

Disclosure Issues

FACT SHEET 61A

DISCLOSING ORIGINS: CHILDREN BORN THROUGH THIRD PARTY REPRODUCTION

by Madeline Feingold, PhD

In my capacity as a clinical psychologist with a specialty in reproductive medicine, infertile couples entrust me with their personal reproductive struggles. My first visit with a couple is often following a heart-shattering consultation with their Reproductive Endocrinologist. After many tests, medication trials, and perhaps several in-vitro fertilization procedures, these couples are given the devastating news that they cannot have a child that is genetically related to them both. However, in the same medical discussion, these couples are presented with the good news that they can possibly have a child by using donor egg or donor sperm, depending upon the nature of the reproductive problem.

Initially, many couples view the option of using donor gametes as part of a reproductive continuum, and subsequently wonder why they have feelings of depression in the face of receiving hopeful news about having a child. In fact, the use of donor egg or donor sperm is not a treatment for infertility, but rather an alternative way of family building. Nonetheless, these couples must grieve their losses.

Acknowledging and grieving the loss of a genetic child, who is tremendously longed for and desperately desired, is the first step to becoming parents through the use of donor egg or donor sperm. It is only after this period of mourning that couples are ready to make the decision to parent a child using such alternative methods as donor gametes. Parenting is a verb, and not inherently related to genetics. However, couples must grieve so that the loss of their genetic child does not cast a shadow that negatively interferes with parenting and loving the child that will be their own.

After couples embrace the idea of becoming parents through donor gametes, they invariably ask this crucial question, “Do we tell our child?” Many couples’ first reaction is to keep the use of donor gametes a secret from their child. They worry that the child will become confused about his/her identity, that he/she may be stigmatized by relatives and others in the community, and further, that the child will fail to bond with, or reject, the non-genetically related parent.

While it is easy to empathize with these concerns, couples must also examine their reasons for wishing to keep their child’s origins a secret. Feelings of shame and humiliation associated with the inability to have a genetically-related child often emerge. I remind couples that as a species we announce loudly to the world our accomplishments and victories while we hide our embarrassments. If fear and shame are at the root of not informing a child about his/her origins, there is much emotional work to do before conceiving a child with donor gametes. Every child deserves to be loved and celebrated for who he or she is, and a cloud of shame should not surround his life or a couple’s parenting efforts.

Secrecy, once the standard practice in donor insemination and adoption, has shifted toward an attitude of openness. Although both nature and nurture affect the developing child, current scientific advances demonstrate the powerful effect of genetics on our unfolding character and physiology. For example, several mental and physical illnesses are linked to heredity and knowing the correct genetic heritage may affect one’s ability to prevent or rectify a medical condition. Another push towards disclosure comes from the belief, shared by many, that all people have a basic right to know their genetic heritage. Withholding factual genetic information will cause children and their descendents to go through their life with inaccurate medical knowledge. Imagine the pain that could be prevented to a girl born through ovum donation whose mother is diagnosed with an inheritable form of ovarian

or breast cancer. Without the truth, this girl might spend her life worrying about getting a disease that she is not genetically prone to inherit. Finally, proponents of openness point to family therapy and adoption literature, which detail how secrets destroy trust and intimacy in relationships.

When I first started working with couples who were considering building a family through the use of donor gametes, I observed an interesting phenomenon. Very few couples actually thought about their future baby as growing into a toddler, child, adolescent and adult. Couples are so traumatized by the losses associated with their infertility, that they often guard themselves from the prospect of yet another loss. Couples can scarcely let themselves believe that they can have a baby. It is far too frightening to daydream about their child's first birthday, entrance to school, graduation and adulthood. Many people have told me, "I am scared of jinxing myself."

Issues of disclosure often are influenced by the sense of deprivation that couples bring to their efforts to have a child with the assistance of a third party. It is rare for a couple to think through the implications of a child's innocent question, "Where did I come from?" When couples think of a baby, this question is abstract, as babies cannot talk. However, when they think of this query as coming from their own child's lips, they must think in terms of telling their child a truth or a lie. In addition, because having a child seems like a distant dream, couples customarily do not recognize that years later they may be the proud parents of an intelligent and thoughtful teenager who takes high school biology, learns about human reproduction, and quite possibly studies a segment on the assisted reproduction technologies. Far from a couple's consciousness is the thought that their teenager may ask, "Mom, how could you have had me when you were 46?" In addition, as couples struggle with their grief and try to embrace a sense of hope, they typically are not thinking about the ease with which their teenager may be able to check all the family's genotypes in a future science class. (In fact, many teens currently participate in science labs that determine their blood type, and through this educational exercise may learn they do not share a blood type with either parent and are not genetically related to either parent.) We must all remember that the field of genetics is growing in leaps and bounds and that our children's education and fund of knowledge will be affected by these changes.

The weighty discussions of grief, loss, secrecy and disclosure naturally lead a couple to this important question, "If we did tell our child he was born through donor gametes, how should we tell him?" First, it is helpful to un-

derstand a child's normal cognitive development. All children move from an egocentric and concrete understanding of the world to an abstract comprehension of events and ideas. Anne Bernstein, in her informative book, *The Flight of the Stork: What Children Think (and When about Sex and Family Building)* (Perspectives Press, 1994), details children's cognitive development, with respect to reproduction, from the concrete idea that they have always existed, to an appreciation that they are created from genetic material.

According to Bernstein's research, the first question asked by a child is one of location, "Where did I come from?" This inquiry typically springs from the lips of a two to seven year old who believes he has always existed. The correct answer is something akin to, "You've come from a special growing place inside Mommy called my uterus." The child has asked a question, and it has been honestly answered.

Four to 10-year-olds view their origins in an increasingly complex fashion. Unlike younger children, they realize that babies have not always existed, that they must be made, and that an action must occur to initiate the "manufacturing" process. These children can be told that the baby-making process begins when a mommy and a daddy love each other, and they want to share their love with a baby. They can also be told that women and men have special things in their bodies—eggs and sperm—that make babies. When the sperm and the egg are combined, they grow into a baby inside the mommy's body.

The very challenging question to the parents of a child born through donor gametes arrives when the child reaches the age between 7 and 12. This child is a fact finder. This child appreciates that the sperm and the egg that created him must come from somewhere, and he wants to know where. This question defines a crossroad in family development because it notifies parents that their child can appreciate the contribution of a donor. In answer to this question, parents will have to decide whether or not to reveal the existence of a donor. In short, will they honestly answer their child's inquiry or will they attribute the sperm to dad and the egg to mom?

Following the discussion of normal child development, the typical response is, "So, if we are going to tell our child about the use of a donor, it seems like we should wait until he is seven." Although a child can comprehend the idea of donor at approximately age seven, seven years is a long time for a parent to wait before sharing such fundamental information. The longer one waits to impart this knowledge, the more monumental and frightening it may feel. Once "the cat is out of the bag," everyone

tends to breathe a sigh of relief. Couples often feel joyful when their child climbs into their lap calling them “Mommy” or “Daddy,” even after learning about the existence of a donor. This demonstrates that children inherently feel the difference between their parents and their genetic origins.

One term to think about regarding the relationship of a gamete donor to the child is, “Helper.” A donor is a person who *helps* a mother and father have a baby. Even a very young child can understand the concept of a helper, and parents are free to express their happiness and love for their baby and their good fortune that there were many people who helped them in their efforts. As a child’s thinking expands and his questions become more complex, the nature of the helper and the significance of the contribution can be explored. Answering the very important question of genetic origins is a process, not an event. The notion of a helper lets a parent tell a child about their origins from the very beginning: There is never a secret between parent and child.

The decision to have a child with donor gametes is an emotional journey that begins with a profound experience of loss, and culminates with a couple’s determination to build a family. Talking with a child about his third party origins commences from a young age and proceeds over a lifetime as the donor is woven into the fabric of the family and becomes part of the child’s story. A family created with donor gametes has one mother, one father, and many helpers.

Suggested Books for Parents to Read to or with Their Children:

Gordon, E.R. (1992) *Mommy, did I grow in your tummy?: Where some babies come from.* Santa Monica, CA: E.M. Greenburg Press

Schaffer, P. (1988) *How babies and families are made: There is more than one way!* Palo Alto, CA: Tabor Sarah Books

Schnitter, J.T. (1995) *Let me explain: A story about donor insemination.* Indianapolis, IN: Perspectives Press, Inc.

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TO TELL OR NOT TO TELL: ISSUES OF DISCLOSURE IN DONOR CONCEPTION

By Carole LieberWilkins, MA, MFT

The single biggest concern of individuals pursuing donor conception (donor egg, donor sperm, donor embryo, RESOLVE Fact Sheet Series

surrogacy) continues to be that of the impact on the children conceived through this family building choice. Patients want to know what is best for these children in terms of disclosure. Simply put, parents want to know whether to tell their children of their genetic origins and if they do tell their children, how to talk to them about this complex subject.

With very few exceptions, the best interests of children and their families are served by children growing up with the knowledge that they are not genetically related to one of their parents. Some reasons for this include:

- Secrets in families are damaging.
- Adoption has taught us a great deal about how children feel in families where there are genetic secrets.
- Children often sense there is a secret; sense there is “something wrong.”
- Children who sense there is something wrong in their family usually assume it is about them and assume the worst.
- Secrets almost never stay secrets forever.
- When secret information finally comes out, the feeling of betrayal can be overwhelming.
- Feelings of betrayal in families often lead to issues of trust.

The first step in addressing the disclosure issue is for parents to examine their own feelings about the donor conception. Did the couple agree on the path to take to parenthood? Did they grieve the loss of the child they thought they were going to parent? Parents can get a feel for their comfort level about how their children came into their lives by asking themselves how it feels to imagine talking to their kids about it. This disclosure involves the acknowledgement that there is a third person or another family that is connected to the child. Some feelings of being threatened by this are normal, particularly before infertility is resolved and before parents are comfortable with using a donor. As the infertile partner comes to terms with their own infertility and grieves the loss of the genetic child they will not have, they will feel more empowered, indeed entitled, to be the parent of a child whose “blood” they do not share.

How Young Children Think

Children are naturally curious about everything. A child of average intellect will ask questions about anything that comes into their head: “Where did the first tree come from?” “Where does the sun go when it’s nighttime?” The degree to which those questions will be raised will depend on the responses the child gets from parents and the atmosphere created by parents to encourage chil-

dren's inquiries. Sometimes questions arise about their birth story, or why they do not look like daddy or mommy, and a parent's discomfort may give the message that it is not a subject open for discussion. The meaning they draw from the message not to ask those questions could be damaging to the way in which the child perceives their entrance into the life of mom and dad.

When and How to Talk with Children

To understand how to talk to children about conception, we might first look at how children think. While they often sound like miniature adults, they think differently from adults. Our best efforts at explanations may be thwarted by the limitations of their developmental stage.

Parents may begin talking to children early on about their conception or how they arrived in the family. In most cases it is not conception the parents are communicating about as much as the unique path by which their child has entered their lives. Thus, the intent is for parents to begin to practice talking about the presence of the other people in that child's life to whom they may be genetically related, before the child is old enough to ask questions. One of my clients had her support group laughing when she immodestly shared that while feeding her infant daughter one morning, she asked her, "So, how do you like being adopted so far?" She was practicing, normalizing language not used in daily parlance, playing with words she knew were awkward, but taking advantage of her daughter's infancy to work her way into the kind of casual conversation about adoption (gamete donation, etc.) that would eventually be part of their conversations in the future. Parents may want to tell their children how glad they are that the donor gave what was needed so that their child could be in their life. Children may be told they have the donor's hands, or their birthmother's toes. They may say how grateful the parents are to the doctor (and donor, surrogate, birthmother, etc.) who made it all possible and how precious the child is to mom and dad.

Books can be an extremely useful tool for introducing the subject of conception and birth when it might otherwise seem awkward to do so. Books that can be helpful are those written specifically about adoption or how babies are born—of which there are many available for preschoolers—or books written for children in which the theme is adoption or blended families or the way babies become part of families.

Parents need to reflect on what feelings may arise after making these comments or after reading certain books. Is the language too awkward? As parents do they feel threatened by mentioning the third party involved in the

child's conception? The pre-verbal months provide a perfect opportunity to try on the various ways of talking to your child about their conception. Children will pick up on the non-verbal—the touch, the affect, the giggle.

What to Say

Parents should always speak the truth, but not necessarily the whole truth every time. They should use accurate, positive language. Babies are made from sperm and ova, not seeds and eggs. Babies grow in a uterus, not a tummy or a stomach or a belly. Couples are infertile for many reasons, not because mommy's tummy was broken and the doctor couldn't fix it. In spite of the value of using accurate language, my own son who was conceived through ovum donation finally told me that the words he most understood were those his dad used in a car analogy to explain his conception. People are like cars. They need all their parts to run. We were missing a part needed to make a baby.

Whether through adoption, surrogacy, gestational carrier or gamete donation, children should ideally start hearing the words related to their conception and birth by the time they are three-years-old. The reason for telling a child about third party reproduction is not because they need to know the technical details of how in vitro fertilization (IVF) or inseminations were actually performed; it is because children need to begin the process of acknowledging that there is another person or people in the world to whom they are connected in a significant and lasting way. It is normal for children to fantasize about the pieces of the puzzle that may not be filled in for many years; this is not sufficient reason to delay talking to them even though they may not yet fully understand. To tell a child of age nine or ten, essentially pre-adolescence, that they are not genetically connected to their mother or father in the way that their friends or other family members are related to their parents would be a tremendous shock, indeed perhaps perceived as a betrayal. Speaking about third party reproduction casually, early and often normalizes it. It makes the information simply a part of the family story.

Children hear words all the time they do not completely understand. They want to know how they can hear grandma's voice on the other end of the telephone. We can explain to them what we understand about sound being carried through wires. They can hear sound and see wires but that is as abstract a concept as a microscopic sperm and ovum meeting, growing inside a place we cannot see and ending up being the baby they once were. My son was told there was a part of my body that did not work. Eventually part of the telling became the labeling. The part of my body that did not work was

called my ovaries. My ovaries did not make the thing I needed to make a baby. That thing I needed is called an ovum. So another woman gave me her ovum so that he could grow inside me and be my son.

Children need an environment in which they can feel safe to blurt out their questions and thoughts. This can provide the parents opportunities to clarify misconceptions, build upon prior knowledge and gradually increase understanding. This will occur when parents bring children into their lives with pride, not shame, and resolution, not unhealed wounds. In an open, sharing atmosphere, this weighty subject need not be a burden to children but part of the multi-faceted journey of childhood and parenting. Sometimes the children will follow our lead. Sometimes the children are our guides. When we listen to the questions they ask, the path becomes clearer.

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