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**OLD LESSONS FOR A NEW WORLD:
Applying Adoption Research and Experience
to Assisted Reproductive Technology**

Policy & Practice Perspective

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Funded and Prepared by: The Evan B. Donaldson Adoption Institute

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Table of Contents

EXECUTIVE SUMMARY	3
INTRODUCTION	6
THE FACTS ABOUT ART.....	8
THE ISSUES	9
1. Openness & Secrecy, Anonymity & Information Access	10
<i>Information Disclosure in Adoption.....</i>	11
<i>Information Disclosure in ART.....</i>	12
2. Who is the Focus of the Service?.....	14
<i>Availability of Services to Diverse Clients</i>	15
3. "Market" Regulation.....	17
4. Legal Regulation.....	20
DISCUSSION & RECOMMENDATIONS	22
1. Access to Personal Information & Maintenance of Records	22
2. Development of Best Practices to Serve All Parties.....	23
3. Research Regarding the Experiences of Those Served	23
4. An Assessment of the Impact of Market Forces.....	24
5. Development of Legal Frameworks	24
CONCLUSION.....	25
REFERENCES	26
APPENDIX	32

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Executive Summary

Adoption and assisted reproductive technology (ART) have much in common; most significantly, both processes are used to create families in which the child is not genetically related to one or both parents. Similarly, adoption and ART policy and practice must balance the sometimes-competing rights and interests of the parties involved, whether they are gamete providers, recipients and donor-conceived offspring, or birthparents, adoptive parents and adopted persons.

ART refers to a range of artificial methods used to achieve pregnancy. This report focuses on those ART services that result in a child who is not genetically related to one or both of the intended parents as a result of sperm, egg, or embryo donation, as these situations most closely parallel adoption.

While adoption has needs for continued research and professionals are still striving to improve its policies and practices, it has a far longer history as a means of family formation than does ART. Adoption has been the subject of more extensive studies and experience, and it has evolved as greater knowledge has been developed about its implications for everyone it affects. Most pointedly, some processes that once were embraced as positive have been found to undermine the best interests of children and families, so evidence-informed policies have taken – and continue to take – their place.

ART has a relatively short history and, as a result, there has been less time to learn about its impact on children, donors, recipients, and newly created families. Evidence-informed practices and policies from the adoption world – developed as a result of research and refined by listening to the voices of adopted persons and birth and adoptive parents – offer guidance applicable to ART. Lessons from adoption could benefit adults who use ART, individuals who provide gametes or act as gestational surrogates, professionals who provide services and, most importantly, children born through reproductive technologies involving donor gametes.

The Adoption Institute published its initial examination of ART in 2000, in the fourth volume of its “Ethics in Adoption” book series; the subject was also part of the Institute’s national conference (cosponsored with Ethica) on Ethics in Adoption in October 2007. The Institute plans, over time, to continue examining a range of issues relating to adoption’s lessons for ART – as well as the implications of those technologies on adoption itself. In this new report, we will focus more narrowly on areas in which ART policy and practice might be strengthened through the application of relevant knowledge derived from decades of adoption research and experience.

Just as there are questions about the use of some words in the adoption world (such as birthmother), some terms in ART also raise issues. Specifically, men and women who provide their gametes for use by others in assisted reproduction are typically called “donors,” suggesting that they – like organ donors – do not receive compensation. In reality, most sperm and egg providers are paid for their reproductive cells and their time. Nevertheless, since the word “donor” is commonly used in the ART world and in public discussion, for clarity it is also sometimes used in this report.

Key Findings

The research in this report leads the Adoption Institute to five principal findings:

- The problematic effects of secrecy and of withholding information – on adopted persons, birthparents, and adoptive families – offer insights for ART policy and practice related to the circumstances of a donor offspring’s conception, disclosure of medical and other background information, and the identities of those involved.
- The child-centered focus of adoption provides a vital perspective for placing greater attention on the children conceived through ART.
- Adoption has knowledge to share concerning the creation of “nontraditional” families, particularly as more single, gay, and lesbian adults use ART.
- ART and adoption can mutually benefit from examination of the impact of market forces (including the costs of services and the potential commodification of the individuals involved) on the ethics and quality of services provided.
- The legal and regulatory framework for adoption provides a model that ART can utilize to inform its standards and procedures.

Recommendations

Based on those findings, the Adoption Institute makes these recommendations:

- *Access to Personal Information and Maintenance of Records.* Children born of ART should be able to learn the circumstances of their births, as well as their biological and medical backgrounds. To ensure that this happens, the U.S. should join Great Britain and other countries in mandating that donor-conceived offspring be given access to this information at age 18, and practice models should be implemented for ART practitioners to provide for such disclosure. The U.S. also should establish a national database to collect, maintain, and facilitate access to information enabling gamete providers to routinely update the medical, historical, and other information they supplied at the time of donation.
- *Development of Best Practices to Serve All Parties.* To develop best practices for ART, further research should identify more clearly the similarities to and differences from adoption in serving the interests of everyone involved, most importantly the children. Counseling should be provided to all participants in ART akin to that in best-practice adoptions, including improved informed-consent procedures for gamete providers and recipients and post-birth counseling to support families in giving relevant information to their donor-conceived children.
- *Research Regarding the Experiences of Those Served.* Research drawing from relevant adoption lessons should be conducted to expand professional and participant understanding of the experiences of all members of assisted-reproduction families – including those headed by gay, lesbian and single parents – and to gauge the extent to which services are available to adults wishing to utilize ART.
- *An Assessment of the Impact of Market Forces.* In order to create more constructive, ethical practices, the market forces affecting adoption and assisted reproductive technologies – supply, demand, costs and income – should be analyzed to develop a better understanding of how they influence decision-making by gamete providers, birthparents, recipient families, and prospective adoptive families.

- *Development of Legal Frameworks.* States should enact legal and regulatory frameworks for ART, based on model legislation and research, as well as on the experiences of other states and nations, to promote ethical practices and provide protections for gamete providers, intended parents, and offspring.

Taking these steps could help ART progress from its current state – of achieving the medically possible – to providing research-informed practices that focus more attention on the long-term medical, psychological and social needs of those it serves.

OLD LESSONS FOR A NEW WORLD: Applying Adoption Research and Experience to Assisted Reproductive Technology

INTRODUCTION

The world of adoption has developed significant knowledge through generations of experience and research, some of which could be used to inform improved policies and practices relating to assisted reproductive technology (ART). Adoption's lessons are particularly relevant when the technology involves the use of "donor" sperm, eggs, and embryos, which create families in which the child is not genetically related to one or both parents. Both adoption and ART are means of creating families outside of the traditional model of a biological mother and father; both are alternatives for adults who are infertile or who do not have partners with whom they can procreate; and both raise ethical and practical implications for everyone involved.

ART is a general term referring to methods used to achieve pregnancy by artificial means, encompassing a range of fertility treatments – from the placement of fertilized eggs from the gametes of the intended parents into the mother's uterus (in vitro fertilization/IVF) to sperm/egg (gamete) and embryo donations.¹ ART has a much shorter history than adoption and, as a result, it has not benefitted from as many opportunities to learn about its impact on children, gamete providers, and intended parents. While sperm donation has been practiced for more than a century,² successful IVF – with the egg and sperm of the intended parents – only began with the 1978 birth of Louise Brown, the first child thus conceived. More recent approaches, such as egg³ and embryo⁴ donation, result in children with no

¹ According to the Centers for Disease Control and Prevention, "Although various definitions have been used for ART, the definition used by CDC is based on the 1992 Fertility Clinic Success Rate and Certification Act that requires CDC to publish the annual *ART success rates report*. According to this definition, ART includes all fertility treatments in which both eggs and sperm are handled. In general, ART procedures involve surgically removing eggs from a woman's ovaries, combining them with sperm in the laboratory, and returning them to the woman's body or donating them to another woman. They do NOT include treatments in which only sperm are handled (i.e., intrauterine – or artificial – insemination) or procedures in which a woman takes medicine only to stimulate egg production without the intention of having eggs retrieved."

² Artificial insemination of humans and animals was practiced in Europe since the early part of the 19th Century, but the first insemination using donor sperm was recorded in the U.S. in 1884 (Blyth, 1999).

³ In egg (or oocyte) donation, eggs are removed from a donor, fertilized in vitro and implanted in the intended mother, who is not genetically linked to the child. Though the intended father is often genetically related to the child because his sperm is used, less commonly the donated egg is fertilized with donated sperm, in which case neither intended parent is genetically linked to the child. Existing embryos conceived with a donor's egg also may be implanted into a surrogate, who becomes the gestational mother. This method (called gestational or carrier surrogacy) – in which the woman carries a fetus with no genetic relationship to her – differs from the traditional form, in which the surrogate contributes her egg for insemination with sperm from the male partner of the intended parents (Seibel, et al., 1993).

genetic connections to one or both of the intended parents, thereby establishing closer parallels to adoption than did earlier ART processes.

Just as there are questions about the use of some words in the adoption world (such as birthmother), some terms in ART also raise issues. Specifically, men and women who provide their gametes for use by others in assisted reproduction are typically called “donors,” suggesting that they – like organ donors – do not receive compensation. In reality, most sperm and egg providers are paid for their reproductive cells and their time. Nevertheless, since the word “donor” is commonly used in ART world and in public discussion, for clarity it is also sometimes used in this report.

The world of adoption, informed by generations of experience and research, offers a body of knowledge that can be useful in the development of ART policy and practice. Adoption itself has evolved, and is continuing to do so, as more has been learned about its implications for the adopted person, birth family, and adoptive family. Most pointedly, some adoption processes that once were embraced as positive have, with experience, been found to work against the best interests of children and families, and evidence-informed practices have taken – and continue to take – their place. The secrecy that characterized adoption’s past hindered the application of its lessons to other realms; as it has emerged from the shadows, however (particularly in relation to increased information sharing and greater openness among those it affects), adoption now can provide an opportunity to gain a deeper understanding of its lessons and, potentially, to broaden the application of these lessons to other means of family formation.

For instance, over the last several decades, adoption has explicitly focused primarily on “the best interests of the child,” a concept that has become its guiding legal and practice principle, while reproductive technology typically continues to place the needs and desires of the intended parents at its core. Similarly, over the past decade, increasing attention has been focused on the market forces in adoption that can impact the ethical professional provision of services – a discussion that has not received the same consideration related to ART. Adoption practice also has evolved to a point where education about adoptive families, counseling relating to non-genetic relationships, and other support services are generally considered integral components of good practice, whereas such practices in ART are in their infancy.

Abuses and dubious practices certainly take place in adoption, but it is governed by international treaties, federal and state laws and regulations, and mandatory licensing requirements; agencies and attorneys, therefore, are subject to legal and regulatory sanctions, as well as lawsuits by clients. ART is less regulated, and in a more patchwork way: State laws require that physicians be licensed, while federal laws require that fertility clinics report success rates for IVF (including the use of donor eggs and embryos), and perform some safety testing on gametes (including for HIV and other infectious diseases as well as an examination of medical records for risk factors). Some states have more

⁴ Embryo donation involves the implantation into an intended mother of a pre-existing frozen embryo created from another’s IVF attempts and donated – usually anonymously – by these individuals. In such cases, the resulting child is not genetically linked to the intended parents. As in egg donation, the intended mother may be the gestational mother or a surrogate. There are more than 400,000 frozen embryos in storage in the U.S, a small percentage of which are available for donation because most intended parents have completed their treatments and few wish to donate the embryos to other couples (Cahn, 2008).

extensive regulations than others, although there are numerous aspects of fertility practice that face little regulation and governmental oversight. For example, there are no federal and few, if any, state legal limits on how many times an individual can provide gametes, so theoretically one sperm donor may father hundreds of children.

Adoption's history – good and bad – offers a rich body of knowledge that could strengthen ART policy and practice to the benefit of the gamete providers, the intended parents and, most pointedly, the children who are conceived. This report examines how adoption's lessons can be applied to the world of donor sperm, eggs, and embryos. It provides an overview of the issues at the intersection of adoption and assisted reproductive technology, and explores how best practices and policies in adoption can provide relevant information for the development of comparable procedures in ART. These lessons could help ART progress from its current state – in which it is achieving the medically possible – to providing research-informed practices that focus more attention on the long-term medical, psychological, and social needs of those it serves.

The Adoption Institute published its initial examination of ART in 2000, in the fourth volume of its "Ethics in Adoption" book series published by the Child Welfare League of America (CWLA); the subject was also part of the Institute's national conference on Ethics in Adoption (cosponsored with Ethica) in October 2007 (<http://www.ethicsconference.net/>). This new report addresses issues that are common to family formation through adoption and ART – practices related to information disclosure, who is the focus of the services, the extent to which market forces shape each service, the special considerations related to these alternative family forms and the legal structures governing the parties to them. Finally, this report suggests steps that could be taken to improve ART policies and practices by learning from adoption-related research and experience – even as adoption professionals continue working to improve their own policies and practices.

THE FACTS ABOUT ART

The use of assisted reproductive technologies has grown dramatically over the past decade, with the number of infants born as a result of ART (not including births from sperm transfers) more than doubling from 20,840 in 1996 to 52,041 in 2005 (CDC, 2007). In 2005, the most recent year for which data are available,⁵ there were more than 15,000 cases of donor egg transfers, resulting in the birth of more than 6,000 babies (CDC, 2007). There is no comparable government record-keeping for births using provided sperm;⁶ estimates of the number of these children born each year range from 30,000 to 60,000. While there are no official statistics on the number of surrogacy births each year, some experts estimate that up to 1,000 babies were born in this way in 2007 (Allie & Kelley 2008). (See Appendix A for additional ART statistics.)

There are no comprehensive, current statistics for the number of adoptions. The best available totals come from the National Center for State Courts (NCSC), but the types of adoptions are often not specified. In 2001, according to NCSC data, there were 127,630 court-recorded adoptions in the U.S.

⁵ The CDC released its report with 2006 data in late January 2009, but relevant data were not yet posted on its website and a hard copy report could not be obtained in time for use in this publication.

⁶ Some women may self-inseminate with donor sperm; and while many women use physicians, doctors who perform such inseminations are not required to report this information.

(Flango & Caskey, 2005), but many international adoptions are not represented in these figures.⁷ Of the NCSC total, an estimated 40 percent (51,000) were by stepparents⁸ and about 50,000 were of children from foster care (Flango & Caskey, 2005). According to U.S. State Department visa data, there were 19,224 international adoptions into the U.S. in 2001. The number of domestic infant adoptions has been estimated at around 14,000 a year (Hamilton, Ventura, Martin & Sutton, 2004), although some believe the number is higher. For the reasons noted – see for instance, footnote 7 – the number of specific kinds of adoptions does not add up to the number of NCSC court-recorded adoptions in this country.

Growing numbers of individuals have sought medical treatment for infertility over the past 25 years (Stephen & Chandra, 2000). According to the National Survey of Family Growth (Chandra, Martinez, Mosher, Abma, & Jones, 2005), by their early 40s, 19 percent of women have used some sort of infertility service (including advice), 2.6 percent have had artificial insemination, and 0.7 percent have used another form of ART. Approximately one-quarter (26%) of women who have not given birth and have used infertility services have adopted a child by ages 40-44 (Jones, 2008). One study found that of those adoptive families who experienced infertility, about half have undergone medical treatment, and they have done so for an average of three years prior to adopting (Barth, Brooks, & Iyer, 1995). Much more needs to be understood about how prospective parents view assisted reproduction and adoption as responses to infertility in order to facilitate informed decisions about family building.

THE ISSUES

Four primary policy and practice issues confront both ART and adoption – issues that adoption researchers, practitioners, and policymakers have studied, debated, and addressed for longer than some types of assisted reproduction have existed:

- A shift from a climate of secrecy and withholding of information to one of greater transparency and the open sharing of information among the affected parties;
- An understanding of which parties are the chief beneficiaries of the service provided and when, with particular attention to the implications for children and the availability of services to a diverse range of clients;
- Heightened attention to the market forces that affect both types of family formation and that can impact the ethical professional provision of services; and
- The need for clear legal regulation that sets the parameters for the provision of the services involved and that enhances accountability.

The focus in this discussion is primarily on ART, drawing from adoption's relevant lessons and with analysis of comparable issues in adoption.

⁷ Most international adoptions are finalized in the child's country of birth rather than in U.S. courts, so only in those cases where parents complete a re-adoption in a U.S. court do international adoptions count in U.S. court statistics.

⁸ This is based on the fact that in 1992 (the last year in which this information was available), 26 states identified stepparent adoptions as 42% of their total adoptions (Flango & Flango, 1995).

1. OPENNESS & SECRECY, ANONYMITY & INFORMATION ACCESS

A Donor-Conceived Individual. Sarah reports that she found out when she was in her 20s that she was conceived through sperm and egg donation. She suddenly realized she had no “real world” connection to her genetic heritage. She wondered if she had biological brothers and sisters – and she had no idea how she could find out. Sarah asked many other questions, too: Why is this absence of information the reality for donor-conceived children? Why do doctors, nurses, and, even, parents think it’s not important for us to have tangible connections to our genetic heritage? People who are adopted seem to be able to get this information – sometimes as a matter of course and sometimes when they locate their biological relatives. Why can’t we?

There is a continuum of information-sharing (or lack thereof) among the affected parties in both adoption and ART, ranging from total secrecy to full disclosure. The types of information involved fall into three basic categories: a person’s status as adoptee or donor offspring (as a child and into adulthood), non-identifying information such as medical and social history, and identifying information on birthparents or gamete providers that reveals their identities or can lead to such identification.

Secrecy was often the norm in adoption during the first half of the 20th Century, to the point where adoptive parents were frequently advised not to tell their children they were adopted. Now, however, it is considered best practice to counsel parents about their children’s need to know their adoptive status early in their lives. Adopted children today, as opposed to those in past generations, typically learn at a young age how they entered their families. Adoption professionals overwhelmingly believe it is best practice to provide this information, and many excellent resources have been developed to help parents do so. Similarly, non-identifying background information about children and their birth families is routinely shared with prospective adoptive parents; and identifying information is increasingly made available to adopted persons because a fast-growing number of adoptions are “open” from the start or through access to their original birth certificates, mutual consent registries, confidential intermediary programs, and a burgeoning array of Internet services.

By contrast, as a recent study concluded: “There has been a longstanding culture of secrecy surrounding the use of donated gametes, at least for the majority of donor-conceived children who are born to heterosexual parents. Indeed, until relatively recently, legal and policy frameworks reflected a prevailing assumption that children conceived in this way would not benefit from having access to information about their genetic origins,” and parents often did not even tell children that they were donor conceived (Freeman, Jadvá, Kramer & Golombok, in press, p. 1). The vast majority of “donations” have been kept anonymous; ART practitioners have frequently counseled parents not to disclose this information; many parents report uncertainty about how to share it, and the extent to which background information is maintained and available varies greatly from clinic to clinic (Sforza, 2007; Freeman, Jadvá, Kramer, & Golombok, in press). Sforza (2007) estimates that “some 100,000 children have been born of donor eggs in America since 1984,” but “the vast majority apparently don’t know it.”

Many experts in the ART field are advocating for broader information disclosure, including the American Society for Reproductive Medicine (ASRM), which encourages parents to tell their children about the gamete donation (ASRM, 2008). Current practices in the donor world with respect to disclosure, as well as current efforts to advocate for more extensive disclosure, are beginning to benefit from ongoing research and analysis (Golombok, in press; Freeman, Jadvá, Kramer & Golombok, in press).

INFORMATION DISCLOSURE IN ADOPTION

As mentioned above, adoption policies and practices related to secrecy have changed dramatically over the past several decades, with information about children's birthparents now routinely shared with prospective adoptive parents and vice-versa. In the early part of the 20th Century, information about family origins was minimal at best, as it was rarely recorded and, to the extent that it existed, it was often inaccurate (Freundlich & Peterson, 1998). Beginning in the 1950s, more background was collected, but disclosure tended to be selective, with only positive information generally shared with prospective parents (Freundlich & Peterson, 1998). Today, it is widely considered as best practice to capture as much information as possible and to make non-identifying portions – health, social, and other data about birthparents and the child's history – available to both adoptive parents and adult adoptees (Freundlich & Peterson 1998).

At the same time, practice has shifted so that in domestic infant adoption, expectant mothers – and fathers, when they are involved – most often select the adoptive parents for their children, and they typically receive background information on prospective adoptive families in order to make an informed choice (Freundlich, 2000; Pertman, 2000). Indeed, Grotevant has suggested that the contemporary model of adoption “is additive: Parenting rights and responsibilities are transferred, while connections established by birth are maintained yet significantly transformed” (Grotevant, 2007, p. 125). Adoption practice has evolved toward more openness to the extent that it is common today for birthparents and prospective adoptive parents to meet, and a growing number maintain contact after the adoption (Henney, McRoy, Ayers-Lopez & Grotevant, 2003; Grotevant, Perry & McRoy, 2005; Pertman, 2000).

Laws about access to original birth certificates by adult adopted persons also have evolved in response to an adoption reform movement throughout the English-speaking world (Carp, 2007). Adult adoptee access to these documents, which contain birthparents' names, has been a hotly debated issue in the U.S. even as the trend has moved toward greater disclosure. At the policy level, this debate has played out in a growing number of states where bills have been introduced to “unseal” original birth certificates; currently, eight states provide access to them for adult adoptees, while many others do so in more limited ways – but the trend toward more disclosure, both retrospectively and prospectively, is growing (Evan B. Donaldson Adoption Institute, 2007). In the international arena, there has been increasing legislation and advocacy on this front, with laws in Scotland, England, Australia, and some Canadian provinces passed to provide adult adoptees with access to their original birth certificates (Carp, 2007).

Clinical literature has highlighted the psychological impact on adoptees of both secrecy and a lack of information about their origins, associating secrecy with barriers to trust and intimacy in the parent-child relationship and the lack of information with confusion, uncertainty, and other negative psychological effects (Brodzinsky, 1987; Hartman, 1993; Schooler & Norris, 2002). The negative impact of secrecy on adopted persons and adoptive family functioning also has been documented in research, beginning with a landmark study (Triseliotis, 1973) and continuing to current research on the impact of secrecy and of withholding information on adoptive family dynamics and intimate relationships for adopted adults (Brodzinsky, 2006; Passmore, Foulstone & Feeney, 2007). Triseliotis found that secrecy and lack of information had negative effects on adoptees' identity and overall mental health, and that finding out accidentally about one's adoption was often traumatic (Triseliotis, 1973; Triseliotis, Feast & Kyle, 2005). A recent Australian study investigated the impact that openness or secrecy in family communication had on 144 adopted adults; it found that those who experienced greater secrecy felt less close to their adoptive parents, perceived them as less caring and more controlling, and experienced more loneliness in the family (Passmore et al., 2007).

Brodzinsky (2005) has asserted that what is most important is the extent to which parents are open with their children in communicating about adoption, regardless of how little or how much information they may have about their children's origins. This concept of "communicative openness" has been shown to be associated with more positive child and family functioning in both adopted children and children conceived through ART (Brodzinsky, 2006; Paul & Berger, 2007).

INFORMATION DISCLOSURE IN ART

Like adoption in its past, assisted reproduction has been marked by both secrecy and anonymity (Benward & Asch, 1999). Sperm donation, the earliest form of gamete transfer, was associated with significant stigma for the intended father and, as a result, virtual anonymity surrounded it. Historically, information on sperm providers, including medical history, was not sought at all, was gathered only minimally or, when collected more completely, was destroyed after a short time (Asch, 1985). Recipients were not told the identities of the sperm providers, who themselves were not informed of the outcomes resulting from their donations. Similar to the rationales in adoption, anonymity in sperm transfers grew from the desire to protect the privacy of recipients, their families, and their legal parenthood; there also was a desire to protect donors against future financial responsibilities for offspring and to protect doctors from future claims relating to the insemination.

The practice of complete secrecy in assisted reproduction has changed, however, at least with respect to the collection of non-identifying information. In the late 1980s, the spread of AIDS – and resulting federal recommendations that all donor inseminations use frozen, quarantined semen – precipitated several changes in information-sharing procedures. Clinics began to collect fuller histories from sperm providers, to disclose this information to recipients, and to maintain more extensive records (Benward & Asch, 1999). Sperm banks now not only collect fairly comprehensive information from providers, but may also maintain records on them; some offer photos and videotapes of them for recipients to review; and there is growing support for providing identifying information on donors to offspring (Benward & Asch, 1999; Cahn, 2009a). Sperm banks also increasingly allow their clients to choose either identified or anonymous donors (Cahn, 2009a). In 2009, the Ethics Committee of the ASRM recommended that donors provide updates of any serious genetic or other health conditions – but there is no long-term legal obligation for the providers to update their records regarding medical or other important information that could affect their offspring in the future.

In contrast to the long-standing practice of anonymity for sperm donors, egg donation began almost exclusively with known providers (Cahn, 2009a). As new technologies decreased the risks associated with the process, however, anonymity became more common (Cohen, 1996) and, today, most egg programs use anonymous providers.⁹ Much as was the case in adoption throughout the 1950s and 1960s, when social workers matched adoptive parents and children without any involvement by birthparents, in ART doctors or nurses traditionally made the match between recipients and donors (Mead, 1999). This practice is changing, with recipients having increased autonomy and control in the selection of egg providers; indeed, recipients can now access enormous amounts of information about them (Plotz, 2005). Nonetheless, it continues to be general practice that egg providers are not given information on recipients and the two parties do not meet, although recipients may see pictures of the donors. As the following account illustrates, it is difficult for providers to update health information that could be important to the children conceived with their eggs:

⁹ For further exploration of the processes involved in egg/ sperm donation and interviews of participants, see Almeling (2007).

Last year Kelly, a 41-year-old egg donor who doesn't want her last name used, lost her mother to colon cancer and her grandmother to Alzheimer's. She believes children conceived from her eggs deserve to know that. Kelly says she tried to contact the clinic she donated to 17 years ago to update her file, but got no response (Kalb, 2008).

The need to know about family health history is one reason cited widely in the adoption field for broader disclosure. The U.S. Surgeon General's Family History Initiative describes this information vitally important in the diagnosis and treatment of medical conditions and illnesses that are genetically based (U.S. Surgeon General, 2005). And the Human Genome Project makes clear that, to take advantage of advances in genetics, people need detailed information about their medical and genetic histories.

The centrality of genetics to one's well-being is widely accepted and increasingly vital. Family health history facilitates the prevention, diagnosis, and treatment of disease and assists in reproductive planning. Genetic information has the potential to aid in the prevention, early detection, pre-symptomatic diagnosis, and treatment of thousands of inherited diseases, including cognitive, sensory, physical and behavioral disabilities, and chronic illnesses. Much more needs to be understood about the reasons families choose not to disclose how their offspring were conceived – but, as with adopted people, it appears that a growing number of donor-conceived individuals want to know more about their origins (Scheib, Riordan, & Rubin, 2005). For example, the Donor Sibling Registry, a non-profit organization, operates a voluntary mutual-consent, internet-based registry for matching offspring and donors. More than 22,000 donors, parents, and children have signed up since the registry began in 2000, and more than 6,000 half-siblings and/or donors have been connected through it (Donor Sibling Registry, 2008), indicating a significant desire for contact for families already formed through gamete donation. We also know anecdotally and through media stories that a rising number of donor-sperm offspring are searching for – and finding – their biological fathers, both to gain medical/biological information and simply to meet them. However, there are no state laws that mandate the disclosure of identifying information on gamete providers or facilitate contact.

Policymakers, ART professionals, and intended parents could profit from the lessons adoption has learned about the medical, psychological, and social benefits of knowing more about one's background. While many activists within the donor movement make this point in arguing for greater openness and disclosure, not all professionals are convinced. Moreover, there are issues related to parent education about disclosure (reasons for disclosure, counseling related to how this is handled, and other services for families), a topic that is becoming the subject of increasing study in both adoption and ART (Jones & Hackett, 2007; Jadva, Freeman, Golombok & Kramer, 2007).

Greater disclosure would yield important benefits in gamete donation beyond providing information to offspring. Unlike in adoption, through ART, a single man is capable of providing sperm for numerous children; the Donor Sibling Registry reports as many as 105 half-siblings from one man's sperm. The disclosure of identifying information would provide safeguards against half-siblings, unaware of their biological relationship, engaging in accidental incest (sometimes called inadvertent consanguinity) by having sexual relations or even marrying each other. It would also yield data needed to limit the number of children created through one person's donations; in England, for instance, a sperm donor can provide gametes to no more than 10 families (Cahn, 2009b).

The American Society for Reproductive Medicine has developed best practice guidelines for professionals involved in assisted reproduction, including recommended (but non-binding) recommendations on the numbers of potential donations (ASRM, 2004; ASRM, 2006a; ASRM, 2007). Whatever the U.S. might ultimately decide, it seems reasonable that the subject should be discussed and policy should be set rather than allowing "anything goes" to be the rule.

As with adoption, issues related to sharing/withholding of information in ART arise in several contexts. As professional organizations and social workers involved in ART recommend greater disclosure to recipients, providers and offspring, adoption can offer legal models, knowledge about the health, psychological and social issues to be considered, and tested practices relating to how, when and to whom information is disclosed.

2. WHO IS THE FOCUS OF THE SERVICE?

A Donor-Gamete Recipient. Wendy Kramer – co-founder of the Donor Sibling Registry – describes how she and her husband made the decision to use donor insemination. They "sat down in front of a secretary at a computer when it came to matching time, and Wendy said, 'I have brown hair and green eyes, but he's only 5-feet-7 inches tall.' Her husband was getting agitated. Wendy pointed at him and said to the secretary, 'Here's what the donor should look like, make it close.' And they left." The clinic arranged for the sperm of a Los Angeles man to be shipped to Colorado for \$500. Their son, Ryan, was conceived over the Labor Day Weekend of 1989. They were given no information about the donor until years later, when they learned his number on a file, a few details about his physical appearance, and that he was an engineering student.

Had Wendy and her husband decided to pursue adoption through a reputable agency, they would have spoken to a trained counselor, not a secretary. The social worker would have helped them assess their readiness to parent a child with other genetic parents and would have worked with them to address any issues relating to their infertility and qualms or questions they might have had. A trained professional would have matched them with a child based on a range of factors that would *not* have included eye color or height (factors that adoption used in the past but has since rejected as superfluous, at best, and sometimes harmful). An expectant mother planning adoption would have selected Wendy and her husband as prospective parents for her child; all of the adults probably would have had the opportunity to meet and to develop a plan for provision of ongoing medical information, get answers to the child's questions over time and, to the extent they mutually agreed, remain in contact. They – and their child – would have received far more than a file number.

Examining the parties served through adoption and assisted reproduction necessarily raises the question of who is the primary client for each service. Adoption is generally perceived as a social process that places importance on the parents' wishes but, first and foremost, should benefit the child. ART, by contrast, usually has been defined as a medical process that addresses solely the needs of infertile adults, with the primary client in egg, sperm, and embryo transfers being the recipients. To some extent, these different emphases stem from the reality that in adoption, a child or pregnancy already exists, while in assisted reproduction, they do not and services are provided prior to conception. Nevertheless, adoption's child-centered focus offers valuable guidance in thinking through the parenting, counseling, and disclosure issues in ART.

Balancing the needs and interests of all parties in the adoption process is an ongoing challenge for practitioners and policymakers. Engaging in unethical practices or ignoring the rights of one party can lead to harmful consequences to every participant, as when a pregnant woman is coerced into making a decision to relinquish her child for adoption. It is not always clear how birthparents or donors are

considered in terms of “client” status, especially when the prospective parents pay all expenses, including for any medical, psychological, or legal services, as well as for material supports to donors or birthparents. This financial arrangement can present a conflict of interest for service providers and can confuse the issue of whose best interests are being considered. There has been growing attention to this issue in adoption as birthparents have gained stronger voices and as their rights have been more widely recognized. The status of gamete providers as “clients” remains less clear.

There are obviously significant differences in the experiences and interests of pregnant women and gamete donors. In adoption, prospective birthmothers may be relatives, friends, or strangers to the prospective parents; similarly, donors may be either related or unrelated to recipients and either known (or identified) or anonymous. Unlike birthparents, for whom expenses such as medical bills can be covered, gamete providers can be explicitly paid for their “donations.” But the body of research on birthparents is substantial (Wiley & Baden, 2005), while there is little research on the donors in ART – so the understanding of their experiences is limited. Studies on birthparent experiences have tended to focus on women who voluntarily place their children for adoption – as opposed to birthfathers of infants or parents whose parental rights were involuntarily terminated (Wiley & Baden, 2005; EBDAl, 2006). This research has yielded important information on the social and psychological impact of relinquishment on the women involved and, consequently, has informed adoption practice and professional training. Far less is known about the long-term implications of being a donor, so more research and analysis are required to ensure that the needs and rights of all parties are respected.

AVAILABILITY OF SERVICES TO DIVERSE CLIENTS

Another aspect related to the focus of services is their availability to a diverse clientele. Can single individuals, Americans of moderate or lower income, and gay or lesbian individuals or couples readily utilize ART services? The vignette below illustrates this issue.

In May 2008, the California Supreme Court heard arguments on the rights of Guadalupe Benitez, a lesbian, to receive infertility treatment. Two doctors – both at the only infertility clinic covered by her insurance – claimed their religious beliefs concerning homosexuality would not allow them to provide her with the treatment she sought (Egelko, 2008). In August 2008, the court decided that, under California antidiscrimination law, the physicians could not refuse services based on the patient’s sexual orientation – although they could still prove they refused to provide services because Benitez was unmarried (North Coast, 2008).

Accessibility of services in ART and adoption involves a range of issues, including economic considerations; concerns related to stigma, equity and discrimination; and the manner in which services are delivered. Social work and other counseling-related professions have a substantial body of knowledge on practice with diverse populations, including techniques for delivering culturally sensitive services, programmatic strategies that facilitate client access and retention, and addressing discrimination in agency policies and state laws. Adoption professionals have addressed these issues as well (McRoy, 2004; Wegar, 2004; Mallon, 2006 & 2007; Matthews & Cramer, 2006; Ryan, Perlmutter & Groza, 2004); and adoption laws and policies have been created to prevent discrimination. These issues have been addressed for decades in the field of adoption, and ART professionals have begun to address them as well (Gurmankin, Caplan & Braverman, 2005; Peterson, 2005; Burnett, 2005).

Adoption is a legal means for creating “families by choice” (Grotevant, 2007, p. 137) – including by single adults, whether they are gay or straight – and the same is true for assisted reproduction.¹⁰ But who can adopt is a question of state law; currently, adoption by gay or lesbian individuals is legal in 49 states, although there are some restrictions in a few other states, such as prohibitions on adoption by unmarried, cohabitating couples. Access to ART depends on the policies of individual clinics. In both contexts, practices run the gamut; that is, there are adoption agencies that are increasingly welcoming of single, gay, and lesbian parents, and others that limit adoption to individuals who are heterosexual and/or are married; and there are clinics that accept a wide variety of clients and others that provide services only to heterosexual couples (Cahn, 2009a). A recently published survey of fertility clinics found that 50 percent were likely to turn away a man who does not have a wife or partner, 20 percent would not accept a single woman, 17 percent would not provide services to a lesbian couple, and 5 percent would reject a biracial couple (Gurmankin, Caplan & Braverman, 2005).

Assuming that a single, gay, or lesbian individual/couple is able to access fertility services, not all states provide legal avenues to establish the parental rights of adults to the children of their unmarried partners; in the states that do not, gay/lesbian partners have less security in their legal rights as parents (Cahn, 2009a). A growing number of states have enacted civil union or domestic partnership statutes, which grant registered couples substantially the same rights as if they were married, and one state (Massachusetts) now allows same-sex couples to marry. Questions remain, however, about parental rights when couples in same-sex marriages, civil unions, or domestic partnerships move outside of the state that legalized their relationship.

Some states do not recognize that assisted reproduction occurs outside of marriage, and that gay, lesbian, and single parents use these services. In Oklahoma, for instance, only doctors can perform insemination, and their patients are limited to married couples; the child is considered the same as a “naturally conceived legitimate child of the husband and wife” (10 Okla. Stat. Ann. §§ 552-53, 2007).

There is still considerable progress to be made in making ART services accessible to adults who have moderate or lower incomes, to single individuals, and to gay or lesbian clients. While there has been a longer history of addressing these issues in the adoption field and there is more protection in state laws against discrimination in adoption services, these concerns continue to require attention by adoption professionals as well.

¹⁰ Many of the issues raised by families formed by single individuals and by gay and lesbian individuals or couples are different, and we do not mean to suggest otherwise. Nonetheless, these are families formed outside of the heterosexual, married couple that has traditionally been postulated as the “appropriate environment” for raising a child. (Pertman, 2000).

3. “MARKET” REGULATION

An Egg Donor. Julia Derek reports that when she first decided to sell her eggs, she thought: “All that couple would ever get from me was an egg – a *cell*. It was kind of like giving someone one of my hairs. Then, later, that hair would become a child to whom I would merely be the *biological* mother. . . Heck, I didn’t even have it in my stomach for nine months, so how could I ever consider it mine? In other words, all I would sell would be a tiny, tiny cell containing my genes.” (Derek, 2004, p. 8) Julia sold her eggs 11 times without counseling about the meaning of doing so or any possible long-term implications.

Julia writes about being attracted to becoming an egg donor by the significant payments created by the supply and demand market; however, she subsequently realized she had given little or no thought to the potential impact on her years later. Had she instead been a pregnant woman placing a baby through a competent adoption agency, she would have received counseling about such things as the mixed emotions she might experience in the future; the questions she might have about the child she helped to create; or the desires she might have to know about or even meet that child. She also most likely would have received specific information about the family raising the child.

Basic market forces influence the professional providers of adoption and ART, the processes themselves, and all parties involved. There is, therefore, a need for regulation to safeguard participants’ rights and to deter unethical practices. The costs associated with both donor ART and adoption (except from foster care) are considerable – often tens of thousands of dollars – so most people who access either service have significant resources. Meanwhile, gamete providers (but not embryo donors) and women who place their children for adoption typically possess far fewer financial or other resources, resulting in what is often described as a “power imbalance” that can influence the services provided (Freundlich, 2001). Those seeking donor insemination or adoption services usually pay the bills for service providers and donors/birthmothers, for example, and they may specify their expectations regarding the age, health, ethnicity, and other characteristics of the children they wish to parent – and those realities presumably can affect motivations, policies, and practices.

Adoption is not an industry in which babies can be legally sold, but one in which prospective parents pay fees to practitioners (usually agencies or attorneys), intended to cover the costs involved in the process, such as home studies, counseling, and legal services. Total expenditures to adopt an infant domestically or a child from abroad vary greatly, from as low as \$5,000 to \$50,000 or more. Adoption from foster care is the exception; any fees are typically reimbursed and sometimes there are subsidies.

In many cases, pre-adoptive parents also cover prospective birthmothers’ expenses during pregnancy and after delivery. When a pregnant woman’s expenses are paid, they cannot legally be contingent on her relinquishing her baby. It is legal, however, for prospective parents to pay for medical care and, in some cases, living and travel expenses during pregnancy (Hollinger, 2008). These laws vary significantly around the country. Some states define the expenses that may be paid (see Vermont Rev. Stat., Tit. 15A, § 7-103(a), 2007); others refer generally to “reasonable and necessary expenses” (see Arizona Rev. Stat. § 8-114(A)-(B), 2008); and yet others have broader rules that allow for payment of the biological mother’s medical and living expenses as well as services such as counseling and attorney fees (La. Ch. C. Art. 1201, 2008).

Inconsistencies in the language and enforcement of state laws on payment of adoption expenses may leave open questions about whether individual cases cross the line between legal reimbursement of

expenses and dubious transactions that could be construed as coercive or even as payment for a child. But the principled authority of state governments to regulate the payment of adoption-related expenses is well-established and the “reasonable fees” standard has been judicially interpreted and professionally debated. In contrast, payments relating to ART are largely unregulated, providing yet another context where assisted reproduction might benefit from adoption’s experience. Moreover, there are ethical and moral issues that warrant discussion; for instance, in both realms, prospective parents may pay amounts significantly greater than average in order to choose children with specific characteristics.

Money is an issue with ART at two levels even before the baby arrives: the overall costs intended parents pay to service providers and the fees paid to gamete providers. While state laws typically regulate which birthparent expenses prospective adoptive parents can pay, they rarely address compensation for gamete providers. Payment for sperm and eggs is legal in most of the U.S., with an explicit ban in place only in Louisiana (Cahn, 2009c). The American Bar Association’s 2007 Model Code Governing Assisted Reproduction provides that compensation must be “reasonable” and not conditioned on “purported quality or genome-related traits” or “actual genotypic or phenotypic characteristics.” ASRM makes nonbinding recommendations on the appropriate levels of payments to donors (ASRM, 2004; ASRM, 2006a; ASRM Ethics Committee, 2007). Their most recent recommendation for compensation to egg donors is \$5,000, with justification for sums between \$5,000 and \$10,000 required, and no payments above \$10,000 (ASRM Ethics Committee, 2007). Individuals are often paid well for their “donations,” with considerably lower amounts going to men (average payment for sperm in 2000 was \$60-\$75 per donation) than to women (payments for eggs range from about \$3,500-\$50,000) (President’s Council on Bioethics, 2004), partly because the process of doing so is far more complex and invasive.

Donor sperm, eggs, and embryos are “sold” and represent part of a multibillion-dollar assisted-reproduction industry in the United States (Spar, 2006). Charges for basic in vitro fertilization begin at around \$5,000. Donor sperm may cost a few hundred dollars, with intra-uterine insemination adding \$2,000 to \$3,000 more, but cycles involving donor eggs and embryos may cost \$10,000 or more. Fewer than one-third of all states require that insurance cover any infertility services (Mundy, 2007; Arons, 2007). There is considerable debate in the infertility community about the exchange of money for gametes in assisted reproduction (Shanley, 2001; Ertman & Williams, 2005). Some argue that such payments do not necessarily translate into a negative practice, while others contend that they amount to “commodification” and that payment for human eggs and sperm is immoral, unethical, and psychologically demoralizing.

Regulations relating to embryo donation and surrogacy – which stand at the intersection of assisted reproductive technology and adoption – vary from state to state. Louisiana law provides that “[i]f the in vitro fertilization patients renounce, by notarial act, their parental rights for in utero implantation, then the in vitro fertilized human ovum shall be available for adoptive implantation in accordance with written procedures of the facility where it is housed or stored” (La. Rev. Stat. §9:130 (2008)). Nationally, several private organizations, including some “traditional” adoption agencies, arrange for embryo “adoption” – rather than sale – in a system comparable to traditional adoption, complete with the screening of prospective parents and home studies. Most pointedly for the purpose of this analysis, there are substantial costs involved with embryo “adoptions.” A “Snowflake Adoption” – one organization’s approach to providing individuals with an embryo that has been created from the egg and sperm of others – requires thousands of dollars in fees because the organization charges a program fee and requires home studies for parental applicants.¹¹ There are serious questions that presumably should be

¹¹ Snowflake estimates that families pay \$12,000 to \$14,000 in program, home study, and medical fees. <http://www.nightlight.org/snowflakefaqsap.htm>, Nightlight Christian Adoptions, “Snowflakes Frozen Embryo Adoptions.”

debated as to whether this “adoption” approach is suitable for embryo transactions: not only is there no guarantee that a child will result from an embryo transfer, but also the concept of embryo “adoptions” treats them as equivalent to a child.

The issues relating to money in assisted reproduction also include compensation to surrogates. Fees for the women who carry and deliver babies for others typically range from \$8,000 to \$15,000, but can run much higher. The acceptability of paid surrogacy is itself hotly debated. There is no uniformity among the states on surrogacy, with a few banning the practice entirely, others enacting laws governing it, and some allowing courts to decide the enforceability of surrogacy contracts on a case-by-case basis.

The gamete market in the United States operates differently from its counterparts in most of the world. In some parts of Europe, most of Latin America, and many Muslim nations, egg donation is prohibited (Mead, 1999; International Federation of Fertility Societies, 2007) and in some countries, fees associated with sperm and egg donation are strictly regulated. According to the International Federation of Fertility Societies, 31 of the 57 countries surveyed – unlike the U.S. – have national laws that deal with ART practice.¹² There are places, however, where there is less regulation than in the U.S.; indeed, a fertility tourism industry has developed, in which prospective parents travel abroad for the hiring of surrogates and other procedures. For instance, the *New York Times* reported in March 2008 that “reproductive outsourcing” is booming in India.

The ethical dilemma for adoption and ART with respect to payment is quite similar: Is a pregnant woman paid for expenses so she can make the decision of whether to relinquish her baby, or with the expectation that she will do so? Is the donor compensated for her time and the medical procedures she undergoes, or is she paid for a potential baby? The question then becomes how much should be paid and for what services. A steady rise in adoption fees, discrepancies found in the processes of placing children of different races and ethnicities, and the willingness of some families to pay higher fees to adopt children who physically resemble them or have “desirable” qualities further suggest that from a market perspective, infant adoption and assisted reproduction have significant parallels.

Neither pre-adoptive parents nor infertility patients view their prospective children as products; in constructing the financial aspects of adoption and donor insemination services, however, the systems that serve them have been the subject of criticism about commercialization. Increasing fees in adoption (particularly for infants domestically and for children from abroad) have precipitated concerns related to the commodification of children, just as higher fees to donors with specific characteristics in ART have been criticized as contributing to the commodification of gametes and to the transformation of babies into products that doctors “manufacture.” These practices also have raised concerns about the impact of high fees on the decisions made by birthparents and donors with limited financial resources. Much more needs to be understood regarding the socioeconomic backgrounds and needs of donors and the extent to which economic issues play a role in decision-making in gamete donation and affect longer-term psychological outcomes for them; for example, should gamete providers get more education/information before giving informed consent? Should they have the opportunity to receive pre- or post-donation counseling? And how should those costs be absorbed?

¹² For a list of the countries and whether they have national laws, voluntary guidelines or neither, see Table 2.1 and page 14 that references new laws in Finland, Portugal and Spain that are not included in Table 2.1 at http://www.iffs-reproduction.org/documents/Surveillance_07.pdf

4. LEGAL REGULATION

Barnard College President Debora Spar, observed:

Because infertility treatments have a substantial medical component and often involve procedures that incite moral debate, the industry is a natural candidate for government oversight. In most parts of the world, such oversight is already in place. In the United States, by contrast, federal regulation is minimal (Spar, 2006, p. 34).

Adoption from the foster care system is subject to both state and federal laws, infant adoption is regulated by state laws, and international adoption is regulated by treaty as well as by federal and state laws – and most of these statutes center on the best interests of the child (as well as the fitness of the parents). Courts are necessarily involved in finalizing all adoptions, and there are clear legal rules regarding the respective rights and responsibilities of the biological and adoptive parents. Furthermore, some states explicitly recognize post-adoption contact agreements, delineating levels of contact between the child’s original and new families.

Adoption services are provided within a coherent, long-standing legal and regulatory structure, and some oversight mechanisms are in place. Agencies must be licensed by state authorities; attorneys must be members of the state bar or subject to disciplinary bodies that oversee professional practice; and courts have ultimate oversight in finalizing adoptions. Although relevant laws vary widely from state to state – and there is ongoing debate about whether there are sufficient laws, rules or monitoring – some aspects of adoption are consistently regulated, such as the requirement that adoptive parents have approved home studies (Hollinger, 2008).

There is one federal statute that regulates ART, the Fertility Clinic Success Rate and Certification Act of 1992; its purposes are to give consumers reliable, useful information about fertility clinic success rates and to provide states with a voluntary model embryo laboratory certification process. State regulation is piecemeal and, to the extent it exists, has evolved slowly through case law and issue-specific provisions in reaction to emerging issues. According to the President’s Council on Bioethics (2004):

In short, there are very few state laws that bear directly on assisted reproduction. Most of these laws relate to the provision of insurance coverage for infertility treatment. A few state laws directly relating to ART focus on health and safety concerns; a handful of states provide modest consumer protections. Some state laws regulating embryo research may indirectly affect ART practice, though the decisional law in this area is unsettled. In the main, however, assisted reproduction is regulated at the state level by the same mechanisms that apply to the practice of medicine more generally, namely, through the licensure and certification of practitioners (Chapter Two, Assisted Reproduction, III. Current Regulation).

Among the issues not regulated are limits on the number of times one person can provide sperm or eggs and how many embryos can be implanted in one woman, raising concerns both about the resulting genetic half-siblings and the health and welfare of children who are among the increasing number of ART-related multiple births. There is also little regulation of contracts between gamete donors, gamete banks and recipients, or of screening of parents (age, health, parenting ability). ASRM has non-binding recommendations on the number of embryos that should be transferred at one time, depending on the patient’s age. The recommendations range from one or two embryos in patients

under age 35, to 5 embryos for patients older than 40, and possibly more for those with two or more previous failed attempts (ASRM, 2006b). According to ART professionals contacted for this report, most clinics follow ASRM recommendations.

The rights of adults who become parents through assisted reproduction differ from state to state. The advent of donor insemination precipitated the need to define legal fatherhood outside of biology or adoption. When initially faced with determining paternity when a wife had been inseminated with donor sperm, some courts opted to treat the child as “illegitimate,” while others deemed the woman’s husband as the legal father based on his consent to the insemination (Cahn, 2009a). Given inconsistent court holdings, state legislatures eventually weighed in, with current statutes continuing the latter approach. These laws provide that a husband who consents to donor insemination is the legal father and the sperm donor has no legal rights or responsibilities for the child (Cahn, 2009a). Until states provide more binding guidance for non-marital families, however, there will be legal uncertainties with respect to the parentage of donor-conceived offspring – for instance, when a lesbian in a relationship does not have legal parental standing with her partner’s child conceived through donor insemination.

The law is less clear regarding determinations of parenthood when egg and embryo transfers are involved. A few states have enacted legislation specifying that providers have no legal responsibility for children who are conceived through the use of their eggs (an approach consistent with laws related to the obligations of sperm donors), but most states have not addressed this issue at all (Cahn, 2009a). Similarly, there are numerous legal questions concerning parentage in adoptive families that are formed outside of the heterosexual married couple, including by single parents and gay and lesbian couples, as there are with ART (Arons, 2007).

The Uniform Parentage Act (2002) (UPA), model legislation proposed by the National Conference of Commissioners on Uniform State Laws, provides that children born through sperm, embryo, and egg donation are to be treated comparably to each other in terms of identification of parents and termination of the rights of donors. The act, however, has been enacted in only a handful of states (National Conference of Commissioners on Uniform State Laws, 2008), although other states that have not enacted the UPA have nonetheless addressed some of these issues in their laws. The ABA’s Model Code Governing Assisted Reproduction (2007) is consistent with the parentage provisions of the UPA. The ABA goes further, however, and “give[s] assisted reproductive technology (ART) patients, participants, parents, providers, and the resulting children and their siblings clear legal rights, obligations, and protections. These goals are accomplished by establishing legal standards for the use, storage, and other disposition of gametes and embryos, by addressing societal concerns about ART, such as clarifying issues of health insurance coverage for the treatment of infertility, and by establishing legal standards for informed consent, reporting, and quality assurance.” The Model Code also addresses donor identity, counseling, compensation, and surrogacy.

An issue of serious concern in ART is the maintenance of information. Although federal regulations mandate safety testing of donated gametes (for HIV and other infectious diseases) and examination of medical records for risk factors, they do not require long-term retention of the donors’ medical and historical information. Indeed, fertility clinics have generally kept limited records about donors and, in an effort to ensure anonymity, some have destroyed all records. A very recent recommendation from the Ethics Committee of the ASRM (2009) is that donors be “strongly encouraged” to update programs with information about serious genetic or other conditions that related to their offspring’s health.

In adoption, medical, historical, and other background information are considered vital; some records containing such information are retained by the practitioners (usually agencies or attorneys) and others are kept by government offices. However, gaining access to this information continues to be a challenge for many adopted individuals. In addition, registries of various sorts are widely utilized to provide information, as well as to expedite searches for biological relatives.

Some in the fertility industry have advocated for the creation of a voluntary registry to assist donor-conceived individuals in gaining information about themselves. One such registry already exists; the Donor Sibling Registry, a non-profit Internet-based databank, has enabled thousands of people to find biological relatives. A more systemic means for addressing access to information might be the creation of a National Donor Gamete Database, along with programs to ensure its effectiveness and confidentiality. In fact, the ABA has crafted a model for states, if a national registry is established, that includes but is not limited to the following:

- *Procedures to allow the disclosure of non-identifying information and, when appropriate, protect the anonymity of donors and gestational carriers;*
- *Procedures to allow the disclosure of identifying information about participants only if mutual consent of all parties affected is first obtained;*
- *Maintenance of medical and genetic information, and updated current health information, including change in health status, about the donor;*
- *Procedures to allow disclosure of non-identifying medical and psychosocial information to the resulting child;*
- *Determination of whether a resulting child may contact a program; and*
- *Retention of all records involving third party reproduction until the resulting child has reached the age of majority (ABA, 2007).*

Through a coherent legal and regulatory structure, along with oversight mechanisms similar to or informed by those in place for adoption, ART could standardize practice and ensure accountability for decisions made on behalf of donors, recipients, and the children conceived through gamete transfers.

DISCUSSION & RECOMMENDATIONS

This report is intended to provide an overview of the significant overlaps between ART and adoption on a range of issues. These commonalities include the involvement of multiple parties in family formation, the lack of genetic connection between at least one parent and child, the history of treating information about the service and about the parties involved as secret or confidential, and economic and market issues that can profoundly affect the shaping and delivery of services.

Evidence-informed policies and practices from the adoption world – developed as a result of decades of research and experience and refined by listening to the voices of adopted persons and birth and adoptive parents – offer much for ART to consider as its own policies and practices evolve. The following recommendations are intended to aid the continued development of strong, ethical processes and protections in the provision of assisted reproduction services.

1. ACCESS TO PERSONAL INFORMATION & MAINTENANCE OF RECORDS

Building on clear lessons learned in adoption, offspring born of ART should have access to information about themselves and the circumstances of their births – from their parents as they grow up and, once they reach the age of 18, through independent access to identifying information about the gamete/embryo donors and medical and social histories. To ensure this information's availability, the U.S. should join Great Britain and other countries in mandating that records be maintained that identify

sperm, egg, and embryo donors. Practice models should be developed for clinics, gamete banks and other entities involved in all aspects of assisted reproduction, including models that provide for the full disclosure of health information, updating of that information, and safeguards to minimize risks to children. Donors should be able to easily and regularly update medical and other information they initially provided, and donor-conceived offspring should be able to make connections through existing and new registries. The growing body of laws and procedures that facilitate greater disclosure in adoption provides a useful model for the ART world.

Work is needed to synthesize the best practice protocols already developed for ART – by the ASRM, the ABA, and the President’s Commission on Bioethics, as well as adoption law and practice – and to advocate for state law to implement procedures for:

- Ensuring the maintenance, confidentiality, disclosure and availability of defined elements of non-identifying and identifying information prospectively and, to the extent possible, retrospectively;
- Disclosing gamete providers’ health histories and ongoing health information to recipients;
- Facilitating contact among parties to ART and their other relatives;
- Establishing safeguards to prevent incestuous relationships by biological siblings, minimize risks to children born through multiple births, and limit the number of gamete donations from one donor and of embryo transfers performed at one time; and
- Developing procedures for informed consent and counseling concerning information disclosure.

2. DEVELOPMENT OF BEST PRACTICES TO SERVE ALL PARTIES

Practices should be carefully analyzed to more clearly identify their implications for the interests of gamete providers, recipients and, most importantly, donor offspring. Careful analysis of the points of intersection between adoption and ART would be helpful to synthesize existing research and best practice protocols for ART providers developed by ASRM, the ABA and the President’s Commission on Bioethics, as well as adoption law and practice, and to advocate for state law or industry best practice to implement procedures for:

- Identifying the extent to which explicit reliance on the principle of “best interests of the child” in adoption may be relevant in the context of donor insemination and the interests of offspring; and
- Developing counseling models for all participants, drawing on adoption’s lessons, including improved informed-consent procedures for donors and recipients and post-birth counseling to support parents in providing information to their children. The informed-consent procedures should ensure that gamete providers understand the terms of their transfers, including their irrevocability. In developing counseling models, attention should be given to the impact of money (both the cost of services and the income generated for providers) on the quality, availability and accessibility of services.

3. RESEARCH REGARDING THE EXPERIENCES OF THOSE SERVED

Additional research should be conducted to expand professional and participant understanding about the experiences of all members of assisted-reproduction families – including those headed by gay, lesbian and single parents – and the extent to which ART services are available to them. Research is needed to expand the understanding of:

- Experiences of all assisted-reproduction family members, donors, and gestational surrogates;
- Access to needed services for gamete providers, recipients, and donor offspring;
- Approaches to equitable access to services and development of appropriate guidelines;
- Factors that lead recipients to decide to disclose or not disclose information to their children;

- Agencies, businesses, and service providers in each area, such as those involved in screening prospective parents, counseling any participants, documentation, and record-keeping; and
- Experiences of gay, lesbian, and single parents in the assisted-reproduction area to determine how they can best be served.

4. AN ASSESSMENT OF THE IMPACT OF MARKET FORCES

The market forces that affect the provision of ART services should be examined, with a particular focus on how they influence decision-making by donors and recipient families, in order to provide a foundation for developing evidence-based policies regarding appropriate payments. This analysis should synthesize and build on research and best practice protocols developed by ASRM, the ABA and the President's Commission on Bioethics, and should advocate for state law or industry best practice to implement procedures for:

- Payments to sperm and egg providers, taking into account the impact of the donor-recipient gap in income and other resources;
- Payments for embryo "adoption" and donation, and their differences; and
- Addressing financial issues for prospective parents, such as access to insurance coverage for infertility services.

5. DEVELOPMENT OF LEGAL FRAMEWORKS

Legal and regulatory frameworks for ART should be developed by synthesizing existing standards and protocols developed by ASRM, the National Conference of Commissioners on Uniform State Laws, the ABA and the President's Commission on Bioethics. Moreover, ongoing development of models must address the needs of all parties, based on research in ART and adoption, and on laws in some states and other countries. Advocacy is needed to bring about implementation of these standards in state laws and industry policies. The focus of research and development of legal frameworks should include:

- Approaches to information collection and disclosure in adoption and ART;
- Approaches to donor market regulation; and
- Legal frameworks for recognizing the parental rights of gamete recipients and the termination of parental rights of providers and surrogates.

Important steps in these processes include:

- Developing appropriate models for providing ongoing information to children (and their parents) conceived through ART and for giving them access to relevant records once they reach age 18;
- Analyzing the need for legislation that provides for secure collection of information about the number of births from all forms of assisted reproduction, and for ensuring that accurate information is collected and stored;
- Assessing the need for legislation in the U.S. that would restrict the number of donations from one individual to prevent inadvertent incest, and that would limit the number of embryos that may be implanted in one woman; and
- Developing legislation governing informed consent for both gamete providers and recipient parents concerning not only the medical consequences of their use of the technology, but also the potential needs of the children conceived.

CONCLUSION

Because there are genuine differences between adoption and ART, and because there is so little research relating to the latter, some comparisons in this report are imperfect and not all the recommendations offered are concrete. Nevertheless, it is apparent that there are significant similarities and intersections; moreover, in many ways (particularly relating to secrecy, stigma, and shame), ART is traveling the same road – and risks making some of the same mistakes – as adoption did in its past. To be sure, policy and practice in adoption has a long way to go, but it nevertheless has much to teach based on its generations of experience and a solid, growing body of research. Many of these old lessons are clearly applicable to the new world of assisted reproduction.

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Appendix

National Data on ART from Centers for Disease Control and Prevention

Figure 49 below shows the increase in ART cycles in the United States, followed by a table providing a national snapshot of ART cycles.

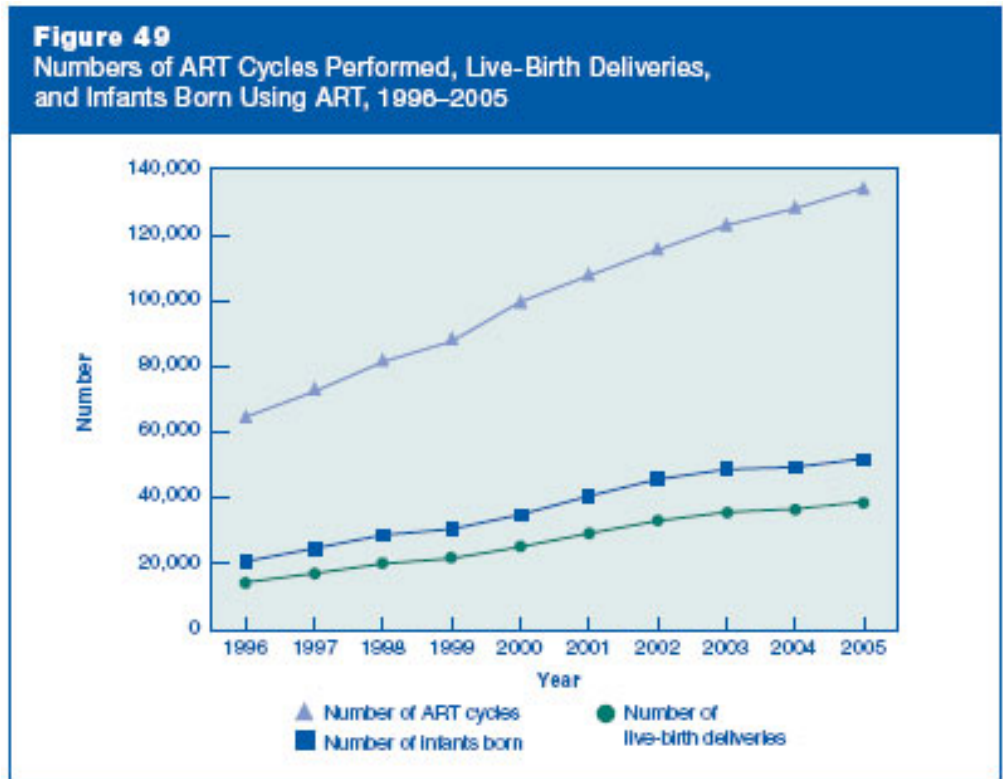


Figure 49 is a line graph with three lines: one line represents the number of ART cycles performed, one line represents the number of live-birth deliveries, and one line represents the number of infants born using ART, by year from 1996 to 2005.

- 1996: 64,681 ART cycles, 14,507 live-birth deliveries, 20,840 infants born.
- 1997: 72,397 ART cycles, 17,186 live-birth deliveries, 24,785 infants born.
- 1998: 81,438 ART cycles, 20,126 live-birth deliveries, 28,851 infants born.
- 1999: 87,636 ART cycles, 21,746 live-birth deliveries, 30,629 infants born.
- 2000: 99,629 ART cycles, 25,228 live-birth deliveries, 35,025 infants born.
- 2001: 107,587 ART cycles, 29,344 live-birth deliveries, 40,687 infants born.
- 2002: 115,392 ART cycles, 33,141 live-birth deliveries, 45,751 infants born.
- 2003: 122,872 ART cycles, 35,785 live-birth deliveries, 48,756 infants born.
- 2004: 127,977 ART cycles, 36,760 live-birth deliveries, 49,458 infants born.
- 2005: 134,260 ART cycles, 38,910 live-birth deliveries, 52,041 infants born.

Source: CDC, http://www.cdc.gov/ART/ART2005/sect5_fig49-60.htm#f49

National Summary Table

2005 ART CYCLE PROFILE

Type of ART ^a				Patient Diagnosis			
IVF	>99%	Procedural Factors:		Tubal factor	10%	Other factor	8%
GIFT	<1%	With ICSI	60%	Ovulatory dysfunction	6%	Unknown factor	11%
ZIFT	<1%	Unstimulated	<1%	Diminished ovarian reserve	12%	Multiple Factors:	
Combination	<1%	Used gestational carrier	1%	Endometriosis	5%	Female factors only	12%
				Uterine factor	1%	Female & male factors	18%
				Male factor	17%		

2005 PREGNANCY SUCCESS RATES

Type of Cycle	Age of Woman			
	<35	35-37	38-40	41-42 ^c
Fresh Embryos from Nondonor Eggs				
Number of cycles	41,302	22,624	19,482	8,997
Percentage of cycles resulting in pregnancies	43.1	35.7	26.8	17.6
Percentage of cycles resulting in live births ^b	37.3	29.4	19.7	10.6
Percentage of retrievals resulting in live births ^b	40.6	33.4	23.2	13.1
Percentage of transfers resulting in live births ^b	43.4	35.9	25.4	14.9
Percentage of transfers resulting in singleton live births ^b	27.9	24.9	19.0	12.7
Percentage of cancellations	8.2	11.8	14.8	19.0
Average number of embryos transferred	2.4	2.6	3.0	3.2
Percentage of pregnancies with twins	32.9	27.3	21.5	13.4
Percentage of pregnancies with triplets or more	4.4	5.0	4.4	2.5
Percentage of live births having multiple infants ^b	35.6	30.9	25.1	14.5
Frozen Embryos from Nondonor Eggs				
Number of transfers	9,575	4,801	2,896	972
Percentage of transfers resulting in live births ^b	31.7	27.7	23.3	15.9
Average number of embryos transferred	2.4	2.4	2.5	2.7
All Ages Combined^d				
Donor Eggs	Fresh Embryos		Frozen Embryos	
Number of transfers	9,649		4,997	
Percentage of transfers resulting in live births ^b	52.3		30.9	
Average number of embryos transferred	2.3		2.6	

CURRENT CLINIC SERVICES AND PROFILE

Total number of reporting clinics: 422			
Percentage of clinics that offer the following services:			
Donor egg	95	Gestational carriers	77
Donor embryo	65	Cryopreservation	98
Single women	89		
Clinic profile:			
SART member			89
Verified lab accreditation			
Yes			88
No			5
Pending			7

^a Reflects patient and treatment characteristics of ART cycles performed in 2005 using fresh nondonor eggs or embryos.

^b A multiple-infant birth is counted as *one* live birth.

^c See [national summary](#) statistics for women older than 42.

^d All ages (including ages >42) are reported together because previous data show that patient age does not materially affect success with donor eggs.

Source: CDC (2007), National Summary Table, <http://apps.nccd.cdc.gov/ART2005/nation05.asp>