
The Social Work Role in Assisted Conception

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SUMMARY

The provision of assisted conception has become a major industry in most industrialized countries, buttressed by powerful professional and commercial interests. Assisted conception has significant implications not only for those directly involved or affected, but also for wider society. The paper summarizes the contribution social work has made to the debate and to service development, especially in the UK. The author argues that the ethical values underpinning social work, and the knowledge and skills possessed by social workers, provide both an opportunity and a mandate for social workers to influence the development of assisted conception services, in particular to ensure that the human implications of providing children for people who are involuntarily childless are not subordinated to the pursuit of technical efficacy.

ASSISTED CONCEPTION SERVICES IN THE UNITED KINGDOM

The 1990 Human Fertilisation and Embryology Act (hereafter the ‘1990 Act’) regulates fertility treatment involving the use of donated embryos and gametes (oocytes and sperm) or fertilisation of gametes outside the human body. Centres providing these treatments are regulated and licensed by the Human Fertilisation and Embryology Authority (HFEA). Three of the Act’s provisions are of special relevance to this paper. First, a licensed treatment centre must not provide treatment ‘unless account has been taken of the welfare of

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any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth’ (section 13 [5]). Second, individuals believing that their birth has resulted from treatment using donated embryos or gametes (donor offspring) may apply to the HFEA for certain information about their genetic origins that may be contained on the Authority’s Register of Information (section 31). Third, ‘proper counselling’ should be made available to prospective donors and treatment recipients and to donor offspring seeking information about their genetic origins held on the Register.

Assisted conception has now replaced adoption as the principal route to parenthood for involuntarily childless adults. There has been a progressive decline in the number of infant adoptions. In 1995 only 379 children under the age of one year were adopted in the UK (Office for National Statistics, 1997; personal communications). In contrast, increasing numbers of children are born following regulated assisted conception treatment. In 1995 7,510 children were born following regulated treatment, of whom 2,548 were born following treatment using donated gametes or embryos (HFEA, personal communication).

SOCIAL WORK AND THE DEVELOPMENT OF ASSISTED CONCEPTION SERVICES IN THE UK

In the UK, social work has contributed to the development of assisted conception services in a variety of ways:

- Two social workers were members of the Warnock Committee, the Government-appointed Committee of Inquiry into Human Fertilisation and Embryology (Department of Health and Social Security, 1984).
- In 1984, the British Association of Social Workers established a Project Group on Assisted Reproduction (PROGAR) whose initial brief was to prepare the Association’s response to the Warnock report. PROGAR also contributed to the subsequent consultation process initiated by the Department of Health prior to the introduction of legislation. During 1989 and 1990, PROGAR co-operated with other organizations in an effort to influence the parliamentary passage of the Human Fertilisation and Embryology Bill. PROGAR is currently supported by the Association of Directors of Social Services, British Agencies for Adoption and Fostering and the British Infertility Counselling Association (BICA), to monitor developments in assisted conception and to participate in consultation exercises initiated by the HFEA and the Department of Health (including consultations concerning sex selection, use of foetal ovarian tissue, payment of donors, consent provisions, and surrogacy arrangements).
PROGAR has also promoted discussion on the availability and quality of counselling in licensed centres and on access to genetic origins information.

- A Director of Social Services was a founder member of the HFEA.
- Many counsellors in treatment centres have social work backgrounds, and social workers involved in fertility counselling were instrumental in establishing BICA.
- Three social workers were appointed to an interdisciplinary committee established by the King’s Fund Centre which was commissioned by the Department of Health to undertake work regarding the 1990 Act’s counselling requirements (King’s Fund Centre, 1991).
- Four social workers were appointed to an interdisciplinary Training in Infertility Counselling Working Group supported by the HFEA.
- Counsellors with a social work background and other social workers have been appointed as HFEA Inspectors.

Furthermore, social workers and agencies have particular responsibilities in relation to surrogacy arrangements: to satisfy themselves, where they become aware of a surrogacy arrangement, that the child is not at risk; to act as guardians ad litem when application is made to a court for a Parental Order in respect of a child born following a surrogacy arrangement (under section 30 of the 1990 Act); and to make counselling available for individuals subject to a Parental Order who seek access to their original birth records (Department of Health, 1994).

Treatment centres may also request information from social work agencies about prospective treatment recipients in pursuance of centres’ responsibilities to take account of the welfare of the child before providing treatment.

Finally, social workers have contributed to debate and research concerning policy development and psycho-social aspects of assisted conception (e.g. Brandon and Warner, 1977; Paul, 1988; Holbrook, 1990; Walby and Symons, 1990; Blyth, 1993, 1995a, 1995b; Daniels, 1993; Daniels and Stjerna, 1993; Monach, 1993; Ryburn and Fleming, 1993; Blyth and Hunt, 1995; Daniels et al., 1996; McWhinnie, 1996).

THE EXPERIENCE OF INVOLUNTARY CHILDLESSNESS AND ATTEMPTS TO OVERCOME IT

Involuntary childlessness frequently exerts an adverse impact on individuals’ feelings about themselves and on their relationships with others (e.g. Department of Health and Social Security, 1984; Monach, 1993; Hunt and Monach, 1997). Individuals’ abilities ‘to function, participate and develop in society’ (CCETSW, 1995, p. 16) may be compromised by their inability to undertake
conventional social roles associated with parenting. Such experiences may characterize not only the time spent in unsuccessful attempts to conceive, but also in investigation, diagnosis and treatment, as well as the period following treatment, especially where this fails to produce the desired outcome of conception and a child. Failure is the most likely outcome for most treatment recipients and even ‘successful’ treatment may be accompanied by residual issues surrounding the loss of fertility and the failure to conceive the child originally intended. The use of donated gametes or embryos may raise consideration of: the role of the donor; the absent or unequal genetic relationship between the child and his or her parents or between the parents; what, if anything, the child and/or members of recipients’ social networks are to be told; and what impact this might have on the child’s self-image and relationships within this network.

The arrival of a child following a lengthy period of involuntary childlessness and of expensive, invasive treatment will not necessarily be without problems. ‘Long-awaited’ and ‘much wanted’ children may spend the rest of their lives having to prove they were worth the effort, and parenthood after such effort will not necessarily match expectations or aspirations. Bringing up large families can be fraught with difficulty (given the contribution of high technology assisted conception services to the prevalence of higher order births).

Obtaining access to treatment may be difficult for two main reasons. First, health purchasers may reject involuntary childlessness as a legitimate health need warranting public funding, afford it low priority or severely ration the amount of funded treatment (Goldsmark, 1997), while expensive ‘high-tech’ procedures have increasingly been located within the private health sector available only to those who can afford to pay. Secondly, access to licensed treatment in the UK is mediated by the requirement to take account of the welfare of the child (section 13[5] of the 1990 Act), providing a mandate for prospective assessment to determine eligibility (discussed below).

**CHILDREN AND FAMILIES CREATED BY ASSISTED CONCEPTION**

While the 1990 Act requires account to be taken of the child’s welfare, it is not afforded any priority over other considerations, and there is little consensus of what ‘welfare’ might mean in the context of assisted conception services (Blyth, 1998). Since unborn children self-evidently cannot articulate their own interests, others have done so, although, as is illustrated below, some donor offspring have begun to write about their experiences. Much of the debate about the welfare of the child in assisted conception concerns
access to information about genetic origins following the use of donated gametes or embryos, although other issues have welfare implications: the consequences of particular forms of treatment; selection of prospective social and genetic parents; and preparing recipients of donated gametes or embryos for parenthood.

The long-term physical, social and psychological implications of relatively new forms of treatment, such as sperm and embryo cryopreservation, intracytoplasmic sperm injection (ICSI)—a technique offering the hope of genetic fatherhood to subfertile men, and embryo reduction (pregnancy termination used to prevent multiple birth following fertility treatment) have yet to be thoroughly evaluated. While donor insemination has been practised for many years, the secrecy that has traditionally accompanied it has also prevented systematic evaluation of its impact on offsprings' social and emotional development or on family relationships. In addition, the long-term effects of fertility-enhancing medication both on the adults to whom they are administered (including donors as well as treatment recipients) and on those who may be born following their use remains to be evaluated, although there is already suspicion that recipients of such medication may be exposed to increased risk of cancer (Ahuja and Simons, 1998).

Additionally, evidence already exists of complex physical, social and psychological implications associated with some forms of treatment, such as in vitro fertilisation (IVF), and gamete intrafallopian transfer (GIFT). Both techniques increase the likelihood of multiple births which, in turn, increase risks of premature births and of perinatal mortality and morbidity, new born survivors of multiple births being more likely to require intensive care. This, together with the added demands placed on their parents, especially the mother, limits parents’ opportunities for initial bonding with their babies, while, in the longer-term, instant large families may encounter a range of health, social and developmental difficulties (Botting et al., 1990).

Selection of both treatment recipients and donors effectively represents selection of the child’s social and genetic parents. Historically, the role of donors has been marginalized or even pathologized. For example, ‘unusual’ interest by a donor in the outcome of donation has been perceived as a contra-indication for selection (Johnston, 1980), the Warnock Committee was concerned about the donor being seen as ‘a person in his own right’ (Department of Health and Social Security, 1984, p. 24), while an earlier UK Government Committee described semen donation as ‘an activity which might be expected to attract more than the usual proportion of psychopaths’ (Feversham Committee, 1960, p. 59). More recent discussion has begun to focus attention on donors as individuals with important needs and views and legitimate interests in the outcome of their donation, rather than simply as somewhat shadowy sources of gametes:
the fact that it [the relationship with the child] is non-reactive [there is no contact] does not diminish the significance of the relationship for the donor (Daniels, 1992, p. 567).

Donors have their own family and social networks, other members of which, including future members, may be affected in various ways by the decision to be a donor and whether or not they disclose their role as a donor to other members of their networks (Daniels, 1992; Daniels and Stjerna, 1993).

The expectation that those seeking treatment 'should somehow prove their fitness as potential parents' has been challenged (Hope et al., 1995, p. 1456), and the HFEA Code of Practice reminds centres to 'avoid adopting any policy or criteria which may appear arbitrary or discriminatory' (HFEA, 1998, p. 14). However, there is evidence of discrimination on the grounds of sexual orientation, marital status, disability or age (Douglas, 1993; Blyth, 1995b), and Ryburn and Fleming (1993) draw on analysis of adoption practice to argue that access to treatment should not be determined by subjective value judgements or spurious predictive tests of parenting competence.

Adoption experiences indicating that raising a child genetically unrelated to the parents creates different and additional parenting tasks to those experienced in 'conventional' parenting (Kirk, 1964) suggest that donor assisted conception may generate unique parenting tasks (Blyth, 1995a). Traditionally, however, those contemplating donor assisted conception have generally been advised to maintain secrecy (e.g. Royal College of Obstetricians and Gynaecologists, 1987; Cook et al., 1995) and parents of children born following donor assisted conception appear reluctant to inform their children of their genetic origins (inevitably compromising any legal rights afforded to donor offspring to information about the donor), even if they have informed friends and/or other family members (e.g. Cook et al., 1995; Golombok et al., 1996; McWhinnie, 1996; Brewaeys et al., 1997). Consequently, although existing research provides no evidence that use of donor assisted conception impairs family functioning or relationships (Baran and Pannor, 1993; Snowden and Snowden, 1993; Golombok et al., 1995, 1996, 1998; Brewaeys, 1996; McWhinnie, 1996; Cook et al., 1995), there is currently no empirical evidence about the impact on either parenting functions or relationships in families where information concerning the use of donor assisted conception has been shared with the children concerned. Contrary to suggestions emanating from adoption research (e.g. Bruce, 1990; Walby and Symons, 1990), Cook et al. (1995) found no evidence that the maintenance of secrecy posed any problems for parents although, as none of the children in their study were older than eight years of age, the long-term impact of such secrets, and the effects of any disclosure, remain to be evaluated.

Meanwhile, emerging accounts from donor offspring themselves do suggest parallels with adoption, and identify three different levels of genetic origins information (e.g. Baran and Pannor, 1993; Snowden and Snowden,
First is basic knowledge about the nature of one's conception. Offspring accounts indicate that this information can be disclosed in sensitive and age-appropriate ways without damaging family relationships. However, where this information is poorly managed or inadvertently disclosed, conflicts about its prior concealment and deception may emerge. Offspring who do not learn of their origins until adolescence or adulthood not infrequently claim awareness of being 'different' as children. While increased openness about donor assisted conception is receiving greater encouragement (see, for example, HFEA, 1996; Johnson, 1997), Cook et al.'s (1995) research indicates that it is hampered by the limited information about the donor made available to parents for passing on to their children. Further, uncertainty about when, how and what to tell children about their origins is compounded by contradictory advice, or no advice at all, from treatment centres. Cook et al. found that, compared to adopters, donor parents lack a 'script' for telling their children about their origins, and that none of the parents interviewed for their study appeared aware of any of the available story books explaining donor conception (modelled on similar books for adopted children).

Secondly, and assuming prior knowledge about the nature of one's conception, is the provision of non-identifying information about the donor. This comprises a major element of offsprings' personal identity, and is assuming increasing significance as a result of awareness of the importance of genetics. The right of donor offspring to non-identifying information is not only constrained by parents' attitudes towards disclosure of their status. In the UK, the lack of adequate guidelines or requirements means that there is considerable variation in the amount and nature of information collected by centres, and made available to recipients and placed on the HFEA Register of Information (Blyth and Hunt, 1998).

Thirdly is knowledge of the identity of the donor, with some offspring considering that they need this in order to make sense of their own identity. Research indicates that oocyte donors appear generally less concerned to preserve their anonymity than their male counterparts (Power et al., 1990; Schover et al., 1992), an attitude shared by surrogate mothers (Blyth, 1994). On the other hand, many current semen donors have indicated their unwillingness to continue to donate if their identity were to be revealed (e.g. Daniels, 1992; Cook and Golombok, 1995; Daniels et al., 1996). Research in Sweden (Nielsen, 1993; Daniels and Lalos, 1995) and New Zealand (Purdie et al., 1992) has shown that it is possible to recruit semen donors who are willing for their identity to be revealed to their offspring and some work has begun to create a profile of men who might be willing to become identifiable donors—men who are likely to be in their 30s or 40s, currently or previously married, with children of their own and with primarily altruistic motives (Daniels et al., 1996).
Together, these findings suggest that much more needs to be done with all parties directly involved in donor assisted conception to consider the management of genetic origins information in donor assisted conception (for a more detailed discussion, see Blyth, 1998).

**DISCUSSION—THE SOCIAL WORK MANDATE**

That relatively few social workers in the UK are directly involved in the provision of assisted conception services means that social work in this area risks becoming marginalized and its voice subordinated to more powerful medical and scientific interests, placing a responsibility on the profession to ensure that this risk does not become reality. As outlined earlier in this paper, social workers in the UK have engaged in service development, although similar involvement appears to have occurred in few other countries.

However, the values to which social workers subscribe, together with their experience of child and family work and adoption, provide both the opportunity and the mandate to take "a leadership role" in meeting "the needs of humanity by helping to develop and to formulate a more enlightened public policy" (Holbrook, 1990, p. 337) concerning involuntary childlessness and its amelioration.

The principles underlying social work as encoded by the British Association of Social Workers (1997) which may be seen as having particular relevance to assisted conception are as follows:

- a responsibility to 'encourage and facilitate the self-realization of each individual person with due regard to the interest of others' (principle 6);
- The 'attempt to relieve and prevent hardship and suffering' (principle 7);
- the obligation to 'contribute to the total body of professional knowledge' (principle 8);
- 'co-operation with those who share professional responsibility for the client's welfare' (principle 8);
- 'the right and duty to bring to the attention of those in power, and of the general public, ways in which the activities of government, society or agencies, create or contribute to hardship and suffering or militate against their relief' (principle 9);
- acknowledgement of social workers' role at the interface between 'powerful organizations and relatively powerless applicants for service' (principle 9);
- Principle 10 also encompasses more detailed 'Principles of Practice' which include challenging discrimination, helping individuals obtain services to which they are entitled, and ensuring 'that these services are provided within a framework which will be both ethnically and culturally
appropriate'. These points are clearly relevant to the provision of assisted conception services, as this paper identifies. While, as has been cited above, some research evidence exists concerning barriers to appropriate services (Douglas, 1993; Blyth, 1995b), there has been little study of either ethnic or cultural aspects of service provision, beyond an acknowledgement of the difficulty of obtaining donated gametes or embryos for certain ethnic groups.

Social work should support debate and research aimed at furthering understanding of the impact of involuntary childlessness and attempts to ameliorate it. This will involve both advocating more equitable service provision that does not disenfranchise those from socio-economically disadvantaged sections of the community resulting from the lack of publicly funded services and the prohibitive cost of private treatment, and also challenging the stigmatization of involuntary childlessness that perpetuates the demand for treatment and effectively reduces choice, since involuntary childlessness is seen as 'no choice' at all (Monach, 1993).

Access to services, and its implications for the selection of prospective social and genetic parents, provides opportunity for discriminatory and even eugenic practices. Social work knowledge and expertise in work with a variety of family structures and forms can challenge unjustified discrimination, especially where this results from attempts to safeguard the welfare of the child. Social workers should be arguing for the establishment of explicit and justifiable selection criteria.

Social workers are also in a good position to help examine the inevitable tensions between counselling, assessment and selection (e.g. King's Fund Centre, 1991; Ryburn and Fleming, 1993; Blyth and Hunt, 1995). For example, application of Howell and Ryburn's (1987) 'preparation and education' model, originally developed in adoption, would allow individuals contemplating assisted conception services to receive necessary information, as well as affording them a suitable opportunity to discuss and reflect on the implications of treatment before deciding whether or not to pursue it. This would help to recognize treatment recipients not only as patients but also as prospective parents and would encourage treatment centres to give more consideration than is presently afforded to preparation for parenthood.

The provision of counselling for prospective donors, treatment recipients, and those born as a result of assisted conception services not only calls on social workers' technical skills, but also locates them as members of the multi-disciplinary team. They would, therefore, be well placed to influence centres’ policies and practices, in particular helping to ensure that the physical aspects of fertility difficulties and treatments do not detract from the recognition that involuntary childlessness and attempts to resolve it are complex biopsychosocial phenomena (Daniels, 1993; Daniels and Stjerna, 1993).
A holistic, psycho-social approach to treatment would acknowledge that, while the goal of technological intervention is to enable people to have a child, most attempts will remain unsuccessful. 'Healing' or resolution must, therefore, be defined in wider terms than simply securing a baby. Such an approach would also encompass the social networks of donors and treatment recipients, the impact of involuntary childlessness and treatment on relationships within those networks, and the outcomes in their social context for those whose existence is the result of assisted conception services.

Social work, by virtue of its child and family and adoption expertise, is also well placed to provide post-treatment counselling and advice to donors, parents and offspring. The only official recognition of donor offsprings' needs for counselling is in connection with a formal request to the HFEA for information about their genetic origins. However, especially where disclosure of the nature of their origins is inadvertent or poorly managed, it is evident that offspring may have wider counselling needs.

Individuals born following a surrogacy arrangement and subsequently the subject of a Parental Order under section 30 of the Act who are seeking access to their original birth records via the appropriate Registrar General will be entitled to counselling from the Health and Social Services Trusts in Northern Ireland and local authorities elsewhere in the UK. Here, the parallels with access to adoption records and associated counselling are unambiguous.

The extent to which access to information on the HFEA Register and access to adoption records may be considered analogous is tempered by donor anonymity. While it may be argued that the analogy is false because adoptees' birth records will often provide information about their birth mother only, while donor offspring already know her identity, the real issue for donor offspring is that, as UK legislation currently stands, they will legally be prevented access to all the potentially available information about their origins. The views of donor offspring cited earlier in this paper highlight that, whatever else distinguishes donor assisted conception from adoption, donor offspring and adoptees share similar views about the importance of, and about their rights of access to, information concerning their genetic origins. Experience of adoption and post-adoption work can be used to help promote the rights of donor offspring through supporting both offspring and parents seeking more information about their children's donors. As part of this work, social workers should be alert to developments elsewhere, for example in Austria, Sweden, and Victoria (Australia), where donor offspring have a legal right of access to the donor's identity. It seems important to ensure that information concerning the impact of this right is adequately disseminated in the UK, as PROGAR is currently doing both as part of its discussions with the Department of Health concerning access to genetic origins information under section 31 of the 1990 Act and concerning the implementation in the UK of the United Nations Convention on the Rights of the Child.
It has not been determined who will provide counselling for donor offspring when they are old enough to access information held on the HFEA's Register of Information, although social workers with post-adoption counselling experience are clearly well-placed to provide this. However, Government policy will dictate the context in which counselling is provided. As noted by the King's Fund Committee (1991), withholding information in the HFEA's possession about the identity of the applicant's genetic parent(s) may well cause 'distress and frustration' to which counsellors will need to respond. Anticipation of such difficulties also underpins the debate about the nature of the information that will be available to donor offspring.

In time, practical experience of providing counselling for donor offspring seeking information about their origins, and the increased articulation and dissemination of donor offspring's own accounts may help to establish the case for removal of donor anonymity, as may increased priority on the political agenda for 'freedom of information'. This, however, will provide little comfort for those for whom information about their genetic origins may already be lost, a point that emphasizes the urgency of the task.

**CONCLUSION**

This paper has identified the actual and potential contribution that social work can make to the development of assisted conception services. It has highlighted some considerable achievements, in global terms the social work profession having influenced developments in the UK more than in many other countries where there is comparable service provision. The paper has also identified where work still needs to progress. Among the most important areas where a social work influence could be exerted are: developing equitable access to services; defining and developing the role of counselling, in particular the as-yet-unexplored areas of longer-term counselling for donors, parents and offspring and counselling when application is made for genetic origins information; evaluating the physical and psycho-social impact of different forms of treatment; encouraging centres to gather detailed information from donors; preparing treatment recipients for parenthood; and helping to create a climate encouraging openness about donor assisted conception, that will facilitate increased information sharing and, ultimately, removal of donor anonymity.

The particular overarching contribution of social work should be to ensure that the objective of providing children for those who are involuntarily childless does not become simply a quest for technical excellence.

*Accepted: June 1998*
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