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DEBATE—continued

Gamete donation and anonymity

Disclosure to children conceived with donor gametes should not be optional

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The use of donor gametes in reproductive technology raises ethical, psychological and social questions that have been significant for the practice of adoption: that is, when, or if, to disclose biological origin to the child. The current wisdom is that adopted children should be told by their parents as early as possible that the family was created through adoption, and we argue that the same model should apply to the use of donor gametes. We argue that privacy concerns or other goals of parents who would prefer to avoid disclosure are outweighed by the negative consequences of holding such family secrets and by the child's right to, and medical need for, information about his/her origin. We believe fertility programmes and professional organizations ought to strongly encourage those using donor gametes to tell their child of their true origin as early as the child can understand reproduction in general.

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Studies indicate that the vast majority of parents do not disclose the use of donor gametes to their children (Klock and Maier,1991; Klock *et al*., 1994). In fact, a retrospective study of parents who conceived using donor insemination found that 86.5% had not told the child and did not plan to tell and 40% had told no one at all (Klock and Maier, 1991). Since current wisdom is that children should be told of their origins by their parents as early as possible in a family created through adoption, a process that is in many ways quite similar to the use of donor gametes to conceive a child, it is worth pursuing whether the arguments for disclosure in adoption are relevant for the issue of (non)disclosure in the use of donor gametes.

It is our argument that the use of donor gametes is sufficiently similar to adoption to justify the equivalent policy of disclosure of true origin that is used in adoption (Daniels and Taylor, 1993). At the basis of our argument is the premise that parents' privacy concerns and the intended benefits for the parents and the child are outweighed by the negative consequences of holding such family secrets and by the individual's right to, and medical need for, information about his/her origin. What gives this argument new importance is the changing face of genetic technology, which may render temporary all decisions by parents not to disclose, as detection of non-paternity becomes ever more likely in genetic testing of children and adults. Secrecy in donation, already difficult to sustain (Snowden *et al.*, 1983; McWhinnie, 1984; Rowland, 1985; Lusk, 1988; Baran and Pannor, 1989), may well become a difficult struggle for an impossible result.

Similarities between adoption and the use of donor gametes include that: both processes involve the provision of a family for those who otherwise might not have had one, the social parent is not the genetic parent, others may know the true origin of the child, and both types of families are faced with the issue of how to deal with their unusual makeup (Haimes, 1988). Differences between the two are that: with donor gametes, the child will in many cases be the genetic or biological child of one of the parents who is to raise the child, the child has not been relinquished by its biological parents, and therefore has no need to come to terms with any rejection and, in most cases, the mother who is to raise the child experiences a pregnancy, which among other things means that friends, family and colleagues are not likely to 'see' evidence of the use of donor gametes. This would reduce the number of others who know the truth about the child's origin, thereby minimizing the risk of the child finding out the truth from others. However, this is only true in theory because, in over half the studied cases where parents have reported their own choice not to tell the child of the use of donor gametes, other relatives or friends were told (Klock and Maier, 1991).

Most importantly for couples, the use of donor gametes raises many of the same ethical, psychological and social issues that are raised by the practice of adoption: when or if to tell, how to tell, whom to tell. Traditionally, in the domain of adoption, couples had been advised not to tell their child of his/her true origin. Secrecy was believed to be in the best interest of the child; it seemed unnecessary to complicate a child's life with such confusing and potentially upsetting information. Little consideration was given to the problems secrecy might create or the questions the child might ask later on, questions that parents would be unwilling or unable to answer truthfully. This tendency towards secrecy has shifted,

however, and today most adoption agencies advise parents to disclose to the child that they were adopted (Brandon and Warner, 1977; Pannor and Baran, 1984; Haimes 1988; Lamport, 1988; MacIntyre, 1990). It is true, however, that some US states still mandate 'sealed records' in adoption. Nevertheless, a similar shift has been seen in attitudes about disclosure to children conceived using donor gametes (Mitchell, 1982; Snowden *et al.* 1983; Asche, 1985; Daniels, 1988; Daniels and Taylor, 1993; Raboy, 1993) and today, the rights and information needs of these children are being given more attention and priority.

Nondisclosure has traditionally been employed to achieve several goals. It is seen as a way to ensure that the non-genetic parent be perceived as equally connected to the child, to ensure that the child grows as strong a bond with that parent as with the genetic parent, to maintain the appearance of a 'normal' family, to avoid distressing the child with the truth of his/her origin, and to allow the nongenetic parent's infertility—a condition that usually carries a negative stigma with it—to remain unknown to others (Rowland 1983; Snowden *et al*., 1983; Daniels and Taylor, 1993; Cook *et al*., 1995). Furthermore, the donor is often untraceable or unknown anyway, and some argue that this means there is little value to disclosure.

However, it is argued that family relationships are harmed when they are based on the continual lies and deception that nondisclosure necessitates (Sants, 1964; Brandon and Warner, 1977; Karpel, 1980; Snowden and Mitchell, 1981; Rowland, 1983; Baran and Pannor, 1989; Mahlstedt and Greenfeld, 1989). Nondisclosure creates family tension (which children pick up very readily) by creating an environment where an uncomfortable and fundamental lie must be concealed (McWhinnie 1967; Triseliotis, 1973; McMichael, 1980; Mitchell, 1982; McWhinnie, 1984; Humphrey and Humphrey, 1988). Family secrets give rise to touchy, problematic zones in the family's communication, which may be detected from the shunning reactions they arouse when approached in conversation (MacIntyre, 1990). Interviews with adopted adults found that children do pick up hidden messages, clues from parental looks, anger and avoidance of particular topics (McWhinnie, 1984). The tension associated with maintaining the secret, combined with these shunning responses, can have a detrimental psychological impact on the child, whose natural curiosity prompts him to ask ordinary questions about the family story (Mahlstedt and Greenfeld, 1989; Matot and Gustin, 1990).

Additionally, the secret can only be kept on the condition that it is never forgotten, but always present in the minds of the keepers (Karpel 1980; McWhinnie, 1984; Triseliotis, 1993). This means that the wound must remain forever open, in the form of a permanent, difficult interrogation: would my child still accept me totally as her parent if she knew I was not? The parents are forever 'caught in a web of a lifetime of deceit, not only with their child but with a network of relatives who will assume a relationship with the child based on kinship' (McWhinnie, 1984). Furthermore, because it is a secret, the keepers cannot seek often needed outside advice or support. The anxieties that result can also mar the couple's relations with sexual troubles and emotional difficulties (Matot and Gustin, 1990).

Attempting to maintain the secret entails a real danger that inadvertent and inadequate revelations could be made by a third party. These revelations could occur in the heat of a family argument, from the stress of a crisis period, or from another family member or family friend who were either told of the use of donor insemination, or found out accidentally (Brandon, 1979; McMichael 1980; Singer and Wells, 1984; A.M.McWhinnie, unpublished manuscript). Such revelations can be quite traumatic for the child, whether as a child or as an adult (Singer and Wells, 1984; Baran and Pannor, 1989).

Triseliotis found that every adopted adult he studied who learned of their adoption late in life or through third parties was resentful and upset, and the betrayal of trust caused irreparable damage to family relationships. Most expressed the sentiment that it 'would have been easier... to come to terms with painful facts about themselves than to live with lies and have their trust in their parents shaken' (Triseliotis, 1973). A study of adult children conceived by donor gametes reported that some suspected 'something was not quite right within their families.' In fact, one respondent reported, 'I searched for evidence of my 'adoption' for many years as a child. The [withholding of information] created a 'shroud of secrecy' and a sense of shame about something I could sense, but of what I had no real knowledge.' When they were finally told of their origin, most of the adult children reported a feeling of distrust of their parents (Turner and Coyle, 2000). If the child finds out his/her true origin inadvertently or late in life, then the child will still get all of the alleged harm of the disclosure in addition to the harm of knowing that the truth had been withheld when he/she had the right to expect it.

Inadvertent disclosure is ever more likely given the growing role of genetics in medical diagnosis and treatment. More than 700 genetic tests are now available, and both an increasing number of tests and an ever-more educated population ensure that many children of donor insemination will discover through genetic testing that they have genetic risks which would not be possible were their parents genetically related to them. Advancing genetic technology will make genetic susceptibility information, with all its ties to the risks one inherits from biological parents, an even more important part of routine healthcare; this in turn makes the possibility of keeping donor insemination forever secret a remote one.

The child has a medical need to know his/her genetic history (O'Donovan, 1988). As genetics play an increasingly large role in the diagnosis and treatment of disease and reproductive decisions, genetic history is becoming increasingly crucial information (Lamport, 1988). For example, many couples seek genetic counselling prior to conception. The potential for less invasive antenatal testing and a wider array of conditions for which tests are available will increase the number that get testing. Before counselling can begin, an accurate pedigree must be compiled for accurate assessment. Although children conceived using donor gametes may be unable to access the specific genetic information of the gamete donor, with disclosure they will, at the very least, not falsely assume that the genetic history of their non-biological parent is their own.

Such a false assumption may lead the child to be misdiagnosed, or to unknowingly forego important care or undergo unnecessary treatment. (Lamport, 1988). The parents must avoid this potential for medical harm by informing the child of his/her true origin early on.

Some may argue that to avoid the potential harm from medical decisions based on incorrect genetic history, parents can provide the health history of the oocyte or sperm donor on all of the child's medical records. This way, the child would have all their relevant medical information, without the parents' needing to disclose the truth. While this approach may deal adequately with health issues while children are young, it will be inadequate as children reach adolescence and adulthood. It is unrealistic to suppose that children conceived with donor gametes will not wonder about their risks for certain diseases when they see family members stricken, or that they will ignore certain tests or engage in certain behaviours because they do not think they are at risk. Also, they may eventually have access to their health records and notice that the history does not match the reality of their family. To wait to tell children about the use of donor gametes until such time as there is perceived to be a 'need' is to risk even greater alienation, self-esteem and trust issues than those which parents sought to avoid by nondisclosure. Again, these issues have been detailed in the extensive literature on adoption, with the resultant consensus that early disclosure is crucial for the psychological health and well being of the child and the family in adoption (Sants, 1964; McWhinnie, 1967; Triseliotis, 1973; Brandon and Warner, 1977; Chess, 1986).

The right to know as much as possible about one's true origin is another and perhaps key reason for informing children that they were born using donor gametes (Daniels and Taylor, 1993). This right has been upheld by Dame Mary Warnock, the Chair of the Committee of Inquiry into Human Fertilisation and Embryology in England, who said that with nondisclosure, the child is being used as a means to the parents' end of having a 'normal' family, and this can never be right (Warnock, 1984). Nondisclosure neglects a child's rights to autonomy and to information about their person, in favour of the parents' wish for privacy. Although parents do have their own right to autonomy, it is a fundamental tenet of Western family law that the best interests of the child should almost always be paramount (Asche, 1985; Daniels and Taylor, 1993).

We have made much of the similarities between adoption and the use of donor gametes, and have not attended equally to the differences mentioned above between these two practices. This is because we do not think that those differences are relevant for the disclosure debate. To be sure, the differences are what makes so many couples chose to undergo fertility procedures with donor gametes, rather than to pursue adoption. A genetic connection with at least one parent (in most cases) and the physical, emotional and social experience of being pregnant, giving birth, breast feeding or being the spouse of such a person, has tremendous meaning for couples on all levels. It will also have meaning for their children. It is true that all of this is different from the experience of adoptive parents and children. However, these differences in origins, genetics, biology, experiences and meanings do not negate the psychological and medical damage that can be done when parents are not truthful from the beginning with their children about something as central to their children's lives as their origins and their own life story. Furthermore, we argue that to withhold this information from children after they possess the ability to understand and process it, violates their autonomy.

We believe then that all available information concerning disclosure should be included as part of the information and counselling that couples receive during the fertility treatment process. Parents should be encouraged to use the health history of the gamete donor in all encounters pertaining to the health of the child and to tell the child about the use of donor gametes, beginning at the time of the child's earliest understanding of reproduction in general. Further, fertility programmes ought to strongly encourage those using donor gametes to conceive to tell their child of their true origin. The Society for Assisted Reproductive Technology, American Society for Reproductive Medicine, and the American Medical Association, should agree to disclosure as a standard of care for donor gamete reproductive medicine.

References

Asche, A. (1985) *Creating Children: Report of the Family Law Council of Australia.* Australian Government Publishing Service, Canberra.

Baran, A. and Pannor, R. (1989) *Lethal Secrets.* Warner Books, New York.

Brandon, J. (1979) Telling the AID Child. *Adoption and Fostering*, **95**, 13–14.

Brandon, J. and Warner J. (1977) AID and adoption: some comparisons. *Brit. J. Social Work*, **7**, 338–340.

Chess, S. (1986) *Principles and Practice of Child Psychiatry,* 2nd edn, Plenum Press, New York.

Cook, R., Golombok, S., Bish, A. and Murray C. (1995) Disclosure of donor insemination: parental attitudes. *Am. J. Orthopsychiatry*, **64**, 549–559.

Daniels, K. (1988) Artificial insemination using donor semen and the issue of secrecy: the views of donors and recipient couples. *Soc. Sci. Med.*, **27**, 377–383.

Daniels, K. and Taylor, K. (1993) Secrecy and openness in donor insemination. *Politics and Life Sciences*, 155–170.

Haimes, E. (1998) 'Secrecy': What can artificial reproduction learn from adoption? *Int. J. Law and the Family*, **2**, 46–61.

Human Fertilisation and Embryology Authority (1993) *Code of practice.* London.

Humphrey, M. and Humphrey, H. (1988) *Families with a Difference: varieties of surrogate parenthood.* Routledge, London.

Karpel, M. (1980) Family secrets: I. Conceptual and Ethical Issues in the Relational Context, II. Ethical and Practical Considerations in Therapeutic Management. *Fam. Process*, **19**, 295–306.

Klock, S. and Maier, D. (1991) Psychological factors related to donor insemination. *Fertil. Steril.*, **56**, 489–495.

Klock, S., Jacob, M. and Maier D. (1994) A prospective study of donor insemination of recipients: secrecy, privacy and disclosure. *Fertil. Steril.*, **62**, 477–484.

Lamport, A. (1988) The genetics of secrecy in adoption, artificial insemination, and *in vitro* fertilization. *Am. J. Law Med.*, **14**, 109–124.

Lusk, J. (1988) The importance of children having knowledge about their parents. In *Truth and the Child: a contribution to the debate on the Warnock Report.* Burce N., Mitchell A. and Priestly, K. (Eds), Family Care, Edinburgh.

MacIntyre, J. (1990) Resolved: Children should be told of their adoption before they ask. *J. Am. Acad. Child Adolesc. Psychiatry*, **29**, 828–829.

Mahlstedt, P. and Greenfeld, D. (1989) Assisted reproductive technology with donor gametes: the need for patient participation. *Fertil. Steril.*, **52**, 908–914.

Matot, J. and Gustin, M. (1990) Filiation and secrecy in artifical insemination with donor. *Hum. Reprod.*, **5**, 632–633.

McMichael, A.M. (1980) Social aspects. In *Artificial Insemination by Donor.* Wood, C., Leeton, J. and Kovacs, G. (Eds), Brown Prior Andersen, Melbourne.

McWhinnie, A.M. (1967) *Adopted children: How They Grow Up*. Routledge & Kegan Paul, London.

McWhinnie, A.M. (1984) Annex: the case for greater openness concerning AID. In *AID and After: papers from BAAF*, *BASW and a Scottish Working Party.* British Agencies for Adoption and Fostering, London.

Mitchell, G.D. (1982) Family making by AID. *Int. J. Sociology and Social Policy*, **2**, 69–74.

O'Donovan, K. (1988) A right to know one's parentage? *Int. J. Law and the Family*, **2**, 27–45.

Pannor, R. and Baran, A. (1984) Open adoption as a standard practice. *Child Welfare League of America*, LXIII, 245–250.

Raboy, B. (1993) Secrecy and openness in donor insemination: a new paradigm. *Politics and the Life Sciences*, **12**, 191–192.

Rowland, R. (1983) Attitudes and opinions of donors on an Artificial Insemination by Donor (AID) Programme. *Clin. Reprod. Fertil.*, **2**, 249–259.

Rowland, R. (1985) Social and psychological consequences of secrecy in artificial insemination by donor (AID) programmes. *Soc. Sci. Med.*, **21**, 391–396.

Sants H.J. (1964) Genealogical bewilderment in children with substitute parents. *Br. J. Med. Psychol.*, **37**, 133–141.

Singer, P. and Wells, D. (1984) *The Reproduction Revolution: new ways of making babies.* Oxford University Press, Oxford.

Snowden, R. and Mitchell, G.D. (1981) *The Artificial Family.* George Allen & Unwin, London.

Snowden, R., Mitchell, G.D. and Snowden, E.M. (1983) *Artificial Reproduction: a social investigation.* George Allen & Unwin, London.

Triseliotis, J. (1973) *In Search of Origins.* Routledge & Kegan Paul, London.

Triseliotis, J. (1993) Donor insemination and the child. *Politics and the Life Sciences*, **12**, 195–197.

Turner, A. and Coyle, A. (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. *Hum. Reprod.*, **15**, 2041–2051.

Warnock, M. (1984) *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, *Department of Health and Social Security.* HMSO, London.