From a Social Issue to Policy: Social Work’s Advocacy for the Rights of Donor Conceived People to Genetic Origins Information in the United Kingdom

Elizabeth Wincott, CSW
Marilyn Crawshaw, MA, BSc(Soc), CQSW, DipAppSocStudies

SUMMARY. This paper outlines a 22 year campaign to introduce openness into the arena of donor conception in the UK. It identifies key aspects of the development of an advocacy based approach to such work and argues that social work values and principles can prove key to identifying structural inequalities which are not necessarily based in socio-economic disadvantage. Donor conceived people may find them-
selves in families which enjoy material privilege but whose exposure to a legislative framework and dominant professional cultures within the treatment centres encourages secrecy around genetic origins. Social workers’ experience of adoption and family work leads them to recognise the danger of such secrets within families. Turning such social issues into policy changes requires vision, strategic long term advocacy and partnership with those directly affected.

KEYWORDS. Advocacy, social work values, donor conception, secrecy in families

BACKGROUND

Following the birth of the world’s first so-called test tube baby, Louise Brown, in 1978, there was a rapid growth in knowledge about, and development of, an ever expanding variety of techniques to assist reproduction. However, the clinics providing these services in the UK were largely private and unregulated except through an emerging voluntary system run by a voluntary licensing authority. The lack of a statutory regulation system on all aspects including gamete storage and donation, access, record keeping and new developments together with the lack of external accountability and scrutiny in this ethically challenging area of medical science led to the government setting up a Committee of Inquiry into Human Fertilisation and Embryology in 1982 to consider recent and potential developments in medicine and science related to human fertilisation and embryology; to consider what policies and safeguards should be applied, including consideration of the social, ethical and legal implications of these developments; and to make recommendations. It was chaired by Dame Mary Warnock, Mistress of Girton College Cambridge and a moral philosopher (Warnock, 1984).

Social work’s professional body, the British Association of Social Workers (BASW), submitted evidence to the Committee through its Health and Handicap Advisory Panel and Sexuality Special Interest Group in March 1983.

The Warnock Committee reported in 1984 and recommended that legislation be brought forward to provide for statutory regulation. In do-
ing so, it made a number of recommendations that had the potential to deeply affect family life and children’s welfare. These included the recommendation that children conceived using donated gametes should not be afforded the right to receive information about the identity of their donor when they attained the age of majority. This was despite the passing of the Adoption Act of 1976 which had extended the rights of adopted people in England and Wales at the age of majority to disclosure of the identity of their birth parents, both retrospectively and prospectively.

Several initiatives within BASW were brought together to set up the Warnock Report Project Group in October 1984 to respond to the Committee’s findings. The membership was drawn entirely from social workers and BASW staff with its focus underpinned by social work values, principles and practice. Of fundamental concern was the Warnock Committee recommendation that gamete donation should be anonymous which was felt to be contradictory to the rights (moral and human) and needs (social and psychological) of people to have access to their personal biographies.

Thus commenced BASW’s lobby for the right of donor conceived people to have parity with adopted people—the only other group of people at that time whose families had come into being as a result of professional intervention and whose access to information about their genetic relationships was regulated by statute. When subsequent legislation to regulate surrogacy (the Surrogacy Arrangements Act 1985) opted for parity with adopted people with regard to accessing identifying information from age 18, donor conceived people were further marginalised and BASW made strong representation about the inconsistency and resulting discrimination.

This paper covers the 22-year period through to the lifting of anonymity and documents the campaign that was conducted through the social work professional association to advocate on behalf of people conceived and to-be conceived using donor assisted conception techniques. It describes the development of the campaign to include those directly affected as well as other professional groups; the attention to strategic planning; and the engagement with policy makers and opinion formers. It argues that social work has a central role to play in such work and that attention to social work values is as vital as ever in offering the vision for such work.
THE INTRODUCTION OF LEGISLATION

In November 1987 the government published a White Paper on the framework for proposed legislation. BASW was invited to provide further input at this stage and also gave oral evidence to a Parliamentary Standing Committee in 1988.

In May 1988 two additional members—an academic social scientist and an experienced counsellor in an assisted conception clinic (and ex-social worker)—were co-opted. In October 1988 the name was formally changed from the Warnock Project Group to the Project Group on Assisted Reproduction (Progar) to avoid confusion with the Warnock Committee.

After the Human Fertilisation & Embryology Bill was published in 1989, Progar continued to lobby extensively around the rights of donor conceived people. However, although some changes were made in the drafting, the underlying policy of retaining the anonymity of donors remained.

The Human Fertilisation and Embryology Act was passed in 1990 and the Human Fertilisation and Embryology Authority (HFEA) set up as the regulatory body in August 1991. It was required to hold a database of the details of all live assisted conception births, including social details of donors and their medical history. From this a Register of Information was to be derived and donor conceived people were given the legal right at 18 to access information about whether they were on the Register (and hence donor conceived) or at 16 to discover whether they were related through donor conception to anyone that they intended to marry. Although Regulations to allow for the release of non-identifying information were not enacted until 2004, it was always anticipated that this would happen. A small section on the official form that is sent to the HFEA about each cycle of treatment is provided for donors to provide pen pictures of themselves and some, though not all, centres encourage the completion of this. However, a study of the information held was found to be patchy and inconsistent (Blyth & Hunt, 1998). Some of the pen portraits were treated so facetiously as potentially to cause distress to any offspring reading them.

The first people to reach 16 will do so in 2008. Between 1991 and April 2005, upwards of 24,000 donor conceived people were estimated to be born and were the only people in the UK for whom the state held identifying information on their genetic origins to which they were denied access.
BUILDING THE CASE FOR LEGISLATIVE AND PRACTICE CHANGES

Following the introduction of the HFE Act, Progar determined to continue to lobby for change. It did so in a number of ways, paying careful attention to strategic planning within limited resources.

Widening the Membership

During the 1990s Progar decided to widen its membership to include those directly affected and their families, other disciplines, and key social welfare organisations including:

- two donor conceived people, one a psychologist and one a lawyer
- a mother of donor conceived children who, together with her husband, had set up a UK wide network of parents of donor conceived children called DC Network
- a representative from the Association of Directors of Social Service, the body which represents all statutory social services in England and Wales
- a lawyer specialising in children’s law and adoption
- a representative from the British Infertility Counselling Association (BICA)
- representatives of three major UK children’s charities

At the same time as inviting the HFEA to attend as observers, an invitation was extended to (and accepted by) the UK Department of Health (DH) to attend, also with observer status.

This extended membership gave Progar links into wider networks thus enabling it to promote and influence wide-ranging and diverse debates. It also undoubtedly afforded it greater clout in its own campaigning and ensured greater coverage of its views in the media and amongst political and other influential figures. From time to time, invitations to meetings were extended to those whom Progar thought had the potential to be allies, not least to assist in discussion of strategy. The fact that such figures as Allan Levy QC, the leading children’s barrister, David Hinchliffe, Chair of the Parliamentary Select Committee on Health and Baroness Mary Warnock herself accepted was an indication of Progar’s growing stature. Indeed it was to Progar that Baroness Warnock indicated her change of mind about anonymity and agreed to share our platform in campaigning for change.
Use of the Media and Being in the Public Eye

Increasingly, members developed a speaking profile in the professional and public media and were regularly sought out for public comment. Growing numbers of written contributions were valued in professional and academic journals and in the media. Members contributed regularly to national and international conferences. The foci of the debates that emerged were wide-ranging and there was active discussion within Progar both about its own standpoint and about the most strategically useful approach to take in different arenas. For example, the arguments were variously presented with a primary focus on the impact of secrecy on psychological well being, the primacy of children’s rights over the rights of infertile adults to found a family, the impact of inadequate or inaccurate medical history on an individual’s health or the moral rights of people to access information held by the state (for a useful summary, see McWhinnie, 2001). The discussion about the use of evidence reflected the growing preoccupation with evidence-based policy and practice elsewhere and two of our members, together with an overseas colleague (all social workers) produced a challenging paper which documented the different standards of evidence that were applied to policy development in social and emotional wellbeing against those used in medical science (Blyth, Crawshaw & Daniels, 2004).

Where appropriate, members identified themselves primarily by their role in Progar; when speaking or writing in a professional capacity through their employee positions, they sought to reference Progar where possible. The opportunity for open, internal debate within Progar was particularly important in helping individual members to develop their reflections and actions in a field where their direct work tended to take place in relative isolation.

Establishment of an Educational Arm, ACER

When a body is solely concerned with campaigning, there can run the danger that it is not taken to have a reflective aspect to its work nor to draw on a credible body of evidence. Progar wished to counter this and decided that there was a strategic value in developing an educational arm which could provide educational seminars and literature. It therefore established ACER (Assisted Conception Education Resources Forum) in 2001 to fulfil this function and was immediately successful in obtaining a grant to run seminars for multi-disciplinary audiences drawn from within the assisted conception field but also from the wider
social work, health, legal and child and family welfare communities in different parts of the UK throughout 2002-3. The presenters were primarily from a social work background (speaking on adoption, surrogacy and identity development) together with a lawyer and, in keeping with social work principles, the parent of donor conceived children drawing on her personal experience.

**Development of Campaigning Literature**

The early part of BASW’s work had seen the production of a booklet called “Truth and the Child” (Bruce, Mitchell & Priestley, 1988) which was designed to influence the debate. Progar decided that the time had come to update that publication and a fuller book (with short individual pieces that were accessible both to the general reader and to the media) was produced, edited by three Progar members and published by BASW (Blyth, Crawshaw & Speirs, 1998). It included a mixture of personal and professional accounts and aimed to reflect the diversity of arguments for openness including social work, medical, genetic, sociological, psychological and legal.

Progar next turned its attention to its promotional literature. An earlier leaflet describing its work and principles was updated, taking care to achieve a more professional image. A new strap line ‘Working to improve the law and services associated with assisted conception treatments’ was agreed. The process proved a useful catalyst for discussion and debate and the reaffirming of its 2 key campaigning targets of:

- the right of people with fertility difficulties to informed choice and quality of care, including counselling, and
- the right of people to have access to identifying information about their genetic origins

In 2003, Progar again built on its earlier literature to produce a series of Briefing Papers, designed to highlight its broad membership and again with a professional image to enhance their readability and credibility. They included:

1. Overview Paper
2. Anonymous and Secret Donation: The legal position
3. The recruitment of identifiable sperm donors: Messages from overseas
4. Some useful psychological perspectives for thinking about donor conception in families
5. Medical indications for providing access to identifying information about gamete donors

The papers were variously authored by Progar members or invited authors and subject to an internal Progar editorial process. They were distributed to the media and influential figures from their introduction onwards and were then distributed through BASW to all members of the House of Commons and House of Lords during crucial Parliamentary processes in 2003/4 (see below).

Building a Relationship with the HFEA

During the 1990s, Progar’s links and dialogue with the HFEA developed. This included giving evidence to a number of public consultations run by the HFEA such as those on the payment of donors and sex selection, taking the decision to invite a member of the HFEA executive to attend their meetings as observer, as already indicated, and holding regular meetings with them (see below). Despite earlier opposition to the lifting of anonymity, the HFEA finally came down in favour of the lifting of anonymity in 2002 when responding to the DH’s consultation (see below) and we believe that this was in some measure due to Progar’s activities.

Progar members made (and continue to make) increasingly diverse contributions to the work of the Authority:

- Three members of Progar became members of the HFEA’s teams of clinic inspectors (though they were appointed independently of their role in Progar). This experience brought a vital perspective to Progar’s work, especially in relation to clinics’ attitudes towards psycho-social matters and the provision of counselling.
- In the late 1990s a liaison group was set up between the HFEA, the British Infertility Counselling Association (BICA) and Progar. All sides have valued these meetings which take place on a quarterly basis.
- One member of Progar was appointed as a member of the HFEA in 2003 (though again not as a Progar representative).

ADDRESSING THE HFEA ANNUAL CONFERENCE—WHY ANONYMITY?

In December 2001, there had come a major breakthrough when EW was invited as Chair of Progar to give a keynote address to the HFEA’s
annual conference. She chose the title for her paper of ‘Why Anonymity?’ seeking to turn on its head the presumption that anonymity—staying with the status quo—was a safe and justifiable option. Progar’s work had come a long way from the time when the issues on which we were campaigning were received in the field of assisted conception with a good deal of scorn and ridicule; when references to adoption were roundly refuted as having no transferable messages of value; and when social work was scapegoated as irrelevant and lacking in credibility.

Some Key Themes of the ‘Why Anonymity Paper’

Views of Donor Conceived People

The presentation started with bringing the voices of those directly affected into the room in order to present the lifelong social and emotional nature of the outcomes to donor assisted conception treatment. David Gollancz (a member of Progar) on learning at age 12 that he had been conceived using donor sperm said: ‘Being told that I had been conceived using a stranger’s sperm was like being hit by a train. It didn’t hurt. I wasn’t angry or grief stricken or excited. I felt annihilated’ (Gollancz, 2001:167).

Christine Whipp, a donor conceived woman who learned of her origins at age 41 said in the book co-edited by 3 Progar members: ‘I have been cheated out of a proper family and created as a second class citizen, illegitimate and with no right to any information about my genealogical roots or family or medical history’ (Whipp, 1998:64).

The Impact of Secrecy

In 1988, Haimes wrote about the difficulties of accessing information about the impact of secrecy following donor conception when she said: ‘However, the empirical evidence is weak so far, if only because we do not have access to the data. In that way secrecy carries within itself its own triumph since it prevents access to data through which it might be challenged’ (p. 7). However, while not yet extensive, there is mounting evidence of its potential to damage, including in an important research study conducted by Turner and Coyle where Jessica’s words illustrate the distress experienced on learning of genetic origins through accidental disclosure:
I was shocked and unforgiving. I now have a total distrust for my mother, and have realised that it is very hard for me to totally trust someone else. (Turner and Coyle 2000: 2045)

Sometimes the secret about a person’s conception emerges in crisis and in an unplanned and damaging manner. There is increasing anecdotal evidence of problems occurring, for example, if there is a dispute between, or relationship break up of, the social parents, or if parents are asked in medical encounters for a family history particularly if the child develops an inherited disorder.

Who Else Knows?

There are worrying data about information being withheld from donor conceived children even though family and friends have been told. Golombok and Murray’s study in 1999 interviewed, among others, 45 families with a child conceived through donor insemination. None had told their children about their origins although 51% had told the maternal grandparents, 20% had told paternal grandparents and 30% had told friends, giving rise to the potential for accidental or unplanned disclosure by a third party, distress and misunderstandings.

Whose Needs?

There is still a stigma attached to infertility and this drives many people to try to shelter behind secrecy. Hunter, Salter-Ling and Glover in their study of the experience of parents telling their children about their origins pointed out that ‘... secrecy serves to protect donors, doctors and parents needs rather than the needs of the child and may also be a response to the stigma of male infertility’ (2000:157).

Legal Issues

There are three significant pieces of legislation and conventions that affect the debate in the UK:

- 1989 UN Convention on the Rights of the Child
- 1950 European Convention for the Protection of Human Rights and Fundamental Freedoms
- The Human Rights Act 1998 (UK)
Douglas, Lavery and Plumtree (1998) argued ‘The international law, though ambiguous, case law and the experience of the working of the adoption legislation all point towards a growing acceptance that discovery of one’s genetic identity is something which should be facilitated, rather than obstructed, by the law. It is likely that, in the next millennium, this acceptance will be extended to the position of children born after gamete donation. Until that occurs, the law remains complicated, inconsistent and unfair’ (p. 13).

Challenges were outlined that were starting to be mounted in the courts (for example Joanna Rose, EM V The Secretary of State for Health and the Human Fertilisation and Embryology Authority) which, though still small in number, have impacted significantly on public opinion and increased pressure on the Government to lift anonymity. It was suggested that, pragmatically, changes would be likely to be forced through eventually with the Human Rights Act used increasingly to mount such challenges.

Parallels with Adoption

While the issues faced by people who have been adopted are not identical to those of donor conceived people there are sufficient similarities for lessons to be learned.

Evidence from adoption, together with the limited but growing research and anecdotal evidence in the field of donor conception, increasingly suggests that people denied knowledge of the identity and/or detailed knowledge of their genetic parents can feel cheated, deprived and incomplete. In adoption, there is growing evidence that those adopted in infancy may be looking for a completion of their identity when seeking out birth relatives rather than seeking substitute parental relationships. Even those who count themselves to be emotionally secure with close loving relationship with adoptive parents are showing a tendency to seek information and/or contact (Howe and Feast, 2000)—and those relationships appear to remain intact even when contact with birth parents is re-established. In an article looking to identify any potential parallels between the expressed needs of donor conceived people and adopted people, Crawshaw (2002) summarised the position for adopted people thus: ‘Adopted people viewed their birth parents as people whom they wanted to know about, rather than simply as genetic vehicles’ (p. 8) and concluded that the comparison with published
accounts of the experiences of donor conceived people suggested important overlaps.

**Messages from Donor Conceived People**

The presentation returned to the words of those most keenly affected: donor conceived people.

Rachel, who took part in the Turner and Coyle study, said: ‘I needed to know whose face I was looking at in the mirror—I needed to know who I was and how I came to be—it was a very primal and unrelenting force which propelled the search and it was inescapable and undeniable (Turner & Coyle, 2000:2046).

Priscilla from the Donor Conception Support Group of Australia said: ‘I’m not looking for a father figure; I already have one. The man who raised me is my Dad as far as I’m concerned but it would be nice to know who gave me the gift of life. Until I find him a part of me is missing’ (Donor Conception Support Group of Australia newsletter, 2000).

**Key Questions**

EW concluded by posing the following key questions:

- Are secrets damaging and dangerous?
- Is it right to deceive people?
- Do you teach your children to be honest? How do you feel when you catch them out in a lie?
- Is it right to discriminate in law against donor offspring?
- Is it right to deny donor conceived people access to information held about them by the state?
- Where does the balance lie of the moral and civil rights of all parties concerned?

**THE ROLE OF THE BRITISH ASSOCIATION OF SOCIAL WORKERS**

Throughout the whole of this time, Progar remained under the sponsoring umbrella of BASW and retained its full support. Crucially, BASW recognised the fact that Progar had come to have some members
who were neither social workers nor BASW members and recognised that it remained appropriate to remain the parent organisation and provide support.

The Significance of Underpinning Principles

The International Federation of Social Workers and the International Association of Schools of Social Work define social work as follows:

The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work. (2001)

The BASW Code of Ethics (2002) is committed to five basic values of human dignity and worth, social justice, service to humanity, integrity and competence. It further argues that every human being has intrinsic value and that all persons have a right to well-being, to self-fulfilment and to as much control over their own lives as is consistent with the rights of others. Alongside respecting basic human rights, the BASW Code sets out social workers’ duty to:

Safeguard and promote service users dignity, individuality, rights, responsibilities and identity (3.1.2.c)

and to:

Bring to the attention of those in power and the general public, and where appropriate challenge ways in which the policies or activities of government, organisations or society create or contribute to structural disadvantage, hardship and suffering, or militate against their relief (3.2.2.a) Seek to change social structures which perpetuate inequalities and injustices, and whenever possible work to eliminate all violations of human rights (3.2.2.c) and Challenge the abuse of power for suppression and for excluding people from decisions which affect them. (3.2.2.f)

In keeping with this, Progar’s work has been built around the principle that it is a fundamental moral and human right that people should not
be denied information about their genetic origins, where it is known. As donor conceived people have not asked to be conceived and, since they cannot advocate for themselves at the point of conception or their entry into society as infants, we have argued that society must ensure the primacy of their needs.

However, Progar also believes that the rights and needs of infertile people and donors are important and that it is unhelpful, unconstructive and against core social work values to collude with debates that seek to polarise the rights of those in intimate relationships with each other and construct them as being ‘good’ and ‘bad,’ ‘deserving’ and ‘undeserving.’ By increasingly seeking to locate its arguments within a child welfare, family and social context, Progar sought to challenge the polarising tendency. In keeping with the need to attend to psycho-social needs as experienced in the here and now while actively engaging in the political debate, Progar has also consistently advocated the need for counselling and support services provided by qualified professionals to be made available to all parties throughout their lifetime.

**WINNING HEARTS AND MINDS**

The lifting of or retaining the anonymity of gamete donors, and indeed the whole subject of infertility, is an emotive subject which generates strongly held views. Historically, some of the medical community have voiced the most strongly held views against the lifting of anonymity. Some of these views are driven by economic and professional self-interest where the fear is held that donor supplies would reduce with the lifting of anonymity. Some are no doubt related to individuals’ personal involvement through their own past donations while others firmly feel that maintaining secrecy is beneficial to family life and parent-child relationships.

Scare stories, typically in the tabloid press, have focussed on the potential for the reduction of sperm donor numbers though rarely on egg donor supply—an intriguing gendered dimension. International evidence suggests that sperm donor numbers do indeed reduce initially but then gradually increase again with an older, more mature donor coming forward—though this remains a hotly contested area. Sometimes, the focus of the tabloid press has been on the spectre of donor conceived people turning up on the donor’s doorstep demanding money or some form of legal rights. The supply/demand arguments rarely engage in debating
the lifelong moral or psycho-social aspects of the families affected (either those containing a donor conceived offspring or those of the donor) but hoist their colours firmly to the consumerist arguments of the couple seeking donor conception treatment and the clinic who wishes to supply them.

However, there has been a gradual but noticeable shift in attitudes. Changing attitudes to openness and children’s rights within wider society and the awareness of the damage caused by secrets and accidental disclosure are now written and spoken about more openly and another, more reflective form of media coverage through television and the quality newspapers has come to the fore. There has been an accompanying gradual shift away from a technical or medicalised approach to infertility to one where infertility is seen more in terms of the lifetime needs and rights of the families to be formed or affected. There has been an increasing recognition of the appropriateness of drawing an analogy with adoption, in part due to the increasing recognition of the validity of professional practice and research experience in social work.

When giving the paper at the HFEA conference in 2001, EW anticipated, based on previous experience, that she would encounter much more opposition than she did. Instead, the discussion focussed on when and how to lift anonymity rather than whether or not to. Times were changing.

THE SITUATION TODAY

Section 31 of the HFE Act required that Regulations be laid before Parliament in preparation for the first donor conceived people having the right to consult the Register of Information in 2008. After several false starts, the DH finally launched a consultation exercise in December 2001 to determine how non-identifying information should be handled and whether and how anonymity should be lifted. If it was to be lifted prospectively (and this was what Progar campaigned for), it would only require secondary legislation. The most crucial part yet of Progar’s long campaigning activity was about to commence.

Progar undertook its campaign in a variety of ways including running a conference with an invited audience in May 2002 generously funded by the internationally recognised Nuffield Foundation. Invitations were drawn up on the basis of influencing a wide range of professional and political opinion. The conference explored the importance of lifting anonymity from the point of view of donor conceived people and social
parents and from a medical, genetic, legal and social work perspective. Baroness Warnock, with whom Progar had developed a dialogue in recent years and who had joined its campaign to lobby for change, gave the keynote address which ensured high national media coverage. She used this platform to announce publicly that she had changed her mind about donor anonymity and why. She stated her belief that withholding identifying information represented the denial of a fundamental moral right for every donor conceived person and that she and the Warnock Committee had not foreseen that their acceptance of donor anonymity would have led to parents withholding vital information about the circumstances of their child’s conception from them. Her announcement was an extremely important contribution to the consultation process and attracted, as anticipated, a great deal of media attention.

Progar subsequently gained a meeting with the then Public Health Minister, Hazel Blears.

In January 2003, the Government announced at the HFEA Annual Conference that they accepted in principle the need for openness and for the paramountcy of the welfare of the children affected but, frustratingly, also said that they needed more time to arrive at a final decision about the lifting of anonymity and set up an additional six month research period. In the same speech, the Minister announced the establishment of the piloting of a UK voluntary information exchange and contact register for people conceived prior to August 1991. The work was awarded to After Adoption Yorkshire, and UK DonorLink (www.ukdonorlink.org.uk) was established and launched in April 2004, with MC (a Progar member) acting as Adviser and Chair of the Advisory Group in her professional capacity.

Individual Progar members contributed extensively to the DH’s work during the period that was set aside for additional research as did Progar as a group. A year later, with a change of Public Health Minister to Melanie Johnson and a meeting between her and Progar, came the announcement that Progar had been waiting for. On 21st January 2004, Melanie Johnson announced that the Government would be putting in place a process that would change the legislation and come into force in April 2005, lifting anonymity prospectively. From that date, donors were to donate in the knowledge that their identity would be open and known from the age of majority of any person whose conception resulted from their donation. Work continued following the announcement including:

- Drafting the Regulations and taking them through Parliament
- Determining how to handle the interim period
• Determining how to allow people who had already donated to alter their consent to allow for openness
• Deciding how to promote openness and a change in culture in treatment centres and amongst the public
• Continuing to address the rights and needs of the families affected

The Government has undertaken publicity initiatives and worked with organisations such as the National Gamete Donation Trust, British Fertility Society, UK DonorLink and, of course, Progar to encourage new and existing donors to come forward and to embed the new culture of openness into services.

CURRENT AND FUTURE CHALLENGES

The challenges in this ethically and socially complex field of work continue. There are a myriad of aspects of donor conception and assisted conception that need to be addressed. The lifetime implications continue to unfold. The scandalous lack of services to either prospective or existing parents to enable them to be supported in telling their children of their conception and coping with the associated parenting demands together with the lack of support services for existing donor conceived people (children and adults) and donors continue to make those affected vulnerable. The needs of donor conceived people who still have no rights to access their records and the needs of those who find out in accidental or unplanned ways at any stage in their lives continue to be of concern. And the ongoing tension between, on the one hand, the commercialisation and commodification of family building and, on the other, the desire to engage in emotionally and socially healthy family building ensures that Progar’s role will continue to be needed.

CONCLUSION

Social work traditionally concerns itself with vulnerable groups and actively seeks to promote the need to attend to, and challenge, the social context within which vulnerability is formed and maintained. Engaging with issues around assisted conception stems from a long tradition within medical social work in particular of seeing those receiving medi-
cal attention as people and social beings first and foremost and thus resisting the medicalisation of social experience. Many of the families formed through donor conception treatment enjoy socio-economic privilege as economically deprived groups (who typically are over-represented among users of social work services) often find themselves unable to access these treatments. The ability of Progar and the social workers within it to see vulnerability without its traditional socio-economic mantle has proved vital to the campaign in which it has engaged.

There are many different stakeholders in this debate. Their political and theoretical orientations have contributed to the polarisation of the arguments. Social work has shown itself here, as elsewhere in its history, to have the potential to bridge those divides and maintain core attention to the lived experience in its social and historical context. Crucially, it sees beyond individualised explanations which reduce and narrow understanding in order to resist the medicalisation or pathologising of experience.

In the current UK social work context, the shift towards the care management social policy agenda in recent years has placed enormous pressure on the profession to adopt a more bureaucratic, consumerist approach to its task. In consequence, medical social work has been pushed towards an undue emphasis on discharge planning out of a predominantly welfare context with people who can afford to buy their own care being increasingly excluded from access to social work services. The need to hold firm on social work principles and values is perhaps more crucial than ever. Progar’s campaign illustrates the importance of seeing the individual/family/social group and their need in context (whether that be predominantly socio-economic or not) and to attend to them within that perspective at the same time as engaging with the policy makers and opinion formers to influence that wider social context.

It is difficult to say how far the other players recognise the social work contribution to the campaign to lift anonymity and it is not the focus of this paper to evaluate its relative influence. However, it is interesting and validating that the Vice Chair of the HFEA recently wrote: ‘Although the HFEA supported this change, it was primarily urged by the social work profession in the light of their experience. . . .’ (Baldwin, 2005:84).

**NOTE ON THE UK LEGISLATIVE PROCESS**

When considering legislation a topic is proposed by the Government of the day and discussed in Parliament. The government then produces a Green Paper which may be handled in a variety of ways but is generally
discussed in Parliamentary Committees. There may be a preceding or succeeding public consultation. A White Paper is then produced and handled in a similar way. The legislation is then drafted and comes before Parliament as a Bill. It will go before the House of Commons and the House of Lords and will often go back and forth between the two Houses, debating and agreeing or rejecting amendments. Some of the earlier stages may be foreshortened. The final legislation known as the Act becomes law after it has received Royal Assent, which is a formality.

Most Acts of Parliament have subsequent regulations and guidance, some of which require Parliamentary consideration.

REFERENCES

Crawshaw M A (2002) ‘Lessons from a recent adoption study to identify some of the service needs of, and issues for, donor offspring wanting to know about their donors’ in Human Fertility Vol 5 No 1 Feb 2002, 6-12
Donor Conception Support Group of Australia (1997) Let the Offspring Speak–Discussions on Donor Conception The Donor Conception Support Group of Australia, PO Box 53, Georges Hall, New South Wales 2198, Australia
Donor Conception Support Group of Australia Newsletter (2000) The Donor Conception Support Group of Australia, PO Box 53, Georges Hall, New South Wales 2198, Australia
McWhinnie A (2001) ‘Should offspring from donated gametes continue to be denied knowledge of their origins and antecedents?’ Human Reproduction Vol 16 No 5 pp 807-817