

**SESSION 4: PROFESSOR MARILYN CRAWSHAW, SENIOR LECTURER IN SOCIAL WORK, UNIVERSITY OF YORK = EXPERIENCES FROM RUNNING THE UK DONOR LINK REGISTER SERVICE**

Speaker	Transcript
S1	<p>Thank you. Perfect introduction Jennie, thank you very much. So, our next speaker is Marilyn Crawshaw who is Senior Lecturer in Social Work at the University of York. In her talk she is going to look at the lessons from the UK Donor Link Register and cover the views of clinic.</p> <p>So, it is extremely important to us at the HFEA that as Marilyn will explain UK Donor Link has had experience of exactly the sorts of the approaches we are going to have over considerable number of years. Instead reading out all of your qualifications, I will just let you tell us.</p>
S2	<p>Thank you and thank you very much for inviting me today. I am delighted on behalf of the UK Donor Link staff to be sharing some of what I think maybe are some of the most relevant of our experiences.</p> <p>So, let me tell you first a little about what UK Donor Link is. It was launched in April 2004, is funded by the Department of Health and has four key parts to its work.</p> <p>Firstly, is the Voluntary Information Exchanging Contact Register which is open for adults, donor-conceived people, pre '91 donors and for adult children. We also have Information Support and Counseling Services. We have the DNA Database and because we do not have written records to go on so our matching is through DNA and I am not going to talk about that today and we have our Promotional Works and I am just going to talking about the first two of these today.</p> <p>The Service is managed by the Post Adoption Service After Adoption Yorkshire and employs a part time Administrator and a part time Service Coordinator, the latter being a professional post. As well as providing direct services, they coordinate and support a UK wide network of Professionals employed on a sessional freelance basis as there is no existing UK professional expertise imposed on a conception searching contact services. When we started we turn to those with the closest existing professional experience, i.e. post adoption work and we provide those workers with relevant training on an annual basis. We also have an advisory group and for the last year, a Registrant's Panel of Donors and Donor Offspring to contribute to Service Developments and finally we consult with all of</p>

our registrants from time to time. Use of our service as with HFEA Register service is entirely voluntary. Access to Information, support or formal counseling is available at any stage of the process, for example prior to Registration if a match is made if direct contact is planned and so on. And many registrants tell us that this provides them with the feeling of security regardless of the extent which they actually use our services. Our services are free which we believed to be ethically important given that donor offspring are trying to resolve experiences not of their making and donors did not expect this to be enough to matter to their donation. So how many people have we had contact with? Well, lots is the answer. There are some straight figures. We have lots and lots of inquiries, so we have a very busy help line. Our annual report for '07-'08 is still in preparation. Some of you know that our Service Coordinator very sadly died in August after a very short illness so we do not have our current annual report available but what I can tell you is at the end of June '07, we had just over a hundred fifty people ranging in age from 18 to 70+ who are either fully registered or in the process of registering with us. Seventeen matches had been identified between genetic half siblings though none yet between donor and donor offspring. Take up from donors were surprisingly high, first, we did not know how many would come forward but just under a third of the registrations are of donors and of course almost all of those are sperm donors because of the area we are dealing with.

So what is our experience of people contacting us searching for information? Well, in the past some professionals assumed that donor offspring and donors would have little or no interest in each other but we have seen a more complex picture emerging. So our experience has been some donors offspring seem to be seeking to alleviate feelings of frustration, anger or distress about the nature of their origin and they come in lack of information. Some tell us that they fear that their children will be medically disadvantaged by not knowing their donor's health history, including up to date information. Others describe themselves as having something that they would call straight forward curiosity, not idle curiosity but a curiosity that driving the search. A small number and it is only a small number seem to hold up the possibility of forming a relationship with the donor that might prove better than that with their social parents. Probably few of us thought that over the year when we thought we might be adopted. And a final group report have a strong drive to find the so called missing piece of their jigsaw, i.e. what appears to be an identity issue and need to know the donor's biography and integrate it into their story. Some are at least as interesting in finding half-siblings and sibling searches appear more straightforwardly motivated has been either about curiosity or a desire for something more a kinship related connectedness.

Quite a number have wanted to talk to us about their feelings that being conceived in what they perceived to be an unnatural way, the age at which our registrants were only concerned registrants were told of their origins that ranges from early infancy to late middle age but those approaching us soon after disclosure when that has happened as adults are typically coping with heightened emotions and turmoil in their family including strained relationships with parents. Where disclosure follow the death of the parents as has happened sometimes. The process of recognising, withholding of information is of course more difficult. Some parents are very supportive of their search even if apprehensive. Indeed 37 biological mothers have provided DNA to assist the matching process, and others are not so supportive. We sometimes found different reactions between siblings within their so called social family, with one putting pressure on another to search and vice versa. But this we are being from the same family guarantees neither similarities amongst its members nor in this case the pace and manner of which reactions to long term knowledge of origins or to more recent disclosures handled were all different. We have a range of experience among donors too. The majority did not receive advice or preparation for any longer term implication at the time of donation. Some of sort support from us in coping with the late impact on them and their families including any realisation that their donation may have inadvertently resulted in distress for those conceived. Some have discussed the fact that they were donors within their personal and social networks including with their children if they have them but some seek help from us in deciding when and how to disclose that they were donors. Whilst others tell us that they intend to keep it private, whilst most registered for altruistic reasons, some also tell us that they are curious about their donor offspring. There have been variations in the speed with which people complete registration ranging from a few weeks to many months. Some start and then suspend the process returning many months later and others have yet to restart. Now this sort of stop/start activity is very familiar in post registration work and may well become a feature of approaches to the HFEA Register especially given that your registrants unlike ours know that they will receive information as a result. Some across all parties, all of our registrants have taken up a formal counseling though relatively few, however, many of us use our professional staff to witness the idea of sample taking and report that this triggers healthful discussions has also happened when they are having contact with the HQ staff. So they do not ask for counseling but what they do have is conversations that their report is very helpful. Following Registration, some have minimal contact while others do so periodically including with best of relative intensity. As in many helping services, a late query that is apparently for information only can turn into a

lengthy exploratory or supportive contact needing sensitive handling.

And finally, as with some donors, some parents have also sought our help and support in deciding how and when to tell their adult children. I had to disclose to their adult children and in managing the aftermath of that. So what is our experience of releasing information to people who are matched? Now adoption social work is used to dealing with complex issues of privacy and confidentiality alongside the right to information, but often only with one primary client, the adopted person and not adoptive person, their birth and adoptive relative we are usually small in number and contained in a relatively small number of families. And donor link's experience of matching has already included working with much larger numbers of related individual spread across in much large numbers of families and this spring unique challenges for professionals but especially for those who are affected and requires careful thought to both, in manner and timing and when to release information to whom and how to manage the repercussions. Although the HFEA will only be dealing with one person at a time, they will undoubtedly find this. We have the information that they provide may prove unexpected or may reach other affected individuals who may not have wanted to receive it and all who are thereby learning of their origins for the first time. The HFEA needs to be ready to deal sympathetically with anyone in this situation who is for example as a result coming to them angry or distressed.

So what we conclude from our experiences to date that we think might be useful. In summary, we think that there are certain key features that we would suggest may need to be in place in the HFEA.

Flexibility. And this relates to both the medium of contact, email, phone, face to face. There can be a variety of mediums and the professional style of contact and they need to be responsive to the pace and the preference of those affected while remaining alert to the danger of becoming bureaucratic. In particular services, will have to be able to accommodate both little and often and stop/ start contacts and to recognise them for what they are.

Infrastructure. There needs to be in our view a front line service staffed by professionals with advance counseling skills and experience in searching and intermediary work complemented by a second staged formal counseling service as well as providing flexibility. This maximizes the identification and collection of shared professional experiences and the use of service uses feedback in informing the future developments of the service. Our experience suggests that this is more

	<p>effective, efficient and appropriate than would be using individually contracted isolated counselors. The use of social worker's experience in adoption search such as in contacts and intermediary work, many of whom are also qualified counselors that have the annual dedicated training and this is encouraging given that there is unlikely other to be sufficient demand to warrant the primary training has start specifically in donor conception such in contact work. Being available to all affected parties we believe there is a duty of care to provide professional support all those either searching or having contact with genetic relatives in a conceived adult, donors and family members of each. As the process is not only potentially, emotionally demanding but can have complex repercussions. Happy ever after in endings are not guaranteed. And finally we think it should be free and that does not mean that the service needs to be expensive. UK Donor Link has experience of running on a shoe string. We have a very small budget and we have to remember that people everywhere self-regulate their involvement in helping services. And I would like to end with 3 sound clips from BBC Radio 4 program which interviewed people who had used our service and who have all agreed to their voices broadcast again today in the absence of them being here. I thought that their words could speak very strongly to us today. And we start with Well, who is a donor, who is keen to be available to any of his donor offspring in case they felt the need to know more about him that is why he registered but he mused that you'll hear him musing, that it might be interesting for him too to meet them and to see what his own children might turn out later. <b>(Audience laughed)</b></p>
S3	<p>"I am sorry it will happen, but if it does not, that is okay. This really is not about what I want out of a game".</p>
S4	<p>"There must be a curiosity because unlike apparently... The child production you do not know what gender, you do not know anything really</p>
S3	<p>"There is absolutely curiosity I can not deny that... so probably I would see my own children. Maybe like in 15, 18 years time. There is no element of possessiveness, benign curiosity and a desire to do no harm and prevent harm and distress.</p>
S2	<p>Interesting note to debate there, what his own children would be going turn out like, but that was what he was talking about. Next, we have Louise and Shirley and these are two women who traced each other, they are genetic half siblings and Louise as a result found out more about her donor and she and her half sister here are talking about their experiences</p>
S5	<p>Even just having a name, having a face, having somebody solid ,just that information, that knowledge just puts a concreteness into me</p>
S2	<p>Although he is our dad this was a prolific donor, so finally Louise has met her 8 half siblings and other adults conceived from his donations and all of them new family.</p>

	The banter of two relatives. This is only the third time that Louise met Shirley
S5	I first met Shirley three years ago when UK Donor Link was beginning and at that time she told me of her longing to meet her half sibling Now she is able to embark on a complicated but fascinating experience.
S6	It is like finding a little piece of yourself. I am looking at Louise. I talk her, Oh it is a little bit like me or I can see so and so and that. And it is like making this web of connections that was... Has been three before.
S2	And on the last one is Louise speaking at the very end of the program and talking about what it is like if she looks back From thinking how she was before and how she is having found someone another part of her and it ends with the theme, the musical theme that went through was the ugly duckling so that is just to give you a clue of what comes at the end... So this is it here...
S6	The progression of medical technology is found to generate ever more complicated ethical issues but for Louise being able to look at the photo of her biological father and to understand her genetic heritage has meant the world
S5	I felt shame just come of me and I never knew that I felt ashamed it was literally like something physical leaving me and I just felt I was holding my head up higher, self acceptance that I've never ever felt before ..
	<b>(excerpt from the song The Ugly Duckling played) Say who is that ugly duckling... Not I... Not I.</b>