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## ORIGINAL RESEARCH

# Emerging models for facilitating contact between people genetically related through donor conception: a preliminary analysis and discussion

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**Marilyn Crawshaw**

An Independent Researcher and Practitioner and Honorary Fellow, University of York, Marilyn Crawshaw has long standing professional and academic psychosocial interests in donor conception, surrogacy, cancer-related fertility and adoption. Marilyn has been a Social and Ethical Inspector and External Adviser to the HFEA; was the National Adviser to the UK DonorLink voluntary register for adults affected by donor conception pre-1991 from 2003 to 2013; is a founder member of the British Infertility Counselling Association and editor of its Practice Guide series; and chairs UK PROGAR the multi-agency group concerned with child and family welfare following assisted reproduction.

**Abstract** Previous research indicates interest among some donor-conceived people, donors and recipient parents in having contact. Outcomes of such contact appear largely, but not universally, positive. This paper seeks to understand better the characteristics of associated support services. Information gathered using the authors' direct experiences and professional and personal networks in different parts of the world indicates the emergence of four main groupings: (i) publically funded services outside of treatment centers; (ii) services provided by fertility treatment or gamete bank services; (iii) services provided privately by independent psychosocial or legal practitioners; and (4) services organized by offspring and/or recipient parents. Key operational features examined were: (i) who can access such services and when; (ii) what professional standards and funding are in place to provide them; and (iii) how 'matching' and contact processes are managed. Differences appear influenced variously by the needs of those directly affected, local policies, national legislation and the interests of the fertility services which recruit gamete donors and/or deliver donor conception treatments. The paper is intended to inform fuller debate about how best to meet the needs of those seeking information and contact, the implications for the way that fertility treatment and gametes donation services are currently provided and future research needs.

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**KEYWORDS:** donor-conceived people, donor conception, donors, information exchange/contact, intermediary services

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## Introduction

There is growing recognition of donor-conceived peoples' interest in learning more about their donor(s) on medical grounds, prompted by the need for more complete genetic information and medical history – not least to aid early diagnosis of disease and inform lifestyle choices to help prevent onset of adult diseases with a known hereditary component – and/or to pass on medical information to the donor and other offspring (Centres for Disease Control and Prevention, 2004; Oberlandesgericht Hamm, 2013; Parliament of Victoria Law Reform Committee, 2012; Ravitsky, 2012) and by documented cases of genetically inherited health conditions (see Tomazin, 2013; [www.donorsiblingregistry.com/resource-library/medical-issues](http://www.donorsiblingregistry.com/resource-library/medical-issues)) including where legal action was undertaken to uncover the donor's medical history (Johnson v Superior Ct, 2000). The documented need to have curiosity satisfied or psychological and social needs met is more long standing (see Blyth et al., 2012; Hertz et al., 2013). Some past donors also have an interest in and curiosity about those conceived with their donation (Daniels and Kramer, 2013; Kirkman et al., 2014; Riggs and Scholz, 2011; Speirs, 2012). There are also reports of donors' parents (Beeson et al., 2013) and offspring (Daniels et al., 2012) having an interest in contact with donor-conceived offspring.

While some donor-conceived people search for their donor(s) only, others also search for what we are here calling 'donor-related siblings' (i.e. those conceived through the same donor or non-donor conceived offspring of their donor(s)) (Jadva et al., 2010; Nelson et al., 2013; Scheib et al., 2005). Recipient parents have also been found to have an interest in learning more about their child's genetic relatives (Rodino et al., 2011). Such interest can extend to families with children conceived with the same donor having contact while the children are still young, with largely positive outcomes (Freeman et al., 2009; Goldberg and Scheib, 2015; Scheib and Ruby, 2008). We are aware of growing numbers of support groups in our own countries, both of donor-conceived people and of recipient parents, pressing for greater opportunities for contact.

The ease with which information about biological and biographical connections can be accessed is often severely limited. This may be through a lack of, or destruction of, records (New South Wales Parliamentary Committee on Law and Safety, 2013; Ravitsky, 2012; Yuen, 2007), guarantees or contracts of anonymity and privacy that may be seen to override the offsprings' desire to know (Pennings, 2001; Sauer, 2009), legislation or regulation preventing access to information (for example see: Belgium, 1996; Spain, 2006) or a clinic's reticence to assist in linkage (Adams and Lorbach, 2012; Oberlandesgericht Hamm, 2013). Even in jurisdictions where information release is mandated (usually age specific), there is no standardization in its management (Allan, 2012).

Some professional organizations have produced ethics statements or guidelines which, although not carrying statutory authority, can influence policy change. The British Fertility Society's recent Policy and Practice recommendations for good practice in information collection at the time of donation and in later information release to donor-conceived people, recipient parents and donors (Wilde et al., 2014) contributed to the decision by the UK regulator, the Human Fertilization and

Embryology Authority (HFEA) to fund a 3-year pilot specialist intermediary and support service for those approaching its statutory register (HFEA, 2014). The non-mandatory ethics statement of the American Society for Reproductive Medicine (Ethics Committee of the American Society for Reproductive Medicine, 2014) recommending the indefinite retention of records regarding gamete donation and the need for every US clinic to have an information-sharing policy also carries some influence. However, clashes with state regulations (where they exist) can lead to such regulations taking precedence, and state variations continue. For example, egg (not sperm) donor records in New York are stored until the offspring reach 21, while those in Washington are kept indefinitely (though this requirement is new so it is still subject to interpretation in practice), and there is a wide variation in clinic policies on donor anonymity. On the latter, some legal commentators have speculated that 'contracts' between donors and clinics designed to ensure anonymity will, regardless of state regulations, increasingly be subject to legal challenge (for a discussion see Rees, 2012).

For donors donating under conditions of anonymity who wish to stay anonymous, and indeed other affected parties who do not welcome contact that is not mutually agreed, the growth of genetic genealogy services (i.e. developed for purposes other than donor linking) is creating concerns. With little government or international debate on these services, they are set to continue to grow and the anonymity of those who wish to retain it following donor conception, adoption, infidelity or the like can no longer be guaranteed.

Little is known currently about routes open to those seeking and/or providing information or how best to meet such needs. Although research has been conducted into the outcomes for searchers and what information may be available to them (Adams and Lorbach, 2012), this has included little analysis of which attributes of services such as skills mix, cost and infrastructure were found to be helpful. The small amount of practice-based literature documenting work with searchers (Crawshaw and Marshall, 2008; Crawshaw et al., 2013; Daniels and Meadows, 2006; Johnson et al., 2012; Kramer and Cahn, 2013) suggests the potential importance of psychosocial (known as mental health in some countries) professional input. This is further supported by research findings that donor-conceived people learning of their origins later in life and/or in unplanned ways may be at risk of acute and lasting emotional distress and may embark on searching soon after disclosure; that some donor-conceived people have dysfunctional family experiences, whether donor-conception related or not; that some contact arrangements can prove difficult to manage; and that family relationships (including those of donors) can be affected by late disclosure and/or searching (Baran and Pannor, 1989; Beeson et al., 2013; Crawshaw and Marshall, 2008; Crawshaw et al., 2013; Cushing, 2010; McWhinnie, 2000; Turner and Coyle, 2000). Past donors have said that they would welcome access to support services in the event of searching and/or being contacted (Crawshaw et al., 2007; Hammarberg et al., 2014; Kirkman et al., 2014; Speirs, 2012).

This paper provides illustrative rather than exhaustive examples of initiatives in different parts of the world that use voluntary routes – i.e. those without legal requirements that mandate information provision or release – to respond to the growing phenomenon of people genetically related

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