Joan Hollinger, Wendy Kramer, and all of the organizers of the DePaul Tracking Changes Symposium. This paper is an expanded version of the talk presented at the Symposium.

² See Nanette Elster, All or Nothing? The International Debate Over Disclosure to Donor Offspring, Inst. On Biotech. & the Human Future (conference materials), avail. at http://www.thehumanfuture.org/commentaries/assisted_reproductive_technology/art_commentary_elster01.html

³ Elizabeth Samuels, The Idea of Adoption: An Inquiry into the History of Adult Adoptee Access to Birth Records, [53 Rutgers L. Rev. 367, 369 \(2001\)](#).

⁴ Professor Gaia Bernstein reports that it was not until 1909 that the first publication concerning donor sperm appeared, discussing "an 1848 case in Philadelphia involving a forty-one year old merchant and his wife . . . [who was inseminated with] semen collected from the best looking member of the medical school

hand, the history of secrecy in the donor eggs context is also fairly recent (indeed, the use of donor eggs has only been possible since the successful development of IVF thirty years ago); donor eggs initially involved known donors, although today, egg providers are more likely to be unknown and promised confidentiality. The pressure for allowing donor-conceived children access to identifying information about their gamete providers is analogous, although less legally well-developed today, to that in the adoption context.⁵ The private Donor Sibling Registry has taken the lead in helping families formed through donor gametes voluntarily find each other, but the Registry's success has occurred without supporting laws.

The history of secrecy in adoption stems from a variety of sources that are comparable to those in the donor gamete situation. Keeping donor sperm or adoption secret has facilitated a couple's appearance of fertility and may have helped with the acceptance of the resulting children, who were not "strangers" within their new families.⁶ Unlike adoption, which, although surrounded by secrecy, involves legal procedures and multiple parties outside the newly formed family, using donor sperm simulated the expected familial relationships because it requires no public involvement. In his 1964 book, Dr. Wilfred Finegold, the Head of the Division of Sterility at the Planned Parenthood Center in Pittsburgh, explained the advantages of artificial insemination: "The husband's infertility is a secret in A. I. To his friends, the husband has finally

class . . . Neither the merchant nor his wife knew what was done. The physician confided in the merchant after the fact. The merchant was delighted but arranged for his wife to remain in ignorance." Gaia Bernstein, *The Socio-Legal Acceptance of New Technologies: A Close Look at Artificial Insemination*, 77 Wash. L. Rev. 1035, 1056 (2002). It appears that the resulting child never knew, either.

⁵ The analogies and comparisons between adoption and reproductive technology are not entirely synchronous. See Madelyn Freundlich, *Adoption and Ethics: Adoption and Assisted Reproduction* (2001); see *infra* for further discussion of the utility and limitations.

⁶ See, e.g., June Carbone, *The Role of Adoption in Winning Public Recognition for Adult Partnerships*, 35 Cap. U.L. Rev. 341, 357-359 (2006).

impregnated his wife . . . In A.I., the child is never told.”⁷ The donor’s characteristics should be, he observed, similar to those of the husband’s and the two men must be of the same religion.⁸ Further, Dr. Finegold explained that “all” physicians require an anonymous donor, and listed a series of precautions for preserving the sperm provider’s anonymity.⁹ These mechanisms provided “cover” for the recipient family so that only the doctor would know for sure.

This article first discusses secrecy in the adoption context before turning to issues involving confidentiality in the donor context. After analyzing the issues involved in maintaining the secrecy of donor gametes, the article ultimately recommends the establishment of a national information registry, similar to that in place in numerous other countries, to keep track of the numbers of children both through donor egg and sperm and the identities of the gamete providers. Participation in the registry would be mandatory for anyone involved in supplying donor gametes. Once donor-conceived offspring reached the age of 18, they would be able to receive identifying information about their donor, and the donor could file a statement indicating his/her lack of interest in being contacted.

Allowing offspring access to this information involves a series of complicated issues, beginning with the question of how will children know that they are donor offspring? Second, what information -- beyond identity -- would be collected? and third, what information -- beyond identity -- would be released? As discussed at the

⁷ Wilfred Finegold, *Artificial Insemination* 25 (1964). Alan Guttmacher wrote the introduction.

⁸ *Id.* at 40.

⁹ *Id.* at 33-35. [Camille – Lori Andrews also talked about this at lunch – will her remarks be published? If so, then I should cite them!]

symposium, the information collection and dissemination issues are highly complex; for example, should genetic samples be preserved for all donors?¹⁰ Should donors and the children conceived through their material be tracked for purposes of follow-up concerning medical issues?¹¹ As a related matter, any change in the current system requires additional counseling for all involved.¹²

Finally, and more pragmatically, beyond satisfying the needs of many donor offspring and their families to find connections, a national registry would prevent the same donor from providing gametes to numerous banks and numerous families. Existing limits within banks are unenforceable across banks unless donors are identified. It might even help with sharing critical medical information between donor-created families.

I. The Adoption/ART Analogy

To be sure, the analogies between adoption and reproductive technology are only that: analogies. There are numerous differences between them, beginning with the regulatory structure and continuing with the relational context. First, adoption is highly regulated, with the foster care system subject to both state and federal laws; infant adoption regulated by state law. State laws focus on the best interest of the child and the fitness of the parents, and there are clear laws on relationship between biological and adoptive parents. All adoptions require court involvement, and there are clear legal rules re: the respective rights and responsibilities of birth and adoptive parents. Some states

¹⁰ As Dr. Hughes noted, testing of all samples at the time of collection does not necessarily mean that all genetic diseases can be screened. [cite to his presentation/article.]

¹¹ See generally William Heisel, Registry May Track Egg, Sperm Donors, L.A. Times, p. B3, Jan. 3, 2008; Jennifer Schneider, It's Time for an Egg Donor Registry and Long-Term Follow-Up (Nov. 14, 2007), avail. at <http://geneticsandsociety.org/article.php?id=3820>.

¹² Indeed, the existing levels of counseling are problematic as well. See Susan Crockin's paper for this symposium; Julie Derek, Confessions of a Serial Egg Donor (2004).

explicitly recognize open contact agreements, allowing for continuing contact between the biological and adoptive parents.

Adoption occurs within a coherent and long-standing legal and regulatory structure and, to a greater or lesser degree, oversight mechanisms are in place. Agencies must be licensed; adoption attorneys must be members of bar associations that oversee professional practice; and courts must finalize adoptions. Although laws differ from state to state, many aspects of adoption are well regulated: all adoptive parents must have approved home studies, and there are clearly established legal relationships between the biological and adoptive families and the child.

By contrast, ART is subject to piecemeal regulations. The extent to which the law regulates adoption clearly far exceeds the regulation of assisted reproduction. The law of assisted reproduction has evolved slowly through case law and issue-specific statutory provisions that are reactive to emerging issues. There are federal laws on the safety of gamete handling and on the necessity of reporting clinic success rates.¹³ The Centers for Disease Control issues an annual report on the success rates of fertility clinics, although this information does not include statistics on sperm donation.¹⁴ There are no limits on the numbers of times one person can donate sperm or eggs, nor are there limits on the numbers of embryos that can be implanted in one woman, causing concerns both about numerous genetically related half-siblings and about the health and welfare of the increasing numbers of multiple children. Private self-regulatory organizations, such as

¹³ The Fertility Clinic Success and Certification Act, 42 U.S.C. § 263a (2007)8); see Lori Andrews & Nanette Elster, Regulating Reproductive Technologies, 21 *J. Leg. Med.*35, 49 (2000)..

¹⁴ Department of Health and Human Services Centers for Disease Control and Prevention, 2005 Assisted Reproductive Technology Success Rates: National Summary and Fertility Clinic Success Rates (2007), figure 49, p. 61, available at <http://www.cdc.gov/ART/ART2005/508PDF/2005ART508.pdf>

the American Society for Reproductive Medicine (ASRM) and the American Association of Tissue Banks, have developed recommendations in many areas for member clinics, such as the number of embryos that should be transferred at one time or the amount of compensation that should be paid, but these recommendations are advisory, not binding.¹⁵

Second, the interests of the family members involved in reproductive technology and in adoption are overlapping, but not identical. Donor children (aside from donor embryo conceived kids) typically live with one biologically-related parent, while the typical adoptee (outside of the significant number of children adopted by family members) has no genetic connection to other family members. Donor offspring don't have the same questions about relinquishment by biological parents as do adoptees, although donor offspring may wonder about the motivations of their biological progenitors.¹⁶ While adoptees typically learn at a young age that they are adopted, donor offspring are far less likely to learn of their status, and a majority of parents do not disclose this information to them. Moreover, while there is some research on biological parents who have relinquished their children for adoption, there is far less research on gamete donors.¹⁷

Nonetheless, both donor-conceived children and adoptees experience the same lack of connection with at least one-half of their genetic heritages. Writer A.M. Homes describes what it was like to learn that she and her biological mother shared certain habits

¹⁵ See, e.g, the ASRM ethics reports available at <http://www.asrm.org/Media/Ethics/ethicsmain.html>

¹⁶ See Naomi Cahn and Jana Singer. Adoption, Identity, and the Constitution: The Case for Opening Closed Records, 2 U. Penn. J. Con. L. 187 (1999)(exploring similarities and differences); Ellen Waldman, What do we Tell the Children?, 35 Cap. U.L. Rev. 517, 533-34 (2006).

¹⁷ See Freundlich, *supra* note __.

as “this indescribable subtlety of biology.”¹⁸ It is this lack of knowledge about their biological progenitors, and the emotional needs for this knowledge that many adoptees and donor offspring articulate, that has motivated advocates within each movement to push for disclosure, and that motivates this article’s call for a national, mandatory registry.

II. Confidentiality and Adoption

In adoption, over the past 50 years, many social workers (and others) have reinforced the belief that a biological connection has no role to play once an adoption has occurred. Whether it be in the context of open adoptions, through which a biological parent retains some contact with the adoptee, or open records, such that an adoptee has access to her original birth certificate, this approach views adoption as a complete substitute for any blood ties, and is thus generally against allowing any type of tie between adoptive and biological families.

In an effort to “overcome” biology, adoption experts have attempted to erase it completely. Accordingly, biological mothers were frequently told that they would be able to move on with their lives, as though they had never given birth to a child. The biological mother was told that she would not have any connection with her child, and doctors attempted to ensure that this occurred. Adoption records were sealed so that the adoptive family served as a complete substitute of the biological family. The biological tie was considered erased for both the birth mother and the adoptee, and, indeed, was legally erased.¹⁴

¹⁸ A.M. Homes, *The Mistress’s Daughter* 102 (2007).

¹⁴ See Naomi Cahn, *Perfect Substitutes or the Real Thing?*, 52 *Duke L.J.* 1077 (2003).

These attitudes are still reflected in contemporary adoption law. For example, under the proposed Uniform Adoption Act, records are sealed for 99 years. The UAA does include provisions for state mutual registries, so that adult adoptees and biological parents can contact each other if they so choose. The state mutual registry option is, however, considered to be the weakest possible support for facilitating reunions because it requires that both parties become aware of it and then file the requisite documents; moreover, if one person registers in one state and another registers in a different state, there is no intrastate cooperation.

When the first "modern" adoption statutes were enacted around the middle part of the nineteenth century, they focused on protecting the welfare of the child. These statutes did not address secrecy or confidentiality. Adoption evolved over the next century, becoming more bureaucratic and professionalized, and ultimately, more confidential.

During the 1930s and 1940s, states began issuing new birth certificates to adopted children, in order to improve the collection of children's vital statistics and reduce the stigma of illegitimacy, rather than to prevent adopted children from gaining access to their original birth certificates. Adoptees during the 1970's began seeking legal access to their original birth records, and, in the 1990's, their efforts paid off through successful court cases and referenda.

Two states – Kansas and Alaska – never sealed their records, and, over the past 12 years, another six states have opened their adoption records and made them available: Alabama, Delaware, Maine, New Hampshire, Oregon, and Tennessee.¹⁹ In almost a

¹⁹ Evan B. Donaldson Adoption Institute, *For the Records: Restoring a Legal right for Adult Adoptees* 3 (2007), available at http://www.adoptioninstitute.org/publications/2007_11_For_Records.pdf.

dozen additional states, there is limited access to this information: adult adoptees born during specific time periods cannot access their birth certificates, while those born either before or after that time period are able to access their records.²⁰

Other states have developed different approaches to the issue of when adoptees should have access to identifying information, enacting mutual voluntary registries or confidential intermediary systems.²¹ Mutual voluntary (or passive) registries require that consents for disclosure be registered for both adoptee and biological parent before the information can be released. Confidential intermediary systems are more active; when an adoptee contacts the state, the state provides the adoption file to an intermediary who is responsible for determining whether the biological parents wish to be contacted.²² Procedures for mutual consent registries vary significantly from state to state. Most registries require consent of at least one birth parent and an adopted person over the age of 18 or 21, or of adoptive parents if the adopted person is still a minor, in order to release identifying information. The Donor Sibling Registry is an example of a mutual consent registry already in existence that works in a similar way – the keystone is voluntary registration that produces the matches.

At least another six states have enacted a confidential intermediary system (also called “search and consent” procedures), which authorize a public or private agency to help in finding biological family members to determine if they’ll consent to the release of information. One variation involves a court-certified intermediary who has access to the

²⁰ For the Records, supra note __, at 11 (there are 11 states in this category).

²¹ Evan B. Donaldson Adoption Institute, *Adoption Registries and Intermediaries by State* (2008), avail. at http://www.adoptioninstitute.org/resources/openrecord_stateregistries_intermediary_programs.pdf.

²² Cahn and Singer, supra note __, at 161-67; Bastard Nation, *State Adoption Disclosure Laws at a Glance* (2005), avail. at <http://bastards.org/activism/access.htm>.

sealed adoption records for the purpose of conducting a search for birth family members to obtain their consent for contact.

Today, in approximately 30 states, adoptees do not have access to their original birth certificates, nor to records from their adoptions.²³ Adoptees can petition a court for identifying information and, for good cause shown, the court may grant access.²⁴

III. Confidentiality and Donor Gametes

Confidentiality protections in the donor gamete context come from various different sources: statutes, private contracts, case law – and many participants' expectations. The Uniform Parentage Act of 1973, in a section dealing with parentage in the context of the donor insemination, provides:

. All papers and records pertaining to the insemination, whether part of the permanent record of a court or of a file held by the supervising physician or elsewhere, *are subject to inspection only upon an order of the court for good cause shown.*²⁵

The UPA was enacted in 18 states; it has now been superseded by the 2002 UPA, which contains no such language in the provisions governing assisted reproduction using donor

²³ Child Welfare Information Agency, Access to Adoption Records: Summary of State Laws (2006), available at http://www.childwelfare.gov/systemwide/laws_policies/statutes/infoaccessapall.pdf

²⁴ See Cahn and Singer; supra note __, at 161-62; Elizabeth J. Samuels, The Idea of Adoption: AN Inquiry into the History of Adult Adoptee Access to Birth Records, 53 Rutgers L. Rev. 367, 426-29 (2001); Child Welfare Information Gateway, Access to Adoption Records (2006), available at http://www.childwelfare.gov/systemwide/laws_policies/statutes/infoaccessap.cfm.

²⁵ Uniform Parentage Act, §5(a)(1973)(emphasis added).

gametes.²⁶ Few other states have established even minimal record-keeping requirements.²⁷

Indeed, few cases involving donor identity disclosure have reached the courts. In perhaps the most famous, *Johnson v. Superior Court*,²⁸ the disclosure of the genetic parent's identity was incidental to the tort claims being brought against the clinic that had provided the allegedly defective sperm. The court did, however, construe the UPA to examine whether the contract between the recipient parents and the bank protecting confidentiality of the donor controlled the issue of whether the donor could be compelled to appear at a deposition. The court noted that there were no reported decisions concerning the "good cause" standard. Instead, the court held that "insemination records, including a sperm donor's identity and related information contained in those records, may be disclosed under certain circumstances."²⁹ This was not a case where donor offspring sought access to information; consequently, the court was not called upon to decide the circumstances under which a court would disclose such information to a child pursuant to the UPA. Nonetheless, the court did not foreclose such a possibility, opining:

And enforcement under all circumstances of a confidentiality provision such as the one in Cryobank's contract with the Johnsons conflicts with California's compelling

²⁶ Uniform Parentage Act §§700 et seq., available at <http://www.law.upenn.edu/bll/archives/ulc/upa/final2002.htm>. The 2002 UPA has been enacted in seven states.

²⁷ See Elster, *All or Nothing?*, supra note __, at pp. 3-4 (listing New York and Ohio, and noting that the ASRM recommends maintaining permanent records). About half of the states have established laws concerning the supervision of sperm banking. See Dawn R. Swink and J. Brad Reich, *Caveat Vendor: Potential Progeny, Paternity, and Product Liability Online*, 2007 B.Y.U.L. Rev. 857, 872.

²⁸ *Johnson v. Superior Court*, 80 Cal. App. 4th 1050, 1057 (2d Dist. 2000), *modified*, 101 Cal. App. 4th 869 (2d. Dist. 2002).

²⁹ *Id.* at 1066.

interest in the health and welfare of children, including those conceived by artificial insemination. There may be instances under which a child conceived by artificial insemination may need his or her family's genetic and medical history for important medical decisions.³⁰

No other court has interpreted this provision, although the term “good cause” has a long history in the adoption context when it comes to courts’ allowing the disclosure of birth records.³¹

In another context, Minor J sued his mother, Diane J., to find out the identity of his biological father.³² Minor J was born in 1989 to Ms. and Mr. J. His parents were divorced in 1995. Although both Minor J and Mr. J had assumed that Mr. J was the biological father, DNA tests after the divorce indicated that there was no biological connection between the two. Minor J sued his mother in 2006, seeking to require her to reveal the identity of his biological father. Both the trial and appellate courts refused to allow the case to proceed because of the marital presumption: the strong assumption that a child born into a marriage is the legal child of the husband and wife.³³

And, in another sperm identity case, again not involving a child’s effort to determine identifying information about a sperm donor, “Michael Hayes” sued an Oregon fertility clinic to determine if his sperm was mistakenly used to inseminate a stranger rather than, as he had intended, his fiancée. M.H., as he is known in the court papers, wanted to establish a relationship with the child who might have been born. The woman who received the sperm – who had not revealed whether she gave birth to a child – wanted to be left alone, without revealing her identity (in the court papers, she is known

³⁰ Id. at 1067.

³¹ For courts’ interpretation of good cause in the adoption context, see, e.g., Samuels, *The Idea of Adoption*, supra note __, at 427-429; Cahn and Singer, supra note __, at 161-62.

³² *Sutton v. Diane J.*, 2007 Mich. App. Lexis 754 (2007).

³³ Murray Davis, “Child Should have Right to Know Genetic Information,” *Detroit Free Press* (March 6, 2007): 9; Christina Stolarz, “Teen Fighting to Find Real Dad,” *Detroit News* (Nov. 20, 2006): 1B.

only as “Jane Doe”).³⁴ She alleges that she was forced to take a morning-after pill, and even offered a free abortion. The judge prevented M.H. from finding out whether he is a biological father, again using the marital presumption to shield the woman and her husband from further scrutiny.³⁵

While donor offspring have not yet organized in the same manner concerning the need for disclosure as have adoptees, the donor movement is beginning to place pressure on the gamete industry for more disclosure. The Donor Sibling Registry has operated a voluntary mutual internet-based registry for matching, but there are no comparable state-mandated procedures. The donor movement could learn from adoption on the reasons for requiring disclosure.

In addition, given that one man is capable of providing sperm for numerous children (the Donor Sibling Registry reports as many as 64 half-siblings from one man’s sperm), information release will provide two additional services: first, it may prevent half-siblings from marrying each other; and second, it may allow for limits on the numbers of children created through one person’s donation. In England, for example, a sperm donor can “father” no more than 10 children. Although the ASRM has suggested guidelines for limitations on donations, they are not binding.

Issues related to the importance of sharing or withholding of information in assisted reproduction arise in numerous contexts, as is the case in adoption. As professional organizations and social workers involved in assisted reproduction begin to recommend disclosure (whether it be of the fact of donor conception or additional

³⁴ Elizabeth Suh and Ashbel S. Green, “Who Gets the Baby?,” *The Oregonian* (Sept. 22, 2006): A1.

³⁵ Ashbel S. Green, “Judge Rules in OHSU Sperm Sample Mix-Up,” *The Oregonian* (April 17, 2007): B2.

identifying or non-identifying information),³⁶ adoption can provide best practices concerning the legal and psychological methods of disclosure and follow-up. In many cases, the bases for these recommendations in gamete donation track the same reasons for disclosure in the adoption context: allowing offspring the opportunity for knowledge, satisfying emotional and psychological needs, and providing genetic information.

There are, of course, various possibilities for using legal language to frame these issues. In the comparable context of adoption, advocates have typically made five distinct, albeit interrelated, legal arguments for disclosure:

1. Adult adopted persons have a fundamental “right to know” personal information about themselves.
2. States do not have a legitimate role in withholding birth and/or adoption information from adopted persons once they are adults.
3. Withholding birth and/or adoption information from adult adopted persons violates legal equal protection guarantees by denying them the same rights as other person.
4. Placing the decision on release of this information in the hands of courts has resulted in inequitable decision-making.
5. Adopted persons should not be bound by decisions on anonymity made by birthparents and adoptive parents at the time of the adoption.³⁷

. The corresponding legal arguments against disclosure include protection: of the rights to familial and reproductive privacy, of the right to prevent disclosure of information, against a violation of adoptive parents’ privacy, and of equal protection.³⁸ Each of these translates into the gamete donation context. Because courts have not yet decided these issues in the ART context, it is difficult to predict which set of arguments will be more successful within the legal system. Based on the adoption analogy, courts are likely to

³⁶ E.G., ASRM Ethics Committee Report, *Informing Offspring of their Conception by Gamete Donation*, 81 *Fert. & Ster.* 527 (2004).

³⁷ For the Records, *supra* note __, at 12.

³⁸ For the Records, *supra* note __ at 17. For an information privacy analysis of donors’ interests, see, e.g., Sunni Yuen, Comment: *An Information Privacy Approach to Regulating the Middlemen in the Lucrative Gametes Market*, 2 *U. Pa. J. Intl . L.* 527 (2007).

uphold as constitutional laws requiring the disclosure of information³⁹; what is less clear is courts' receptivity to arguments compelling the release of information.

Beyond consideration of these legal rights – and regardless of the outcome of court cases -- however, there are additional reasons to require a registry involving the interests of donor-conceived offspring⁴⁰, the recipient parents, and the donors themselves. As banks increasingly allowing their clients to choose either identified or anonymous donors, there is no obligation on the behalf of donors to provide accurate information to banks, and no obligation for one donor not to donate repeatedly. A national registry might help with the veracity of information as donors know that they will be accountable beyond the bank, but also to future offspring, and that the banks will be keeping track of how many times they donate.

Given the importance to many parents of having a genetic connection to their child, it should be unremarkable that children are themselves interested in learning about those to whom they have a genetic connection. In the case of gamete provision, where couples establish a genetic attachment between one of them and a child, it should not be surprising that children would want to know about other aspects of their genetic heritage.

Professor Mary Lyndon Shanley explores the irony:

Secrecy and anonymity suggested that the identity of the donor involved in begetting the child *was* important: if the genetic tie had no significance whatsoever, it would not need to be hidden. . . .

But many people who used donated sperm or eggs to conceive a child who was genetically related to one parent attributed a different kind of significance to their genetic link to the child. Having a child genetically related to one member of the couple gave a sense of continuity.⁴¹

³⁹ See Jennifer A. Baines, Note: Gamete Donors and Mistaken Identities: The Importance of Genetic Awareness and Proposals Favoring Donor Identity Disclosure for Children Born from Gamete Donations in the United States, 45 Fam. Ct. Rev. 116, 126 (2007).

⁴⁰ See, e.g., TAN 65 (citing Benward); Cahn, Test Tube Families (chapter 12), *supra* note __.

⁴¹ Shanley, *supra* note __, at 89.

This kind of continuity, with both the future and the past, is, understandably, important to many donor offspring.

One of the major concerns about removing confidentiality is the question of what would happen to the supply of donor eggs and sperm. Indeed, studies have repeatedly shown that about half of both egg and sperm donors would not participate if anonymity were removed – but that the other half would continue to provide gametes.⁴² Early studies from countries that have moved towards mandatory donor identification similarly showed that donors were less willing to provide gametes if they knew their identity would be disclosed.⁴³ Even the future possibility that a law will require such disclosure may have a dampening effect.⁴⁴ Indeed, after Sweden enacted legislation in 1985 that required the release of information concerning gamete providers when the child reached the age of 18, there was some concern that the legislation had caused a severe decline in the number of sperm donors.⁴⁵

⁴² See Eric D. Blyth, Lucy Frith, and Abigail Farrand, “Is it Possible to Recruit Gamete Donors Who Are Both Altruistic and Indentifiable?,” *Fertility & Sterility Journal* 84 (2005): S21, Supp. 1, http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6T6K-4H88108-1T&_coverDate=09%2F30%2F2005&_alid=451336191&_rdoc=1&_fmt=&_orig=search&_qd=1&_cdi=5033&_sort=d&view=c&_acct=C000031558&_version=1&_urlVersion=0&_userid=1193445&md5=6289394e3d8fced9e1f6f37fa5acc030.

⁴³ See June Carbone and Paige Gottheim, *Markets, Subsidies, Regulation, and Trust: Building Ethical Understandings into the Market for Fertility Services*, 9 *J. Gender, Race & Just.* 509, 540 (2006); K. Daniels and O. Lalos, *The Swedish Insemination Act and Availability of Donors*, 10 *Human Reproduction* 1871 (1995).

⁴⁴ June Carbone and Paige Gottheim, *Markets, Subsidies, Regulation, and Trust: Building Ethical Understanding into the Market For Fertility Services*, 9 *J. Gender, Race & J.* 509 (2006).

⁴⁵ K. Daniels and O. Lalos, *supra* note ___; F. Shenfield, “Privacy Versus Disclosure in Gamete Donation: A Clash of Interest, of Duties, or an Exercise in Responsibility?,” *Journal of Assisted Reproduction and Genetics* 14 (1997): 371; A. Lalos, K. Daniels, C. Gottlieb, and O. Lalos, “Recruitment and Motivation of Semen Providers in Sweden,” *Human Reproduction* 18 (2003): 212.

³⁵ Shenfield, *supra* note ___: 371.

On the other hand, allowing for the limited release of donor identity might result in the development of new methods to recruit donors.⁴⁶ Moreover, the publicity associated with new laws may encourage different types of donors to come forward. By changing advertising techniques to emphasize helping others rather than the amount of payment, banks may be able to recruit donors who care less about money and more about facilitating the creation of families. As one physician at a fertility center in England explained, “we need to change our strategies to target older men in established relationships. Since it appears they are likely to offer help for altruistic purposes, we must . . . increase public knowledge of the need for donors up to the age of 40.”⁴⁷ Payment does seem to remain a critical component; when Canada outlawed payment for sperm donors was cut off, the sperm supply decreased dramatically.⁴⁸

In the comparable context of adoption in the United States, open records have not compromised the integrity of the adoption process. The two states which never closed their records had higher-than average rates of adoption.⁴⁹

It appears then, that the requirement that children receive access to donor information will not necessarily result in a dramatic decrease in donors.⁵⁰ It is their interests, and, in many cases, the interests of their parents, which are respected through a disclosure regime.

4. Recommendations for Disclosure.

³⁷ Blyth, Frith, & Farrand, *supra* note ____.

⁴⁷ <http://www.oxfordjournals.org/eshre/press-release/nov051.pdf>.

⁴⁸ “Sperm Donor Shortage Hits Canadian Fertility Clinics,” CBC News (Dec. 19, 2006), <http://www.cbc.ca/health/story/2006/12/19/sperm-shortage.html>.

⁴⁹ See Naomi Cahn and Jana Singer, *Adoption, Identity, and the Constitution: The Case for Opening Closed Records*, 2 U. Penn. J. Con. L. 187 (1999). Indeed, as Professor Joan Hollinger observes, more than 80% of the biological mothers who have relinquished children for adoption in Michigan since 1980 have consented to the disclosure of their identity when their children become adults.

There are numerous issues – and potential solutions -- to the questions surrounding the development of a registry. Once the decision is made to develop a registry, the first question is what purposes it will serve.⁵¹ Next, there are two dimensions with respect to the registry itself: mandatory or voluntary, private or public. “Voluntary” itself has two different aspects: clinics can participate voluntarily and choose whether to provide information; and/or donors/offspring can participate voluntarily, so that matches occur only when there is a mutual desire for contact.

These can, in turn, be expanded to four specific options on how to proceed:

1. do nothing, and continue with the private system that we have (kudos to Wendy Kramer and the Donor Sibling Registry);
2. establish a national voluntary registry with standards, and with an administrative board composed of stakeholders, including donor offspring, donors, recipients, and the fertility industry, with private funding;
3. develop a state-based voluntary or mandatory registry; or
4. develop a national mandatory or voluntary registry.

Within this set of choices, I believe that the optimal outcome is the final one, the development of a national mandatory registry, where offspring over the age of 18 can obtain access to information.

Congress should enact legislation requiring that fertility clinics, sperm and egg banks, and physicians’ offices maintain records for each child born through donor gametes and guaranteeing that gamete offspring have the right to access those records.

⁵¹ At the Symposium, numerous speakers articulated a series of different possible purposes, ranging from limits on the number of donations to record-keeping to information disclosure. In his proposal recommending a voluntary registry, California Cryobank’s Charles Sims suggests [please fill in based on his symposium contribution].

While the fertility industry has a strong stake in ensuring the effectiveness of such a registry, and an interest in administering it, there are numerous other stakeholders who must be involved. Governmental mandates can ensure widespread participation, and can sanction entities that do not report. There is also the concern, as expressed by Wendy Kramer at the symposium, that: “I believe that a national registry that is set up, run, and governed by the sperm banking industry is only a fearful reaction to the possibility of the FDA imposing its own regulations and will only serve to protect this industry’s own best interests.”⁵²

One alternative to either the fertility industry or the federal government operating the registry might be state implementation.⁵³ There are, however, four problems with this approach. First, even if uniform legislation is developed, states might modify the legislation prior to enactment, so the registration and disclosure requirements could vary dramatically. Second, children might not know the state in which their parents obtained gametic material and underwent fertility treatment., and so might need to engage in searches of multiple state registries. Third, even if states attempted to coordinate their registry systems, this would require yet another oversight body to ensure the necessary cooperation. Finally, rather than establishing one system for information collection and retention, all 50 states would have to set up their own systems, causing a potentially overwhelming amount of duplicative work. A federal-level structure could more efficiently and effectively implement any large-scale collection of information and oversight of the process.⁵⁴

⁵² Wendy Kramer, Donor Sibling Registry, <http://www.donorsiblingregistry.com/chicagotalk.pdf> at 6.

⁵³ See, e.g., Baines, *supra* note __.

⁵⁴ See *infra* nn. __.

This right to know includes two interrelated parts: the rights to know that one has been conceived through donor gametes, and the right to know the donor.⁵⁵ Requiring that parents tell their children of their donor-conceived status is highly problematic; not only is it difficult to enforce, but it is highly intrusive of intrafamilial relationships.

There are, however, other methods to ensure that children know that their biological and legal parents are different people. One option is for birth certificates of children conceived with donor gametes could be stamped with “by donation” next to the mother and/or father’s name.⁵⁶ Although this places pressure on parents to inform their children of their biological origins, it also ensures that, regardless of whether parents inform their children, the children will know. Or, babies might receive two birth certificates, one that becomes part of the public record which does not include this information, and a second one, which would only be available once the child turns 18 and which would include identifying information about the donor.⁵⁷ This allows a child’s origins to be kept secret until she turns 18.

A comparable system is already being considered in Britain. In late 2007, some members of the British Parliament suggested that birth certificates indicate the donor

⁵⁵ Lucy Firth, *Beneath the Rhetoric: The Role of Rights in the Practice of Non-Anonymous Gamete Donation*, 15 *Bioethics* 476 (2001).

⁵⁶ See Frith, *supra* note __. The Ethics Committee of the ASRM has noted that, with respect to disclosure: [c]linicians, mental health professionals, academics, and children themselves have in recent years called for more openness in donor conception in order to protect the interests of offspring. Because of persons’ fundamental interest in knowing their genetic heritage and the importance of their ability to make informed health case decisions in the future, the Ethics Committee supports disclosure about the fact of donation to children. It also supports the gathering and storage of medical and genetic information that can be provided to offspring if they ask. It recognizes, however, that disclosure is a personal matter to be decided by the participants.

Ethics Committee of the ASRM, *Informing Offspring of their Conception by Gamete Donation*, 81 *Fert. and Ster.* 527, 530 (2004).

⁵⁷ See Alison Motluk, *Okay, So Who’s Really Your Daddy?*, *Toronto Star*, Feb. 16, 2008, at D6.

status of a child with a special stamp or by including the words ‘from donor.’”⁵⁸ Children born after 1990 can already petition the HFEA to disclose whether they are donor-conceived.⁵⁹

Changing current law will be difficult. A variety of interests – clinics, some recipients, some children, and many past, present, and future donors – are opposed. The culture of gamete use has come to value secrecy or, at least, the choice of identity release. In the analogous context of open records for adoption, advocates have laboriously proceeded state-by-state, using lawsuits, lobbying, and referenda in an ongoing effort to change the existing closed records situation. On the other hand, as technology enables the donor world to obtain more information through genetic tests and internet registries⁶⁰, existing practices are clearly being challenged.

Others have suggested model legislation that would require the state to maintain records concerning the identity of gamete donors and recipients, but would permit donors to choose to remain anonymous⁶¹ or that would require the release of medical and genetic information, but not identifying information.⁶² Depending on how these information requirements are administered – if, for example, there is a national mandatory registry -- these proposals might guard against donor siblings marrying each other, and might also prevent one donor from creating more than a specified number of children. Such a national registry could also be used to prevent one person from becoming the biological

⁵⁸ See Caroline Jones, “The Changing Face of Families: A Controversial New Proposal Would Mean a Special Stamp on the Birth Certificates of Babies From Donor Eggs or Sperm. How Will This-and Other New Laws-Affect Families?,” *The Mirror* (London), Jan. 10, 2008, p. 40.

⁵⁹ Add in IFFS surveillance *Fert. & Ster. Re variation in national programs*.

⁶⁰ For discussion of this, see, e.g., Swink and Reich, *supra* note ____.

⁶¹ Sara Cotton, et al., *Model Assisted Reproductive Technology Act*, 9 *J. Gender, Race & Justice* 79-80 (2005).

⁶² Pino D’Orazio, “Half of the Family Tree: A Call for Access to a Full Genetic History for Children Born by Artificial Insemination,” 2 *J. Health & Biomedical Law* 267 (2006).

progenitor of countless (literally) offspring. Without a central information repository, even if an individual bank imposes a limit, nothing prevents the donor from offering his or her services elsewhere; a national, mandatory registry could protect against this outcome.

On the other hand, these proposals do not go far enough in recognizing the offspring's needs for information, nor the donors' and recipients' needs for closure and connection.⁶³ It is important to acknowledge that genetic ties may be important for a variety of reasons. Without essentializing the notion of genetic connection, children may still want to know where they came from.

The British Human Fertilisation and Embryology Authority (HFEA) provides one model of a national, mandatory system where clinics must report information on all cycles involving donor eggs, sperm, and embryos, beginning with identifying information concerning the donor and continuing through to the outcome of the treatment.⁶⁴ Additional countries are similarly confronting changes in their laws concerning donor anonymity.⁶⁵

Actual implementation of the registry could be modeled on the HFEA, which operates pursuant to an enactment of the British Parliament.⁶⁶ While the HFEA is administered by the government, a US national registry could be administered through

⁶³ While this is admittedly a self-selected group, messages posted on the Donor Sibling Registry message board by mothers of donor children repeatedly mention issues of "community."

⁶⁴ www.HFEA.gov.uk. The HFEA model cannot, of course, be transferred entirely to the US context. For commentary on the British model, see, e.g., Mary Foster Reilly and Richard A. Merrill, Regulatory Reproductive Genetics: A Review of American Bioethics Commissions and Comparisons to the British HFEA, 6 Colum. Sci. & Tech. L. Rev. 1 (2005); Alicia Ouellette, et al., Lessons Across the Pond: Artificial Reproductive Technology in the United Kingdom and the United States, 31 Am. J.L. & Med. 419 (2005).

⁶⁵ See Howard W. Jones, Jean Cohen, Ian Cooke, and Roger Kempers, IFFS [International Federation of Fertility Societies] Surveillance 07, 87 Fert. & Ster. S1, S8-13, S33-36. (April 2007).

⁶⁶ <http://cop.hfea.gov.uk/cop/COPContent.aspx?M=0&S=71&SM=83&P=58#content>.

federal funding and mandate with a board composed of all stakeholders. Information would remain private, except to the donor, the offspring, and the gamete recipients. The HFEA system allows children to check whether they result from donor gametes. Donors might also be required to update their information when the child turns 18. When children turn 18, they should be able to receive identifying information about their donors. The “no contact” statement would be helpful as children considered what to do with the information.

Allowing for the release of a donor’s identity recognizes that biology is not everything, but that a child’s identity develops through multiple sources. Releasing this information does not change the identity of the child’s parents. In this connection, the law must guarantee that donors cannot assert parental rights based on their status as donor; in the case of known donors, if the donor signs a contract providing for contact with the child, or if there is some other basis – such as functional parenthood – then, of course, the donor may be able to use these other legal mechanisms for establishing rights.⁶⁷ Legal certainty concerning the rights – or lack thereof – of donors must accompany the establishment of a registry in order to protect the interests of the recipient parents in the stability of their new family.

Adults created through gamete provision have a strong interest in having access to information about their biological origins. Regardless of whether anyone involved actually seeks this information in any particular situation, there are a variety of justifications to make it available and to mandate a national mandatory registry that would include stakeholders, but that would involve public, governmental oversight. For

⁶⁷ See Naomi Cahn, *Test-Tube Families*, chapter 12 (forthcoming 2008); Susan Crockin, presentation for symposium.

the now-grown child, this information may be critical to a sense of identity, satisfying emotional and psychological needs.⁶⁸ Moreover, the private nature of the process, keeping the donor's identity confidential, does not accord with the realities for many recipient families, as shown by the enormous success of the Donor Sibling Registry in helping biologically-related families find one another. Offspring, as well as their families, often want connections. Once offspring learn information about their donors, they can search for others who share the same genetic heritage. The numbers of donor-conceived offspring is increasing -- in 2005, the most recent year in which data is available there were more than 15,000 cases of egg donation and more than 6,000 babies born, and, while there are no reliable data, estimates of the number of children born each year range from 30,000-60,000 -- and, as they learn of their origins and the lack of knowledge available to them, these offspring will create additional pressure to maintain and then disclose information.

A final issue concerns the retroactive/prospective nature of a registry. It is important to acknowledge that permitting access may disrupt the expectations of some donors and recipients who have relied on continued secrecy. Nonetheless, as in other areas of family law, the interests of adults and their settled expectations are subject to override based on public policy concerns, including a child's best interests or other reasons underlying the change in controlling law.⁶⁹ And, going forward, a new system could guarantee that all involved in the donor process are aware of the changing aspect of disclosure through mandated counseling. All donor records would still remain sealed, except in the limited circumstance of allowing an offspring access to information.

⁶⁸ [please add in cites for Andrea Braverman and Jean Benward's article for the symposium.]; see Keith Griffith, *Who Am I? Your Right to Know* (2008)(unpublished paper on file with author).

⁶⁹ See supra at nn. ___ (discussion of Johnson and the UPA); Cahn and Singer, supra note ___.

For multiple reasons, the United States should move towards a mandatory registry that would collect information on donor gametes. All clinics and sperm banks would be required to report certain data. Sperm banks should provide information on each donor, including number of “donations,” as well as identity. Clinics should provide comparable data on egg and embryo donors (they already provide data on the number of pregnancies and births).⁷⁰ To ensure the security of this information, the registry would be required to establish sophisticated encryption systems. Second, donors could keep their identity secret, but only until any future offspring reached the age of 18, at which time the offspring could seek access to the identifying information. In recognition of the donor’s interests, the donor could file a non-binding no contact preference form; in recognition of the offspring’s interests, the identifying information would nonetheless be disclosed (together with the existence of the no contact form). Finally, the United States should consider mandatory limits on the number of offspring produced by any donor’s gametic contributions.

Private mutual registries already exist. The next steps require more regulation. Taking those next steps requires the involvement, participation, and cooperation of the multiple stakeholders both within and outside of the donor world.

⁷⁰ As Susan Crockin points out, there may be no need to include egg and embryo banks or recruiters because use of eggs or embryos requires a clinic’s involvement. See [paper for symposium].