

University of Warwick institutional repository: <http://go.warwick.ac.uk/wrap>

This paper is made available online in accordance with publisher policies. Please scroll down to view the document itself. Please refer to the repository record for this item and our policy information available from the repository home page for further information.

To see the final version of this paper please visit the publisher's website. Access to the published version may require a subscription.

Author(s): Fiona MacCallum and Susan Golombok

Article Title: Embryo donation families: mothers' decisions regarding disclosure of donor conception

Year of publication: 2007

Link to published version: <http://dx.doi.org/10.1093/humrep/dem272>

Publisher statement: This is a pre-copy-editing, author-produced PDF of an article accepted for publication in Human Reproduction following peer review. The definitive publisher-authenticated version MacCallum, F. et al. (2007). Embryo donation families: mothers' decisions regarding disclosure of donor conception. Human Reproduction, 22, pp. 2888 – 2895 is available online at: <http://dx.doi.org/10.1093/humrep/dem272>

1     **EMBRYO DONATION FAMILIES: MOTHERS' DECISIONS REGARDING**  
2                     **DISCLOSURE OF DONOR CONCEPTION**

3     **Abstract**

4     BACKGROUND: Findings are presented of a study of families with a child  
5     conceived using donated embryos. This paper focuses on the patterns of disclosure of  
6     the method of conception from mothers to children and other family members.

7     METHODS: A total of 21 embryo donation families with a child aged 2-5 years were  
8     recruited through UK fertility clinics. Mothers were administered a standardized semi-  
9     structured interview, obtaining data on the extent of their disclosure to others and their  
10    reasons for this decision. RESULTS: Less than 10% of mothers had told their child  
11    how they were conceived at this stage, with 24% of mothers reporting that they were  
12    planning to tell the child in the future. However, nearly three-quarters of mothers had  
13    disclosed to other family members. Reasons cited for non-disclosure to the child  
14    included the desire to protect the child, the belief that disclosure is unnecessary, and  
15    the concern that family relationships would be damaged. Reasons in favour of  
16    disclosure included the desire to avoid accidental disclosure and the belief that the  
17    child has a right to know. CONCLUSIONS: Embryo donation mothers resemble  
18    parents of donor insemination and oocyte donation children in their attitudes towards  
19    disclosure of donor conception.

20    **Introduction**

21    Embryo donation is an assisted reproduction procedure that can be utilised either  
22    when both members of a couple are found to be infertile, or when previous IVF or  
23    ICSI treatments using the couples' own gametes have been unsuccessful (Trounson et  
24    al., 1983). In the UK, embryo donation is still relatively uncommon compared to other  
25    forms of assisted reproduction, with an average of around 35 children conceived in

26 this way born each year over the last decade, compared to ~800 by sperm donation  
27 and ~400 by oocyte donation (HFEA, personal communication). This is partly due to  
28 couples' desire to use their own gametes where possible, and also to the scarcity of  
29 available donated embryos. The majority of donor embryos used in treatments in the  
30 UK had originally been created by another couple in their own IVF cycles. Thus, the  
31 recipient couple will raise a child that is genetically related to the donor couple and  
32 who may have full genetic siblings elsewhere; a situation that structurally parallels  
33 adoption. Nevertheless, embryo donation parents differ from adoptive parents in that  
34 the recipient mother is also the gestational mother.

35         One significant consequence of this gestational relationship in embryo  
36 donation families is that it allows parents a choice about whether or not to disclose the  
37 non-genetic relationship to others and to the child. The issue of disclosure of the  
38 method of conception in families with children conceived using donor gametes has  
39 been the centre of extensive debate (Daniels and Taylor, 1993; Shenfield and Steele,  
40 1997; McGee et al., 2001; Patrizio et al., 2001). Historically, secrecy was the accepted  
41 position in gamete donation, with clinicians typically advising couples that no one  
42 else need know (Mahlstedt and Greenfeld, 1989). Over the last two decades concern  
43 has grown about the possible adverse effects of this secrecy, particularly with regard  
44 to family relationships and the psychological well-being of the child. The result has  
45 been a worldwide change in climate towards encouraging disclosure, reflected in the  
46 implementation in the UK of legislation ending the previous practice of anonymous  
47 donation and allowing donor offspring conceived since April 2005 (although not those  
48 conceived prior to this) access to the identity of the donors on reaching age 18.

49         The disclosure debate has involved international experts from the fields of  
50 mental health and social work, as well as assisted reproduction clinicians, patients,

51 and donor offspring (e.g., Daniels and Taylor, 1993; McWhinnie, 2001; Shenfield and  
52 Steele, 1997; Walker and Broderick, 1999). Those in favour of openness draw  
53 parallels between donor conception and adoption. There is an emphasis in the  
54 adoption literature on the importance of knowing one's genetic origins, and that not  
55 being given this information may have a detrimental effect, particularly on identity  
56 development (Triseliotis, 1973; Howe and Feast, 2000). Part of the process of  
57 establishing a coherent sense of identity for non-adopted individuals involves  
58 incorporating knowledge about their past and their family into their sense of self  
59 (Erikson, 1968). An adoptee lacks this genealogical continuity and so may find  
60 difficulty in developing a secure and healthy sense of ego identity, possibly resulting  
61 in insecurity and emotional problems. However, evidence suggests that adopted  
62 children deal better with this issue when there is open communication about adoption  
63 in the family (Brodzinsky et al., 1998). In the same way, it is argued that donor  
64 offspring may suffer similar harm to their emotional and identity development if they  
65 lack knowledge about their genetic background, and would benefit from open  
66 discussion (Snowden et al., 1983; Baran and Pannor, 1993; Daniels and Taylor, 1993).  
67 However, donor conception families differ from adoptive families in that the child has  
68 not been relinquished by existing parents, the child has a biological link to the mother  
69 through gestation, and the father has been present throughout the process. Thus, the  
70 challenge of forming a coherent identity faced by adoptees will not necessarily be  
71 encountered by donor offspring.

72 Another source of endorsement for openness draws on family therapy work.  
73 Studies suggest that the deception involved in secrecy can adversely affect honest  
74 communication and relationships between parents and children (Clamar, 1989).  
75 Children may become aware that their parents are keeping information on certain

76 topics from them, which could provoke anxiety and confusion and possibly lead to the  
77 development of emotional problems (Papp, 1993). Moreover, if other family members  
78 are aware of the donor conception, there exists a distinct possibility that the child  
79 could find out from someone else. Such accidental disclosure may break the bonds of  
80 trust between parents and children, and is suggested to be more harmful than planned  
81 disclosure during early childhood (McWhinnie, 2001). Some support for this comes  
82 from a study by Turner and Coyle (2000) of offspring who learnt of their donor  
83 conception in adolescence or adulthood and reported consequent negative feelings  
84 about their parents, although the participants were recruited from support groups so  
85 are not necessarily representative of all donor offspring.

86 Further support for sharing information about the donor conception with the  
87 child is based on human rights arguments (Gollancz, 2001). Non-disclosure is claimed  
88 to be against a child's right to autonomy and to information about their person  
89 (McGee et al., 2001). Legally, Article 8 of the 1950 European Convention on Human  
90 Rights guarantees the right to 'respect for private and family life'. It has been argued,  
91 e.g. in Blyth (2002), that knowledge about genetic origins is an essential element of  
92 private life, and that the child's right to this information should be the paramount  
93 consideration.

94 In contrast, those who defend non-disclosure to donor conception offspring  
95 argue that competing with the child's 'right to know' is a right of the parents to  
96 privacy and to make autonomous decisions about issues that may affect the welfare of  
97 the child (Shenfield and Steele, 1997; Walker and Broderick, 1999). To enforce  
98 disclosure would be to confer lower standards of rights to privacy and liberty to  
99 infertile couples than to fertile couples (Patrizio et al., 2001). From this perspective,  
100 parents have the prerogative to opt to keep the information private. It has also been

101 suggested that disclosure of the donor conception to the child could damage the  
102 relationship between the child and the non-genetic parent(s), with negative  
103 consequences for the child's emotional development (Snowden and Mitchell, 1981).  
104 Furthermore, it is argued that there still exists social stigma surrounding infertility and  
105 the use of donor gametes. Privacy about the conception allows both the child and  
106 couple to be protected from any negative societal attitudes, and prevents the family  
107 from being treated differently (Nachtigall et al., 1997). The notion that disclosure is  
108 not essential is supported by research showing that adolescents conceived by gamete  
109 donation who are unaware of their conception do not exhibit increased levels of  
110 emotional difficulties or dysfunctional relationships with their parents as compared to  
111 control groups of naturally conceived adolescents (Golombok et al., 2002; Murray,  
112 MacCallum, and Golombok, 2006). However, problems may still emerge as these  
113 offspring enter adulthood.

114         Turning from the academic debate to empirical research, early studies of  
115 gamete donation parents found that the majority tended not to disclose the donor  
116 conception to the child. In a review of studies published between 1980 and 1995 of  
117 donor insemination families, Brewaeys (2001) found that few parents (between 1%  
118 and 20%) intended to tell their child about their genetic origins. The European Study  
119 of Assisted Reproduction Families, conducted in Spain, the Netherlands, Italy and the  
120 UK, found that less than 10% of donor insemination parents had told their child about  
121 their conception by early adolescence (Golombok et al., 2002). A study of UK oocyte  
122 donation families by Murray and Golombok (2003) found slightly higher disclosure  
123 rates, but still only 29% of couples stated that they were definitely planning to tell  
124 their child. In contrast, adoptive parents as a rule begin to explain the circumstances  
125 of the adoption to the child from a young age (Brodzinsky and Pinderhughes, 2002).

126 However, more recent research on gamete donation families in the UK with children  
127 conceived from 1999 onwards, has found some evidence that attitudes are changing.  
128 When the children were aged 9-12 months, 46% of donor insemination parents and  
129 56% of oocyte donation parents stated that they intended to tell, demonstrating a  
130 marked increase (Golombok et al., 2004). Nonetheless, it remains to be seen whether  
131 the parents will carry through this intention as the children grow up.

132         Research assessing why gamete donation parents decide not to tell the child  
133 has found consistent patterns. One reason frequently cited by both donor insemination  
134 and oocyte donation parents is to protect the child either from the distress of  
135 discovering that he/she is not genetically related to one parent, or from the upset  
136 caused by not being able to discover any information about the donor (Nachtigall et  
137 al., 1997; Lindblad et al., 2000; Murray and Golombok, 2003). Another common  
138 reason for non-disclosure is the protection of the non-genetic parent and their  
139 relationship with the child (Cook et al., 1995; Murray and Golombok, 2003). Many  
140 donor insemination parents also report that disclosure is unnecessary, since the non-  
141 genetic parent is the one who has raised the child (Lindblad et al., 2000), and in the  
142 case of oocyte donation, the parents point out that the mother has carried and given  
143 birth to the child (Murray and Golombok, 2003). Thus, non-disclosing parents often  
144 highlight the social and gestational relationships between parent and child as being  
145 more relevant and important to parenthood than the genetic relationships.

146         So far there has been little research focusing specifically on embryo donation  
147 families and their decisions regarding disclosure. Soderstrom-Antilla and colleagues  
148 (2001) interviewed 27 couples in Finland who had been treated with donor embryos  
149 and found that 69% of them thought that a child conceived in this way should be  
150 informed about the manner of their conception. However, only 11 of these couples

151 (41%) had actually had a child at the time of study, only 5 of these had definitely  
152 decided to inform the child, and it is not reported how old the children were or  
153 whether disclosure had already taken place. Therefore, questions remain as to whether  
154 parents in embryo donation families will tend towards the adoption model of full  
155 disclosure, or will resemble more closely other donor conception families in keeping  
156 the method of conception relatively private.

157 To address these issues, the present study examined the disclosure patterns of  
158 a group of embryo donation mothers from the UK with a child aged between 2 and 5  
159 years, asking whether they had told their child and their family about the use of donor  
160 embryos. Mothers' reasons for their decisions were explored in order to look at the  
161 thinking processes behind opting for disclosure or non-disclosure.

## 162 **Materials and Methods**

### 163 *Participants*

164 Twenty-one families with a child conceived using donated embryos were recruited  
165 through three UK fertility clinics. All two-parent heterosexual couples with an  
166 embryo donation child aged between 2 and 5 years inclusive at the time of study at  
167 each of the participating clinics were asked to take part. Children born at less than 30  
168 weeks gestation were excluded, as were those with severe congenital abnormalities.  
169 To maintain confidentiality, parents were approached in the first instance by a letter  
170 from the clinic's Medical Director. The study was approved by the Ethics Committee  
171 at City University, where the research team was based. Thirty-seven families were  
172 contacted and 29 families replied (8 declined to participate), giving a response rate of  
173 72% of those whom it was possible to trace (since the couples had been treated up to 5  
174 years prior to the study, some had since moved house). Due to confidentiality  
175 regulations, no further information was available on those families who refused to



176 take part. Fifteen of the participating families had children born from singleton births,  
177 and six families had twins. Findings from this sample relating to quality of parenting,  
178 parental psychological state, and child development have been reported elsewhere  
179 (MacCallum et al., 2007).

180         There were 13 boys and 8 girls in the group, with the mean age of the children  
181 being 3 years and 6 months, and the mean age of the mothers being 43 years. Twenty  
182 of the families had two co-habiting parents, and one couple had separated since the  
183 birth of the target child. All couples had conceived using anonymously donated  
184 embryos (i.e. prior to the UK legislation change in April 2005).

### 185 *Measures*

186 A researcher trained in the study techniques visited each family at home. Parental  
187 attitudes towards disclosure of the use of donated embryos were assessed using semi-  
188 structured interviews administered to mothers and fathers separately (data from  
189 fathers and inter-couple comparisons will be reported in a future article). The  
190 following information was obtained from mothers: 1) whether or not they had told or  
191 planned to tell the child about the method of conception; 2) their reasons for this  
192 decision; 3) the extent of mothers' disclosure to family about the child's donor  
193 origins; and 4) their reasons for disclosure or non-disclosure to family. Interviews  
194 were tape-recorded (with mothers' permission) and transcribed verbatim.

195         Information from the interviews were analysed in two ways. Firstly, data  
196 relating to the extent of secrecy, and the reasons given for disclosure or non-  
197 disclosure were coded into pre-set categories, according to strict coding criteria  
198 derived from previous theory and investigations of disclosure in gamete donation  
199 families (e.g. Cook et al., 1995). For those mothers who did not intend to share this  
200 information with their child, their reasons for this decision were classified into the

201 following variables, each of which was rated as ‘yes’ or ‘no’: 1) to protect the child;  
202 2) to protect family relationships; 3) no need to tell; and 4) don’t know what/how to  
203 tell. Data from those mothers who had told their child, or planned to tell them in the  
204 future were coded thus: 1) the child has a right to know; 2) to avoid accidental  
205 disclosure; and 3) no reason not to. With respect to disclosure to family members, the  
206 responses of mothers who had not told their family were rated according to the  
207 following categories: 1) to protect the child; 2) to protect the mother; 3) to protect the  
208 father; 4) to avoid disapproval; and 5) no need to tell. Similarly, the responses of  
209 mothers who had told their family were classified thus: 1) wanted to share; 2) no  
210 reason not to tell; 3) to avoid accidental disclosure; and 4) had to tell/no choice.  
211 Mothers were not constrained to giving a single response, but had the opportunity to  
212 describe all the reasons influencing their disclosure decision. Where more than one  
213 reason was reported, each of these was rated, e.g., if a mother who had not disclosed  
214 to her family mentioned wanting to protect the child and wanting to avoid  
215 disapproval, both of these categories were coded as ‘yes’.

216 Secondly, the transcripts were content analysed according to the themes  
217 defined by the quantitative variables above. The NVIVO statistical software package  
218 was used to assist in the exploration and coding of the transcribed texts (Gibbs, 2002).  
219 This method was adopted to obtain more in-depth information about the specific  
220 issues encompassed by the response categories, e.g. if a mother mentioned a desire to  
221 protect the child, the transcript was examined to establish what she was trying to  
222 protect him/her from.

## 223 **Results**

### 224 *Extent of Disclosure*

#### 225 *Disclosure to child*

226 Of the 21 embryo donation mothers, only 9% (n = 2) had already told the child about  
227 the method of conception. A further 24% (n = 5) reported that they were planning to  
228 tell the child in the future. Forty-three per cent (n = 9) had definitely decided that they  
229 would never tell the child, and the remaining 24% (n = 5) were undecided.

#### 230 *Disclosure to family*

231 Seventy-two per cent of the embryo donation parents (n = 15) had told at least one  
232 family member about the donor conception, leaving 28% (n = 6) who had not told any  
233 of their family. Maternal grandparents were significantly more likely to have been  
234 told about the method of the child's conception than were paternal grandparents (n =  
235 11 vs. n = 9; 53% vs. 43%;  $\chi^2 = 7.47, p < .025$ ).

#### 236 ***Reasons for disclosure/non-disclosure to child***

237 For the purposes of examining parents' reasons for disclosure or non-disclosure to the  
238 child, the families were divided into 2 groups. The first group included all parents  
239 who were inclined towards non-disclosure, and comprised those mothers who had  
240 definitely decided not to tell and those who were undecided (n = 14; 67%). The  
241 second group included all mothers who were inclined towards disclosure, and  
242 comprised those who had already told their child and those who stated an intention to  
243 tell when the child grew older (n = 7; 33%). This approach follows that of previous  
244 studies (Brewaeys et al., 1997; Lycett et al., 2004) where those who had already told  
245 formed a composite group with those who were intending to tell.

#### 246 *Non-disclosure to the child*

247 *To protect child.* Sixty-four per cent of the non-disclosing mothers (n = 9) reported a  
248 desire to protect the child from the possible negative consequences of disclosure.  
249 From the content analysis, two separate concerns emerged. Firstly, the most  
250 frequently identified issue was a fear that the child would be upset or confused on

251 learning that his/her parents were not genetically related to him/her, as illustrated by  
252 this quote:

253 “I think it would cause a lot of insecurity with [child] really and a lot  
254 upheaval, a lot of upset...”

255 The second factor in protecting the child stemmed from the practice of clinics using  
256 anonymous donors. Mothers felt that the lack of genetic information available would  
257 make disclosure more distressing than beneficial to the child:

258 “He’s not going to be able to find out so why make him think Daddy and I  
259 weren’t his real parents?”

260 “The people that actually donated embryos wanted their anonymity, and if you  
261 start telling children..., they could quite easily go in search of trying to find out who  
262 the real parents are, the biological parents, which could be very upsetting for them.”

263 *To protect relationships with family members.* Forty-three per cent of the non-  
264 disclosing mothers (n = 6) expressed a concern that family relationships, particularly  
265 parent-child relationships, would be damaged by disclosure. They feared that the child  
266 may reject them on learning of the absence of a genetic link. As one woman stated:

267 “Possibly you’d get the ‘you’re not really my parents’, you know, ‘what right  
268 have you got?’”

269 Mothers were also concerned that the child would feel isolated from the rest of the  
270 family if they were aware that they were not genetically related:

271 “I don’t want him to feel left out, I want him to know he’s got a family that  
272 will look after him, ...I want him in with sort of like the family rather than outside”

273 *No need to tell.* In addition, forty-three per cent (n = 6) of the non-disclosing mothers  
274 were rated as feeling there was simply no need for disclosure. The most common

275 justification given was that since the mother had carried the child in pregnancy and  
276 given birth, she is to all intents and purposes the ‘real mother’.

277 “You’re going to be carrying them for 9 months, you’re going to be feeding  
278 them for 9 months, to all intents and purposes, you are their mummy.”

279 Similarly, since both the mother and father have been the nurturing parents from the  
280 beginning of the child’s life, the fact that they are not the genetic parents is irrelevant.

281 “We’ve brought them up, so it’s not an issue that’s important really. The  
282 important thing is that... they’ve got a mum and dad who loves them and the actual  
283 genetics is a by-the-by.”

284 *Don’t know what to tell.* Only one mother specifically stated that she and her husband  
285 were inclined towards non-disclosure due to uncertainty over how to tell their child:

286 “It would be very difficult to explain, it’s complex, it’s hard for adults to  
287 understand, so how would he understand?”

288 *Disclosure to the child*

289 *To avoid accidental disclosure.* The most common reason, given by five of the seven  
290 mothers (71%) who were inclined towards disclosure, was a fear that otherwise the  
291 child may accidentally discover the facts later and find this difficult to cope with. This  
292 was particularly prevalent when other people had been told, for example:

293 “[Husband’s] family knows about the treatment, my family know about the  
294 treatment, so in effect it could be an innocent comment one day that was said to  
295 [child] and then he’s going to have the option to turn to me and say ‘but you didn’t  
296 tell me’.”

297 *Right to know.* Over half of the disclosing mothers (57%, n = 4) stated that the child  
298 had a right to know the truth. In-depth analysis of the transcripts found that responses  
299 in this coding category could be further divided into two sub-categories. Some felt

300 that the information was part of the child's life story, particularly from a medical  
301 perspective:

302 "If they had a medical problem that wasn't hereditary from us but could be  
303 hereditary from the donors, they might question as to why. And I feel they should  
304 know in advance."

305 For other mothers, the feeling was more that children generally have a right to honesty  
306 from their parents, including the information about their genetic backgrounds.

307 "I do believe in being honest, no matter how much you don't like the truth, it's  
308 always best to be upfront."

309 *No reason not to tell.* Two of the disclosing mothers reported that there was simply no  
310 reason not to tell the child, since they felt the treatment was nothing to be ashamed of:

311 "I don't see why it should be a secret, I wouldn't think of it as anything to be  
312 concerned about."

### 313 ***Reasons for disclosure/non-disclosure to family***

314 The reasons for non-disclosure were analysed for the six mothers who had told no  
315 family members, including the maternal grandparents, about the donor conception.

#### 316 *Non-disclosure to family*

317 *To protect the child.* Three of the 6 non-disclosing mothers (50%) had not told the  
318 family in order to protect their child. Analysis of the transcripts revealed that these  
319 women were concerned that the family would treat the child differently if they knew  
320 that there was no genetic relationship, as the following quote demonstrates:

321 "As far as my family are concerned..., we've just had a little boy and he's still  
322 family..., he hasn't been bought into the family as an outsider."

323 *To avoid disapproval.* Three of the mothers (50%) were concerned that the family,  
324 particularly the grandparents, would react negatively to the use of donor conception.

325 The feeling seemed to be that since the grandparents were older, and as one mother  
326 put it, “of a different generation”, they would not understand or approve.

327 “You see my mum’s 83 and she’s a very very devout Catholic. And she would  
328 not understand. And for her to find out now, it would do her more harm than good...,  
329 it would upset her immensely.”

330 *Other reasons.* Two mothers (33%) had not fully disclosed to their family due to the  
331 husband’s wish to keep *his* infertility secret. In both cases, the families were aware  
332 that the couple had undergone IVF treatment but not that donor embryos were  
333 involved, although one woman did tell her family that she was using donor oocytes:

334 “I didn’t want [husband] to feel that, because his sperm is no good, I didn’t  
335 want it to reflect on him..., I didn’t want the family to sort of be ‘Oh he’s no good, he  
336 can’t produce any children’..., so I just said it was my fault..., so we done donated  
337 eggs but you know the sperm is [husband’s].”

338 In addition, two mothers (33%) strongly felt that the donor conception was a private  
339 matter between the couple, and not something to be discussed with anyone:

340 “It’s something that’s very personal and private, you know it’s the less people  
341 know really, isn’t it? You know, it’s something that’s keeping within a very close  
342 circle.”

#### 343 *Disclosure to family*

344 The reasons given for discussing the child’s origins with the family were assessed for  
345 the remaining 15 mothers..

346 *Wanted to share.* The most common reason for disclosure to the family was simply  
347 that the mother wanted to share this information with them, cited by 87 % (n = 13).

348 These women said that they generally discussed most personal matters with their  
349 families, and therefore did not see why this issue should not also be discussed.

350 “I think it’s just that we’ve got quite a close relationship with both sets [of  
351 parents] really that it seemed to be a big thing not to tell.”

352 *To avoid disclosure.* Twenty percent of the mothers (n = 3) had told their family  
353 because they were concerned that they would find out from another source:

354 “Can’t really keep secrets, can you? They always come out of the woodwork  
355 somehow, people always find out the truth, I don’t know how they do it, but they do.”

356 *No reason not to tell.* Twenty percent of mothers (n = 3) responded that there was no  
357 reason not to tell their family, since they did not feel it necessary to keep the method  
358 of conception secret, and they preferred to be honest with family members:

359 “I don’t really know, just couldn’t see any reason not to tell them really...,  
360 I’ve always thought it’s important to be truthful.”

361 *Other reasons.* Two women gave other reasons for telling their families about the  
362 donor conception. One mother felt that she had no choice but to disclose, since the  
363 families were already aware of her fertility problems:

364 “Because everyone knew I couldn’t have children anyway so...”

365 For the other mother, disclosure to the family was related to her intention to disclose  
366 to her children. She felt therefore it would be easier for “if they knew that Grandma  
367 knew, and still loved them for themselves and not for ‘what they are’.”

### 368 **Discussion**

369 The findings demonstrate that embryo donation parents do not follow the full  
370 disclosure model of adoptive families, with the large majority of embryo donation  
371 mothers deciding not to tell the child about the method of conception. Only one-third  
372 of mothers had told or were planning to tell the child, and just under half reported that  
373 they had definitely decided against telling. In contrast, most had disclosed the facts of  
374 the donor conception to someone else, with 72% having told at least one family



375 member. In this respect, embryo donation parents resemble earlier studies of gamete  
376 donation parents with children born before 1995 (Brewaeys, 2001; Murray and  
377 Golombok, 2003). However, a recent study of donor conception parents with infants  
378 conceived between 1999 and 2001 found that almost half of donor insemination  
379 parents and more than half of oocyte donation parents were planning to disclose  
380 (Golombok et al., 2004). This implies that, unlike other gamete donation parents, the  
381 attitudes of embryo donation parents may not be changing in line with the prevailing  
382 attitudes towards openness, and that they may be particularly private about this issue.

383         The proportion of embryo donation mothers in the current study who were  
384 inclined towards disclosure is much smaller than the 69% of embryo donation  
385 recipients in a Finnish sample (Soderstrom-Antilla et al., 2001) who reported that they  
386 believed children should be told about the method of their conception. The less open  
387 attitudes seen in the UK sample may reflect cultural differences. Although there was  
388 no explicit legislation regarding assisted reproduction in place in Finland when the  
389 research was conducted, the fundamental principle guiding the use of such treatments  
390 is the protection of the rights and interests of the child (Burrell, 2005). It is possible  
391 that this emphasis has engendered more positive attitudes towards disclosure in  
392 Finland than are seen in the UK, where the rights of the parents are considered to be  
393 of equal importance. However, it is important to note that not all of the Finnish  
394 couples had actually had children, and of those who had, more than half had not  
395 disclosed to their child. Couples' reported intentions regarding disclosure are not  
396 always reflected in their future behaviours (Golombok et al., 2002), so in practice the  
397 Finnish sample and the mothers in the current UK study may not be so different.

398         When the reasons for non-disclosure to the child were examined, the most  
399 common rationale was that disclosure could be more harmful than beneficial to the

400 child, either because learning that he/she is genetically unrelated to both parents  
401 would be disturbing in itself, or because donor anonymity would cause frustration if  
402 the child wished to trace the donors. The same reasoning has been consistently given  
403 previously by non-disclosing gamete donation parents. (Nachtigall et al., 1997;  
404 Lindblad et al., 2000; Murray and Golombok, 2003). It may be especially salient in  
405 embryo donation where there is no information on the genetic background, whereas in  
406 other gamete donation families half of the child's genetic heritage is known.

407 Another frequently stated reason for non-disclosure was anxiety that  
408 knowledge about the donor conception would adversely affect family relationships,  
409 particularly between parents and children. Protection of the non-genetic parent's  
410 relationship with the child has been used as an explanation for non-disclosure in  
411 previous studies of gamete donation parents (Cook et al., 1995; Murray and  
412 Golombok, 2003). With embryo donation, *both* parents lack a genetic link resulting in  
413 the fear that disclosure would lead to *both* parents being rejected by the child. Again,  
414 the complete absence of a genetic relationship between the parents and the child  
415 seems to be contributing to the comparatively high rate of non-disclosure in embryo  
416 donation families.

417 Donor insemination parents have often reported that disclosure is not needed  
418 because the social relationship between father and child is more relevant than the  
419 biological relationship (Golombok, et al., 2004; Lindblad et al., 2000). Oocyte  
420 donation parents have additionally justified their non-disclosure on the basis that the  
421 mother is the biological parent through gestation (Murray and Golombok, 2003). The  
422 embryo donation mothers cited both of these factors as rendering disclosure  
423 unnecessary. Assisted reproduction techniques allow the separation of different  
424 aspects of parenthood that usually co-occur, i.e. genetic, gestational and social

425 contributions. Non-disclosing embryo donation parents tended to emphasise the social  
426 and gestational components as more vital to parenting than the genetic.

427         In part, the reasons given for non-disclosure by embryo donation mothers  
428 reflect differences between embryo donation and adoption. For some couples, the  
429 decision not to disclose arose from the experience of pregnancy and birth and the  
430 presence of the father throughout the process, which does not occur in adoption.  
431 Moreover, unlike adoptive parents, embryo donation parents have no information to  
432 give the child about their genetic heritage. From this perspective, it has been  
433 suggested that anonymity of donors supports non-disclosure (Daniels and Taylor,  
434 1993). Conversely, it has been argued that parents might feel that donors would  
435 present a greater threat to family cohesion if they were identifiable, and therefore  
436 disclosure would be less likely (Pennings, 1997). Studies of UK donor conception  
437 families with children conceived after the implementation of the donor identity  
438 legislation would help in establishing which of these influences were at work.

439         Considering the few embryo donation mothers who had decided to disclose to  
440 the child, over half agreed with the argument propounded by many professionals  
441 working in the area of assisted reproduction that the child has a right to know his or  
442 her origins (Daniels, 1995; Blyth, 2002). Moreover, two mothers felt that there was no  
443 reason not to tell the child, since there was no shame in conceiving in this way.  
444 However, the reason most often cited was that parents wished to avoid disclosure  
445 from someone else. All three of these explanations, in particular the child's right to  
446 know and the desire to avoid disclosure by others, have been previously found to be  
447 common reasons for disclosure in gamete donation families (Golombok et al., 2004)

448         This concern regarding accidental disclosure may be justified since 72% of  
449 parents had disclosed to family members, a proportion comparable to or higher than

450 that found in previous studies of donor conception families, For example, in Murray  
451 and Golombok's (2003) study, 65% of oocyte donation couples had told a family  
452 member, and in Brewaeey's (2001) review of studies of donor insemination families,  
453 approximately 50% of all couples had disclosed to someone in the family, although  
454 many regretted this openness once the child was born. Similarly, in a study by Klock  
455 and Greenfeld (2004) of disclosure by oocyte donation couples, although 82% of  
456 women and 66% of men reported telling others, the majority of couples regretted this  
457 disclosure and stated that if they were to do it again, they would not tell. It is possible  
458 that couples are willing to disclose to others during treatment, but that their attitudes  
459 change after the birth when the information becomes more salient. If views on  
460 disclosure alter once the child is born, this could explain why, of those who had told  
461 family members in the present study, only 47% were also planning to tell the child.

462 In contrast, just over one quarter of the couples had told no one about the  
463 embryo donation. These parents were concerned that the family would ostracize the  
464 child or would show overt disapproval of the treatment, implying that they perceived  
465 some stigma associated with the method of conception or with their infertility.  
466 Previous research suggests that women may be more comfortable disclosing oocyte  
467 donation than men are disclosing donor insemination, either because there is more  
468 shame attached to male infertility (Daniels and Taylor, 1993), or because the mother's  
469 gestational relationship makes the lack of genetic link less important (Greenfeld et al.,  
470 1998). This was true for two mothers in this study, who felt that it was acceptable to  
471 tell the family about their own infertility but not that of their husbands.

472 The major methodological limitation of this study is the small size of the  
473 sample. To some extent, this was unavoidable since embryo donation treatment is  
474 infrequent in the UK. The participating clinics were in different areas of the country,

475 ensuring that the families were dispersed across regions in an attempt to recruit as  
476 representative a sample as possible, and the response rate for these families was  
477 moderate to high. Nonetheless, it is not known what the disclosure patterns would be  
478 in those families who refused to participate. Replication of the research with a larger  
479 sample would increase the validity and allow wider generalisation of the results. In  
480 addition, since practices surrounding embryo donation, and its prevalence may differ  
481 internationally, cross-cultural comparisons would provide useful information. The  
482 study is also limited by presenting the views of mothers only. Fathers may have  
483 different feelings on this issue, since previous research shows that couples in gamete  
484 donation families can hold dissimilar opinions regarding disclosure (Klock &  
485 Greenfeld, 2004). Although data was collected from fathers, it was felt that to discuss  
486 fully the issue of fathers' attitudes and inter-couple discrepancies would require  
487 empirical and theoretical investigation beyond the scope of the current paper, and  
488 therefore would be better presented separately in a future article. Despite these  
489 limitations, the study represents the first investigation of its kind to provide important  
490 preliminary findings on embryo donation families in the UK.

491       Concerns that non-disclosure will cause difficulties do not seem to be borne  
492 out at this stage, since the families were found to be functioning well in terms of  
493 parent-child relationships and child adjustment (MacCallum et al., 2007). Although  
494 parallels have been drawn between embryo donation and adoption, it is possible that  
495 the differences that exist between the two situations mean that disclosure is more  
496 necessary in adoption. However, the embryo donation children were very young so  
497 the possibility remains that problems will develop as they grow older, and perhaps  
498 become aware that there is a secret in the family, or indeed find out about the donor  
499 conception. A follow-up study is currently being conducted to investigate this issue.

500 It is also worth noting that the concerns voiced by the non-disclosing parents  
501 may not be valid. A study of a small number of donor insemination parents who had  
502 told their child about their conception reported that, rather than being distressed by  
503 this information, the children generally reacted with either curiosity or disinterest  
504 (Lycett et al., 2005). Similarly, studies in New Zealand (Rumball and Adair, 1999)  
505 and in the US (Scheib et al., 2003) found that children conceived by donor  
506 insemination largely responded either positively or neutrally upon learning about their  
507 conception. This contrasts sharply with the negative consequences seen for donor  
508 offspring who learnt the facts later in life (Turner and Coyle, 2000), supporting the  
509 notion that if disclosure is to occur, the process is best begun at a young age and  
510 approached by parents in an age-appropriate manner. Presenting this more positive  
511 view of disclosure to donor conception parents may encourage more to initiate this  
512 process themselves, avoiding the risks of inadvertent disclosure with its potentially  
513 detrimental effects for the child and for family relationships (McGee et al., 2001).

514 The views of the embryo donation parents in the present study demonstrate a  
515 marked discrepancy from the advice given by the UK regulatory body, the HFEA,  
516 which states in its literature for parents that “It is certainly best to be open with your  
517 child/children about the circumstances of their conception. Secrecy on this subject  
518 isn't in their interests” (HFEA, 2007). If the aim of the HFEA is to reach the stage of  
519 adoptive families, where the overwhelming majority of parents are open with their  
520 children about the adoption from a young age, there is some way to go. Adoptive  
521 parents are educated about disclosure by social workers as part of the adoption  
522 preparation process, in addition to which they have access to post-adoption support  
523 services, and disclosure aids such as the child’s life-story book and materials  
524 explaining adoption in child-friendly terms. Similar information and support could be

525 made available for embryo donation couples. Useful resources to support the  
526 disclosure process are being produced, such as the “Telling and Talking” booklets  
527 published by Donor Conception Network (2006), but awareness of such materials is  
528 generally not high. Moreover, currently in the UK, couples can receive counselling if  
529 they wish through their fertility clinic during treatment, but as mental health  
530 professionals, counsellors should attempt to maintain neutrality on the issue of  
531 disclosure in order to protect the therapeutic relationship and allow the couple to come  
532 to a decision independently (Klock and Greenfeld, 2004). Thus, there may be a place  
533 for the establishment of post-treatment services specifically for couples who actively  
534 seek advice on when and how to tell the child after the birth. Parents should not feel  
535 forced into disclosure but should be equipped with all the available information in  
536 order to make the decision that best suits their family.

### 537 **Acknowledgements**

538 We would like to thank the clinics that recruited the participating families including  
539 Sheffield Fertility Centre, Manchester Fertility Services, the Assisted Conception Unit  
540 at St James’s Hospital, and especially the staff at Bourn Hall Clinic. Thanks also to  
541 Sarah Keeley at the University of Warwick for her help in coding the transcripts.

### 542 **References**

- 543 Baran A and Pannor R (1993) *Lethal Secrets*. Amistad, New York.
- 544 Blyth E (2002) Information on genetic origins in donor-assisted conception: Is  
545 knowing who you are a human rights issue? *Hum Fertil* 5, 185-92.
- 546 Brewaeys A (2001) Review: Parent-child relationships and child development in  
547 donor insemination families. *Hum Reprod Update* 7, 38-46.
- 548 Brewaeys A, Golombok S, Naaktgeboren N, de Bruyn JK and van Hall EV (1997)  
549 Donor insemination: Dutch parents' opinions about confidentiality and donor

- 550           anonymity and the emotional adjustment of their children. *Hum Reprod* 12,  
551           1591-1597.
- 552   Brodzinsky D and Pinderhughes E (2002) Parenting and child development in  
553           adoptive families. In Bornstein M (ed.), *Handbook of Parenting*, vol 1.  
554           Mahwah, NJ, Lawrence Erlbaum Associates, pp. 279-311.
- 555   Brodzinsky D, Smith DW and Brodzinsky AB (1998) Children's adjustment to  
556           adoption. *Developmental and clinical issues*. Sage Publications, London
- 557   Burrell R (2005) *Assisted Reproduction in the Nordic Countries*. Nordic Committee  
558           on Bioethics. Retrieved June 10, 2007 from <http://www.ncbio.org>
- 559   Clamar A (1989) Psychological implications of the anonymous pregnancy. In  
560           Offerman-Zuckerberg J (ed.), *Gender in transition: a new frontier*. New York  
561           and London, Plenum medical book company, pp.111-112.
- 562   Cook R, Golombok S, Bish A and Murray C (1995) Disclosure of donor  
563           insemination: Parental attitudes. *Am J Orthopsychiatry* 65, 549-559.
- 564   Daniels K and Taylor K (1993) Secrecy and openness in donor insemination. *Politics*  
565           *Life Sci* 12, 155-170.
- 566   Daniels KR (1995) Information sharing in donor insemination: A conflict of rights  
567           and needs. *Cam Q of Healthc Ethic* 4, 217-224.
- 568   Donor Conception Network (2006). *Telling and Talking*. from [www.dcnetwork.org](http://www.dcnetwork.org)
- 569   Erikson EH (1968) *Identity: Youth and Crisis*. Norton, New York
- 570   Gibbs GR (2002) *Qualitative Data Analysis: Explorations with NVIVO*. McGraw-Hill  
571           Education, Maidenhead, UK
- 572   Gollancz D (2001) Donor insemination: A question of rights. *Hum Fertil* 4, 164-167.



- 573 Golombok S, Brewaeys A, Giavazzi M, Guerra D, MacCallum F and Rust J (2002)  
574 The European study of assisted reproduction families: The transition to  
575 adolescence. *Hum Reprod* 17, 830-840.
- 576 Golombok S, Lycett E, MacCallum F, Jadva V, Murray C, Abdalla H, Jenkins J,  
577 Margara R and Rust J (2004) Parenting children conceived by gamete  
578 donation. *J Fam Psychol* 18, 443-452.
- 579 Greenfeld DA, Greenfeld DG, Mazure CM, Keefe DL and Olive DL (1998) Do  
580 attitudes towards disclosure in donor oocyte recipients predict the use of  
581 anonymous versus directed donation? *Fertil Steril* 70, 1009-1014.
- 582 HFEA (2007) For parents of donor-conceived children.  
583 [www.hfea.gov.uk/en/1185.html](http://www.hfea.gov.uk/en/1185.html)
- 584 Howe D and Feast J (2000) Adoption, search and reunion: The long term experiences  
585 of adopted adults. The Children's Society, London
- 586 Klock SC, and Greenfeld DA (2004) Parents' knowledge about the donors and their  
587 attitudes toward disclosure in oocyte donation. *Hum Reprod* 19, 1575-1579.
- 588 Lindblad F, Gottlieb C and Lalos O (2000) To tell or not to tell - what parents think  
589 about telling their children that they were born following donor insemination.  
590 *J Psychosom Obstet Gynecol* 21, 193-203.
- 591 Lycett E, Daniels K, Curson R and Golombok S (2004) Offspring created as a result  
592 of donor insemination: A study of family relationships, child adjustment, and  
593 disclosure. *Fertil Steril* 82, 172-179.
- 594 Lycett E, Daniels KR, Curson R and Golombok S (2005) School-aged children of  
595 donor insemination: A study of parents' disclosure patterns. *Hum Reprod* 20,  
596 810-819.

- 597 MacCallum F, Golombok S and Brinsden P (2007) Parenting and child development  
598 in families with a child conceived through embryo donation. *J Fam Psychol*, in  
599 press.
- 600 Mahlstedt P and Greenfeld D (1989) Assisted reproductive technology with donor  
601 gametes: the need for patient preparation. *Fertil Steril* 52, 908-914.
- 602 McGee G, Brakman S and Gurmankin AD (2001) Disclosure to children conceived  
603 with donor gametes should not be optional. *Hum Reprod* 6, 2033-2036.
- 604 McWhinnie A (2001) Should offspring from donated gametes continue to be denied  
605 knowledge of their origins and antecedents? *Hum Reprod* 16, 807-817.
- 606 Murray C and Golombok S (2003) To tell or not to tell: The decision-making process  
607 of egg donation parents. *Hum Fertil* 6, 89-95.
- 608 Murray C, MacCallum F and Golombok S (2006) Egg donation parents and their  
609 children: follow-up at age 12 years. *Fertil Steril* 85, 610-618
- 610 Nachtigall RD, Pitcher L, Tschann JM, Becker G and Szkupinski Quiroga S (1997)  
611 Stigma, disclosure and family functioning among parents of children  
612 conceived through donor insemination. *Fertil Steril* 68, 83-89.
- 613 Papp P (1993) The worm in the bud: Secrets between parents and children. In Imber-  
614 Black E (ed.), *Secrets in families and family therapy*. Norton, New York, pp  
615 66-85.
- 616 Patrizio P, Mastroianni AC and Mastroianni L (2001) Disclosure to children  
617 conceived with donor gametes should be optional. *Hum Reprod* 16, 2033-  
618 2036.
- 619 Pennings G (1997) The double track policy for donor anonymity. *Hum Reprod* 12,  
620 2839-2844.

- 621 Rumball A and Adair V (1999) Telling the story: Parents' scripts for donor offspring.  
622 Hum Reprod 14, 1392-1399.
- 623 Scheib J, Riordan M and Rubin S (2003) Choosing identity-release sperm donors: The  
624 parents' perspective 13-18 years later. Hum Reprod 18, 1115-1127.
- 625 Shenfield F and Steele SJ (1997) What are the effects of anonymity and secrecy on  
626 the welfare of the child in gamete donation? Hum Reprod 12, 392-395.
- 627 Snowden R and Mitchell GD (1981) The Artificial Family. George Allen & Unwin,  
628 London
- 629 Snowden R, Mitchell GD and Snowden EM (1983) Artificial Reproduction: A social  
630 investigation. George Allen & Unwin, London
- 631 Soderstrom-Antilla V, Foudila T, Ripatti U and Siegberg R (2001) Embryo donation:  
632 outcome and attitudes among embryo donors and recipients. Hum Reprod 16,  
633 1120-1128.
- 634 Triseliotis J (1973) In Search of Origins: The experiences of adopted people.  
635 Routledge & Kegan Paul, London
- 636 Trounson A, Leeton J, Besanka M, Wood C and Conti A (1983) Pregnancy  
637 established in an infertile patient after transfer of a donated embryo fertilized  
638 in vitro. Br Med J 286, 835-838.
- 639 Turner AJ and Coyle A (2000) What does it mean to be a donor offspring? The  
640 identity experiences of adults conceived by donor insemination and the  
641 implications for counselling and therapy. Hum Reprod 15, 2041-2051.
- 642 Walker I and Broderick P (1999) The psychology of assisted reproduction - or  
643 psychology assisting its reproduction. Aust Psychol 34, 38-44.
- 644
- 645