SHARING THE NATURE OF THE CHILD'S CONCEPTION
IN FAMILIES FORMED AS A RESULT
OF DONOR INSEMINATION

A STUDY OF THE FACTORS INFLUENCING
PARENTAL
DECISION-MAKING IN GERMANY

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Abstract

Most parents do not disclose their use of donor insemination (DI) to their child or to significant others. The reason for this has been associated with the stigma surrounding DI and male infertility, the latter being the most common reason for the use of DI. A number of jurisdictions have enacted legislation supporting information sharing, but this seems to have only limited impact on parental decision-making regarding DI. The aim of this study was to understand the factors influencing parental decision-making in sharing information about DI. The study was conducted in Germany, where legislation regarding DI is confusing and information sharing about DI not the norm.

For this research study, a total of 46 respondents, representing 23 couples were interviewed both as individuals and as a couple. Semi-structured interviews were carried out and a feedback form administered.

Results showed that both male infertility and DI were highly stigmatised conditions. Male infertility was associated with a lack of virility and perceived to be a humiliating experience. DI was considered to be "disgusting" and "suspicious" and only "silently accepted". Professional services were perceived to contribute to this stigma by withholding information about DI, misinforming clients or viewing DI negatively. Furthermore, the confusing legal framework was seen to corroborate the stigma. Despite this, most respondents had sufficient confidence to share their experience of male infertility with significant others. Also, most intended to share information about their use of DI with their future children, and some had already shared this with significant others. No negative reactions were reported as a result of disclosing the use of DI to others, but respondents were of the view that most people did not understand what DI entailed.

This suggests that many factors, including individual confidence, public perceptions, professional advice, as well as the cultural climate and legislation, can influence parental decision-making about information sharing relating to DI. In order to consider and understand parental decision-making, it is essential to analyse these micro, meso and macro-level factors. Change on all three levels is required in order to transform attitudes and beliefs about DI and to promote DI as a different, yet acceptable family building option.
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This thesis would also not have been possible without the assistance of my supervisors. My sincere thanks go to my chief supervisor, Assoc. Prof. Ken Daniels whose support and encouragement started well before I embarked on this thesis. As an external examiner for my MA thesis, he raised my awareness of the need for further research in the area of family building with the assistance of donor insemination (DI), and heightened my interest in carrying out such research. The research projects we subsequently carried out together helped me to develop a better understanding of the research process itself and of international developments in the field of DI. As previously, during the progress of this thesis he contributed significantly by sharing with me his extensive knowledge and experience in the area of DI, contributing valuable insights and providing on-going intellectual stimulation and support. Not only did he do this during my stay at the University of Canterbury (October 2002 to March 2003), but also before and after this period, during his visits to Germany as well as via email and telephone. Prof. Dr. Marlies W. Fröse, who is not involved in the field of DI, also provided me with her expertise and critical appraisal in the area of research. She provided valuable assistance in that she was located in Germany and therefore available to me to clarify issues as they arose.
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Introduction

"Deep inside I wonder why I don't simply say the truth, why I don't admit that we used DI to have our child. And then, when I think about doing it, I get afraid about the sort of reactions I might get. And this stops me from talking to others and from talking to our child."

This was the answer a female client I had several years ago gave when I asked her and her husband for the reasons they had not disclosed their use of donor insemination (DI) to anybody. Clearly for her, the fear of negative reactions or a lack of understanding and empathy stopped her from sharing any information about DI, although this seemed to go against her intuitive feelings.

My motivation for carrying out research in the area of family building with the assistance of DI largely stems from my experiences of counselling couples and carrying out preparation seminars for those considering DI. I have been involved in infertility counselling for over 10 years and my initial driving force for this involvement was my own experience of infertility. Almost fifteen years ago, in 1991, while pursuing medical treatment, I founded a self-help group for women experiencing infertility. It was the discussions I had and sharing with these women that made me realise how strong the taboo surrounding infertility was in Germany at that time. Fortunately, but sadly in contrast to other group members, I conceived spontaneously after several fruitless attempts at treatment cycles. Combining my knowledge as a social worker and family therapist with my personal experiences, I started to work as an infertility counsellor in 1994, offering individual and couple counselling as well as group work. At the same time, I began to collaborate with contact people from other self-help groups in Germany, and in 1995, a number of us established the German patient organisation for infertility, Wunschkind e.V. Though occasionally there were women and couples in the self-help group who had used DI, it was only as an infertility counsellor that I fully realised the challenges these couples were facing. As a social worker, I became

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1 The literal translation of “Wunschkind” is “the child you wish for”. The abbreviation “e.V.” stands for the formal acknowledgement for any charitable organisation in Germany.
profoundly aware of the taboo and stigma associated with this way of building a family, and at the same
time I was appalled by the lack of information and legislation, and the marginalisation these families
experienced. As a family therapist, I started to become interested in the family dynamics and especially
the impact of the secrecy about the semen provider's contribution. Realising from my personal experience
how empowering information and sharing with others in the same situation can be, I developed a concept
for preparation seminars for couples interested in DI. This concept differed from other group work in the
area of infertility, which primarily focussed on exploring and managing psychosocial issues arising from
the experience of infertility. As a social worker, I was aware of the importance of information and
education, especially in the area of family building by DI, where, in the middle of the 1990s, little had
been published, and legislation and medical guidelines were vague and contradictory. One of the main
aims of the seminars was to provide psychosocial, medical and legal information as a means of
empowering participants. Furthermore, I considered a group setting as ideal for breaking through the
silence and enabling participants to get to know others pursuing DI. This challenged the marginalisation
and the stigma associated with DI. Information sharing, both with the child and with significant others,
has been a central issue of these seminars. I have carried out these seminars since 1996, and with Prof.
Daniels as a male co-facilitator since 1998. Many participants of these seminars have remained in contact
with each other and some established the German patient organisation, Information Donogene
Insemination (IDI). For several years, this organisation has held bi-annual meetings to provide support for
families built with the assistance of DI. Given the lack of literature on family building by DI, I undertook
to summarise the discussions of these preparation seminars and added issues I considered relevant. These
I collated in a booklet and published in 1997, with a section on the legal provisions written by Dr. Helga
Müller (Thorn, 1997). Dr. Helga Müller has contributed as a legal expert to the groups from the
beginning.

From 1996 to 1999, I studied towards a second degree in the area of social therapy. My main motivation
for this course was to contribute towards a better understanding and change in the area of family building
with the assistance of DI. I wanted to gain knowledge and experience in order to carry out a small piece
of research on dynamics in families built by DI, which I did for my Master of Arts thesis. I was invited to
present the results of this study at an international conference (Thorn, 1999). This led to further research.
In 1999, Prof. Daniels and I surveyed the medical practice of DI in Germany (Thorn & Daniels, 2000a),
and between 2001 and 2003, we carried out research investigating the impact of the preparation seminars (Thorn & Daniels, 2003; Daniels, Thorn & Westerbrooke, 2005). As a result of my cooperation with Prof. Daniels, as well as extensive opportunities to travel abroad and to learn about the policies and practices in other countries, I became acutely aware of the fact that not only was legislation in Germany inadequate, but there was a lack of public awareness of family building by DI, as well as a lack of opportunities for psychosocial professionals to exchange their knowledge and experience in infertility and family building by DI. This inspired me to write several articles on infertility and family building by DI (for example: Daniels & Thorn, 2001; Huck & Thorn, 2001; Thorn, 2000a; Thorn, 2001; Thorn & Daniels, 2000b) and to contribute towards the establishment of a national organisation for infertility counselling. The German infertility counselling network, Beratungsnetzwerk Kinderwunsch Deutschland e.V. (BKiD), was established in 2000.

Almost in a parallel process to my professional journey in the area, DI in Germany underwent several changes and achieved greater public awareness. In 1995, the Arbeitskreis für donogene Insemination e.V. (Medical Association for Donor Insemination [AKDI]) was founded. This association was the first group to establish guidelines for medical treatment with DI (Arbeitskreis, 1996). Although binding for their members only, these guidelines signified an important step in the hitherto reluctant acceptance of DI by the medical community; they indicated that DI was significant enough and sufficiently accepted by society in general that such guidelines should be written up and published in the medical community. As a result of my contributions in the area of DI, I was asked to become a member of AKDI in 2001, at that time the only non-medical member and until today one of the very few female members. Realising that the culture of DI had been dominated and sustained by medical professionals, I welcomed this invitation as I saw it as an opportunity to contribute towards change in the medical field of DI. At the same time, I felt marginalised in this group, not least because I was the only social worker and counsellor whose “comfort zone” was counselling, not discussing medical practice with doctors. This has changed over the last four years; I now feel more comfortable, and the medical members have increasingly welcomed the psychosocial perspective of my contributions. Currently, AKDI is revising its guidelines and I have been able to contribute from a psychosocial perspective to these revisions.
Until the end of the 1990s, medical as well as psychosocial writers in Germany favoured secrecy in DI (Schaible, 1992; Schilling, 1995; Seikowski & Glander, 1980) or conveyed a neutral attitude (Seikowski & Glander, 2000). Only recently has one doctor tentatively indicated in public that information sharing can be favourable for the parents and for the child (Katzorke, 2001). At the same time, two doctors have been known to require pre-treatment counselling and the counsellors they refer to favour information sharing. In addition, in 2002, a change in legislation provided more legal certainty for married heterosexual couples using DI, and in fact, for the first time in German legislation, family building with the assistance by DI was acknowledged through the reference to "the man who provides his semen". Although this indicates that policies and practice regarding DI are undergoing changes, in comparison to other European countries, such as Austria and Switzerland, this has been a slow process. We still lack a consistent legal framework, guidance books for individuals and couples using DI, as well as training opportunities for psychosocial professionals who provide counselling for recipients of DI.

Retrospectively, one could almost assume that there was a structure in my contributions to the area of family building by DI - from providing counselling to couples to offering group work, to carrying out research and publishing, to contributing towards change in the medical area of DI, to being increasingly considered a German expert on the psychosocial aspects of DI. However, at any given time in this process, I merely undertook what, as a social worker, I considered to be the next significant step in contributing towards an increase in awareness and acceptance for families built by DI. This reflected the psychosocial perspective of social work. All my involvement has shaped my thinking about DI, especially my contact with many couples and individuals who have chosen DI as a family building option, my involvement with the AKDI and my international exposure. The individuals and couples I have seen as a counsellor and group facilitator, many of whom now have children, have confirmed to me that their decision to build a family by DI was the right decision. They are pleased that they had the option of using DI, and despite the ongoing critical attitudes regarding DI, consider their family as legitimate as any other family. Though most of their children are still young (from just a few months to 12 years), they have confirmed that sharing the information about DI family building does not result in any difficulties for the children, and, in fact, leads to less strain and anxiety for them as the parents. They have also confirmed the importance of mutual and ongoing support after pregnancy has been achieved. In my travels, especially to New Zealand and Australia, I had the opportunity to discover family building options using
gamete donation were much more accepted in other countries than in Germany. This not only includes DI, but also oocyte donation and surrogacy. Counselling concepts discussed with international colleagues have shaped my clinical practice in Germany, and clients have appreciated my extensive knowledge and my professional contacts. At the same time, this broader social and, in some countries, legal acceptance of diverse family forms has had a significant impact on my thinking and has widened my narrow German horizon in this respect. Germans with more conservative views tend to perceive my increasingly liberal stance as provocative, and they are not always as appreciative or supportive of the family diversity resulting from various forms of assisted human reproduction (AHR) as I am. Also, in discussions with professionals and lay people in Germany, I often have the impression that individual private opinions regarding new family building options are more liberal than those voiced in public. This may be indicative of the strong and ongoing impact measures such as eugenic selection had during the Nazi regime. Though born a decade and a half after the Second World War, I am not completely untouched by such sentiments. I can understand the German need to ensure that legislation does not leave loopholes for such measures to re-emerge. At the same time, Germany cannot isolate itself from developments elsewhere, especially at a time of increasing globalisation where, with the help of Internet communication, geographical distances are becoming more and more insignificant, and information gathering, and thus awareness of other cultures, more easily facilitated and common.

Despite the reserved attitude towards family building by DI in Germany, I consider it as valid a family formation as any other. In my view, it is neither better nor worse, but its uniqueness does raise specific issues that need to be considered. These include management of this family composition in a culture with a reserved attitude towards DI, and limited understanding of the contribution of the semen provider and of managing information sharing about DI. I also believe it is of advantage that couples and individuals considering DI learn about these different issues before embarking on treatment, and that semen providers should also be given the opportunity to explore the implications of DI for themselves and their (future) family. In line with current recommendations in the area of adoption, I consider sharing information about the type of conception with the child from an early age as beneficial both for the child's development and for the family as a whole. I firmly believe that parents in Germany, as in many other countries, who share the nature of conception with their child/ren are pioneers who do so regardless of ongoing scepticism.
about DI, often in the face of adverse recommendations by professionals and, more frequently, despite the lack of support and resources.

The theme of marginality seems central to this thesis. It was evident in the feelings of couples who have built their families with the assistance of DI. It was a feeling I experienced when I compared policy development between New Zealand, where I was registered for my doctoral studies, and Germany. It was a feeling I experienced personally when, as a social worker and a woman, I joined the circle of mainly male doctors who had established the AKDI. It was also a feeling I re-experienced when I wanted to study towards a Doctor of Philosophy (PhD) as a social worker. In Germany, social work is taught at universities of applied sciences, which, prior to beginning this thesis, could not accredit a Master of Arts (MA) degree. Social workers in Germany had to complete a Master of Arts accredited by a university in order to begin a PhD programme. Therefore, it was common for social workers to study for a Master of Arts degree at a university in the area of psychology, education or sociology, and then study for a PhD in these areas. It was not possible to study for a PhD in social work. I received both my university degrees from a university of applied sciences, which meant I would have had to study for an MA at a German university and complete a doctoral programme in a department of psychology, education or sociology. Being a social worker, however, I was interested in working from a social work perspective for this doctoral thesis. My aim was to look at and evaluate individual, professional and social policy factors and thus contribute to a holistic or systems understanding of parental decision-making, where micro, meso and macro-level factors are explored. Previously, some writers have concentrated on individual (located at the micro level) and/or professional factors (located at the meso level) only (for example: Baran & Pannor, 1989; Brähler, 1990; Klock, 1997; Mahlsted & Greenfeld, 1989), without taking into account that these issues function interdependently with legislation and/or social policy (at the macro level). Others have concentrated on the future implications and factors located at the macro level and, for example, argue for the need to take the welfare of the resulting child into account (for example: Blyth & Hunt, 1998; Zypris, 2003), without necessarily considering that the child will inherently become part of the family built by the couple and thus will be subjected to factors located on the individual and professional levels (micro and meso-level factors). My aim was to analyse all of these factors and to understand if and

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2 These universities of applied sciences can be compared to polytechnic schools in some countries.
how they are interrelated – to understand the relationship between the private troubles and the public
issues that emerge from the field of DI.

Given the difficulties I would have encountered in Germany in applying such an approach, I welcomed
the opportunity to study towards a PhD at the University of Canterbury in the Department of Social
Work, when, at my request, Prof. Daniels agreed to supervise this PhD thesis. On a personal and
professional level, this meant that I was able to apply a holistic social work focus instead of a different
social science perspective to this research. It also meant that I was granted the possibility of undertaking
this PhD under the supervision of an experienced and prolific researcher and writer with whom I shared a
similar understanding of many issues and approaches, not least because we are both social workers. On an
academic level, it meant that as a social worker I did not have to resort to other disciplines in order to
further knowledge and academic development in the field of social work. This may have been one of the
first times in Germany that a social worker was granted this privilege.

Language and terminology used in this thesis
Although families built with the assistance of DI are not a new type of family, as a result of the secrecy
surrounding this method of family building, our understanding is only beginning to emerge. This is not
only reflected in the limited number of publications available, but also in the language which is used to
describe this family as a whole and all the individuals who have contributed to the creation of this family
(see Chapter 2, pages 34-38, for a detailed outline of the terminology used in family building with the
assistance of DI). In this thesis, I have attempted to use language which best describes the meanings and
roles of family members and the man who provides the semen, realising that this terminology may not be
universally endorsed. I believe, however, that the terminology I use is a more accurate representation of
the experiences of this group of people.

When writing about the families resulting from DI, I will use the term “families built with the assistance
of DI” and similar notions. More recently, writers have used the phrase “DI-family”. In my view this
qualifies this family type primarily in terms of the type of treatment undertaken and in fact attributes a
higher priority to this than to the fact that it is foremost a family unit. In the phrases I will use, these families will be qualified primarily as families, indicating that this takes precedence over the way in which they were built.

In accordance with current literature, the term “donor insemination” (DI) will be used throughout this thesis in order to point out that the semen of a male other than the (usually male) partner was used for building a family.

The term “information sharing” will be used for discussing the use of DI with the child and with significant others. Daniels and Thorn (2001) argue that terminology such as “openness” or “secrecy” has emotional connotations attached to it, which can cloud discussion of the topic and polarise issues. Information sharing allows for degrees of sharing and this was considered important in this thesis, as respondents may share limited information with one particular group, but more comprehensive information with other groups and/or the child.

A person conceived with the assistance of DI is often referred to as a “DI child”. Haimes (1992) argues that this tends to infantilise these persons and ignores their later adult status. I will use terminology such as “offspring” and “adults conceived with the help of DI” where appropriate, and refer to “children” only where small children and young teenagers are described. Only a few respondents in this study had children. Therefore, where appropriate, I will refer to their “future” children and/or place “future” in brackets in order to point out that this includes those children already born and those not yet born.

The role of the father in a family built with the assistance of DI is often described as uncertain and it is not unusual that the semen provider is referred to as “the biological father” or the “donor father” (for example: Baran & Pannor, 1989; Scheib et al., 2004; Turner & Coyle, 2000). I will use “father” or, where appropriate, “social father” to describe the man who takes on the responsibility for the upbringing of the child, and reserve “semen provider” and “genitor” for the man who gave his semen. In Chapter 7 where the results of this research are reported, passages from the interviews with respondents will be quoted. These interviews were conducted in German and translated by myself. In Germany, the semen provider continues to be referred to as the “donor”; no other terminology has yet been developed. This is the word
both respondents and I used in the interviews, and in the translated passages of these interviews, the English word “donor” was considered the most literal translation.

A certain part of this thesis is concerned with the significance of nature and nurture in the upbringing of children. In this context, the meanings of biological and social bonds are discussed. More recently, increasing knowledge in the area of genetics has resulted in viewing the genetic component as important as it can provide information about potential diseases and/or dispositions for diseases. Therefore, increasingly, terms such as “genetic connection” or “genetic origin” are being used. In this thesis, I will use “biological” and “genetic” connection or origin interchangeably.

In most cases, DI is used as a response to male infertility. “Infertility” and “impaired fertility” are used to describe the male partner’s difficulty in fathering a child; in some of these cases, couples have the possibility of conceiving with the assistance of medical intervention. The term “sterility” is used when the male partner’s body does not develop any viable semen; in these cases, the only way to build a family is with the use of DI or adoption. Where relevant, the term “third party reproduction” is used to describe DI, oocyte and embryo donation as ways to build a family. The term “assisted human reproduction”, or AHR, is used for those medical interventions which individuals and couples with impaired fertility, or those who, for reasons pertaining to sexual preferences or social status, use in order to conceive and build a family.

As a social worker, I am concerned with the psychological as well as the social meanings and implications of DI. I will use the combined term of “psychosocial” when referring to these issues.

**Structure of the thesis**

The first chapters of this thesis will provide an overview of family building with the assistance of DI. In Chapter 1, I will describe various reasons why individuals and couples use DI, including the use of DI by lesbian and single women. This chapter will also explain the emotional impact of male infertility, the most common reason for the use of DI, on the male partner and the couple.
In Chapter 2, the historical and current understandings of kinship, as well as families built with the assistance of DI, will be outlined. This chapter will provide a detailed overview of research carried out with children conceived with the assistance of DI and their families, as well as research with semen providers.

Chapter 3 will provide a picture of family building by DI in Germany. In this chapter, I will outline the historical and current developments regarding legislation, social policy, counselling and research. As will be noted, I will refer to clinical experience in several instances when describing the practice of DI in Germany. This was necessary as in some areas, little written material is available. All of the material from German articles used in this chapter and in others was translated by myself.

The next chapter, Chapter 4, will provide a similar overview on an international level. It will describe the historical development and current debates regarding information sharing from various disciplines. It will also illustrate the development of policies and practice in those countries which are at the forefront of enacting legislation for family building with the assistance of DI.

Chapter 5 will outline theories that contribute to the understanding of parental decision-making. These will include theory development in the area of social work and, more specifically, the influence of systems theory on social work. It will also outline the biopsychosocial model, a perspective not widely used in medicine but nevertheless helpful in drawing attention to a holistic understanding of diseases. Social stigmatisation theory will be drawn upon in order to explain why individuals or groups are discriminated against and how anticipated normative expectations are influential over behaviour.

In Chapter 6, the methodology applied to carry out the research for this study will be described. Chapter 7 will then describe the results of the interviews carried out for this study. This will include a brief portrait of the respondents, as well as demographic information. It will also outline the respondents’ reasons for pursuing DI, the information they were able to gather about DI, any discussions they had with significant others and with professionals, and the viewpoints voiced by these groups, as well as the relevant factors
influencing respondents' decisions regarding information sharing. All passages quoted directly and indirectly from the interviews used in this and the following chapter were translated by myself.

In Chapter 8, the results of this thesis will be discussed alongside existing knowledge, research, policy and practice. This chapter will be divided into factors influencing parental decision-making at the micro, meso and macro levels. Micro-level factors will include intrapersonal aspects as well as factors related to the couple and the nuclear family. Meso-level factors will analyse those resulting from the interaction with significant others and professionals. Macro-level factors will be discussed including those issues pertaining to the social attitude in general, legislation and social policy.

Finally, in Chapter 9, Conclusions, the main arguments of this thesis will be summarised and an overview of the contribution this study makes to the understanding of information sharing in relation to the use of DI will be provided.

Each chapter will begin with a brief overview of the contents and conclude with a summary of the chapter, except for Chapter 8, which will discuss the results alongside existing knowledge, and where overviews and summaries are included for each of the micro, meso and macro-level sections.
Chapter 1

Factors leading to the use of DI

This chapter will summarise the prevalence and causes of male infertility, the most common reason for using family building with the assistance by DI. It will also outline the way men and their female partners respond to male infertility and explain gender differences as well as typical couple dynamics. It will conclude by describing a more recent phenomenon, the use of DI by lesbian couples and single women.

Male infertility

According to the World Health Organization, infertility is the inability to conceive after at least one year of unprotected coitus (Vayena, Rowe & Griffin, 2002). In general, it is believed that one in ten couples experience infertility. Infertility rates worldwide vary greatly amongst countries from less than 5% in some to over 30% in others (Vayena et al., 2002). For Germany, Brühler, Stöbel-Richter, Huinink and Glander (2001a) estimated in 2001 that up to 10% of couples in West Germany and up to 5% in East Germany were involuntarily childless. Explaining this difference, the authors stated that it was easier for mothers in East Germany to remain in the workforce; infertility resulting from an advanced age was therefore less likely in East than in West Germany. Of a population of 42,278,000 of men and women between 15 and 45 years of age (Statistisches Bundesamt, 2004), this would suggest that between approximately two and four million individuals experience infertility in Germany. Henning and Strauß (2000) suggest that in approximately 30 to 40% of these cases, infertility can be partly or fully attributed to the male partner; this indicates that approx. 600,000 to 1,6 mill. males suffer from infertility.
Some of these couples can be helped with medical interventions, such as minor surgery and the use of ICSI (Intracytoplasmatic Sperm Injection\(^3\)). Other men suffer from complete sterility; in these cases, there is no semen that can be used for ICSI and the only option for building a family is by the use of DI or adoption. Men with genetic disorders but who are fertile may choose DI in order to avoid passing on the condition to the child. DI involves the insemination of the female partner with semen of a fertile male, who in most cases is unknown to the couple. In contrast to ICSI, this is considered a less invasive treatment as the female partner does not undergo substantial hormonal stimulation and oocyte retrieval. The following discussion will focus on male infertility and the use of DI by heterosexual couples as well as by two additional groups, lesbian couples and single women.

Many different factors can lead to impaired male fertility or sterility. These include infections, exposure to toxins, cryptorchidism,\(^4\) surgery as well as genetic and endocrine disorders.\(^5\) However, as the symptom of male infertility is usually reduced semen quality, the degree to which certain diseases contribute to or cause infertility is difficult to ascertain. In many cases therefore only male infertility as such can be diagnosed and it is not possible to tell the cause of the infertility. This proportion of so-called idiopathic infertility\(^6\) currently ranges from 14% (Keye, 1999) to 30% of all cases (Ochsendorf & Beschmann, 1996); for Germany, this means that between 84,000 and 480,000 men do not know the reason for their infertility.

Traditionally, it was assumed that the female was nearly always the "responsible" partner in terms of reproduction (Carrell & Urry, 1999). Male infertility has been described as remaining "somewhat in the dark ages" (Lee, 1996, p. 29) and has only recently become the focus of both medical and social science research. This may have contributed to the fact that for many years male infertility was a neglected issue, not only worldwide (Keye, 1999) but also in Germany. Commenting on observations in Germany, Mehrzens (2004) remarks that andrology only became a subject of interest in the 20th century, whereas general interest into gynaecology started at the end of the 18th century. Frick-Bruder (1980) in analysing publications on the cause of infertility between 1935 and 1963, found in most cases it was the female

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\(^3\) When applying ICSI, single spermatozoa are injected into the oocyte after having retrieved them from the ovaries. This medical treatment is used for men with extremely low sperm counts.

\(^4\) Cryptorchidism results from undescended testes leading to infertility or sterility if not treated at a young age.

\(^5\) The most common endocrine disorders are Klinefelter's Syndrome and Cystic Fibrosis.

\(^6\) Idiopathic or unexplained infertility is said to occur when a comprehensive array of screening tests and investigations fails to identify a cause of the infertility.
partner who was assumed to be infertile. Psychological studies investigating the impact of male infertility have also been found to be rare (Strauß, 1991). In a review of the literature, Bents (1985) found that amongst 121 articles on infertility published between 1948 and 1985, 56% referred only to the female partner, 29% to both partners and only 15% solely to the male partner. Of the 52 papers in which male factor infertility was considered, 17 were articles reporting on theoretical analysis and meta-studies, 14 were prospective and 11 retrospective studies. What can be concluded from this review is that male infertility has until recently been a neglected area. Two factors are likely to contribute to this: the general lack of awareness of male health issues and the social stigma attached to infertility. Brähler, Goldschmidt and Kupfer (2001b) when researching to determine the number of publications on male and female health found that between 1977 and 1999, there were 118 hits for issues on “men and disease” versus 327 hits on “women and disease”. With “men and health”, there were only 76 hits versus 544 hits for “women and health”. They concluded that there was a lack of a men’s movement as active as the women’s movement, that a differentiated representation of male health issues was not presumed to be necessary as men were considered “the actual human being” (Brähler et al., 2001b, p. 13) and that the notion not only of infertility but of male health in general was intertwined with sexual functioning to such a great degree that men confronted with health issues feared a negative impact on their reputation as virile males. According to Brähler et al. (2001b), men therefore perceived statements regarding their own diseases as a narcissistic insult. Meryn, the chief editor of the newly founded Journal of Men's Health and Gender, spoke out for more awareness of gender-specific medicine. In his view, this would complement the women’s and men’s movements and that such a higher level of recognition must also encompass medical and social studies (Meryn, 2004). In addition, living without children, whether voluntarily or involuntarily, has been described as a form of deviant behaviour in marriage. Miall (1986, p. 268) stresses that childlessness is perceived as:

... a violation of prevailing norms of acceptable conduct. When cultural norms and values encourage reproduction and celebrate parenthood, childlessness becomes a potentially stigmatising status which can adversely affect the identities and interpersonal relationships of married persons.

The lack of awareness of male health issues, the strong association of male health with fertility and virility as well as social stigmatisation of infertility in general are likely to contribute to the disregard for
issues related to male infertility (See Chapter 5, pages 100-114, for a detailed discussion of social stigmatisation).

The emotional impact of male infertility

For both men and women who wish to have children, infertility has been described to be a major life crisis (Covington, 1987; Lalos, 1999; Menning, 1980). In a study conducted by Freeman, Boxer, Rickels, Tureck and Mastroianni (1985), 49% of female and 15% of male respondents indicated that infertility had been the most stressful event in their lives. Involuntary childlessness is often associated with feelings of loss (Menning, 1980) and depressive reactions (Kerr, Brown & Balen, 1999), although the majority of people with infertility do not experience clinically significant emotional reactions (Hammer Burns & Covington, 1999). Regarding the impact of infertility on men and women, there is less agreement. Some authors support the concept that men and women find infertility equally distressing (Daniluk, 1997), others believe that women experience greater levels of distress than men, and report that they score lower in regard to self-esteem, are more depressed, report lower life satisfaction, show greater tendencies to isolate themselves from "the fertile world", are more active in regard to seeking information and treatment, and are less inclined to stop treatment (Freeman et al., 1985; Hammer Burns & Covington, 1999; Greil, Leitko & Porter, 1988; Wright, Bissonette, Duchesne, Benoit, Sabourin & Girard, 1991). In her attempt to understand these contradictions, Daniluk (1997) identified three factors that contribute to the gender differences. According to her, a critical reflection of the social context, a gender-specific focus of the medical approach and the biology of reproduction, as well as methodological considerations, may explain these diverse findings.

The social context may contribute to gender differences in the way in which men and women have been socialised to cope with negative affect. As men tend to display fewer emotional reactions, this "may result in the erroneous perception that they are not as bothered by their inability to produce a child" (Daniluk, 1997, p. 111). In addition, Nachtigall, Becker and Wozny (1992, p. 118) advise that:
... gender roles, from which gender differences emerge, are the social expression of gender identity, reflecting the social and cultural context of individual's lives, not simply their personal psychology. Differences between women's and men's responses to infertility can be attributed to different perceptions of the procreative role specified for one's gender.

Furthermore, women have been described as perceiving more relationship distress and to be more open towards counselling than men (McCartney & Wada, 1990). Daniluk (1997) also reports that the social worlds of infertile men and women are different. Whereas men's friendships with other men undergo few changes, women's friendships alter once women become mothers: the space reserved for friendships is taken up by the family responsibilities. She also indicates that women seem to have a protective stance towards their husbands. As some female partners perceive male infertility as associated with a greater stigma than female infertility, they present themselves as infertile, thus protecting their male partner.

Regarding the medical and biological context of treatment, as described above, historically it was the woman who was the primary focus and this is only slowly changing. Women still tend to undergo more medical interventions than their male partners, such as basal body temperature charting, laparoscopy, ovulation induction and inseminations, independent of whether they or their male partners have been diagnosed with infertility. In addition, in infertility treatment, powerful drugs are used to induct ovulation growth. Daniluk (1997, p. 110) criticises the fact that medical treatment is not taken into account:

... none of the studies that have reported gender differences in response to infertility have considered the role of these reproductive medications or procedures in heightening or exacerbating the psychological sensitivity or responsiveness of infertile women. It is impossible to say with any certainty then, how much of the emotional lability and expressivity of infertile women is a consequence of the medications commonly prescribed in the treatment of infertility.

With advances in assisted human reproduction (AHR) such as epididymal sperm aspiration, infertile men can be subject to invasive medical interventions, and therefore may experience similar distress in response to these investigations. In addition, the greater emotional suffering may also be explained as independent from the diagnosis, it is the woman who fails to become pregnant and who lives with the monthly biological reminder of her failure, her regular menstruation cycle.

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7 This refers to the surgical removal of semen.
There are methodological considerations suggesting that results of studies supporting differences in the ways in which men and women respond to infertility should be interpreted with caution. Writers have criticised the fact that much of the research on which the assumptions of gender differences are made, are based on small, homogeneous samples of white, middle-class, married couples who voluntarily agree to participate in research, with men characteristically being underrepresented in much of this research (Daniluk, 1997). Greil (1997) further points out that distortions may occur as a result of ignoring factors beyond immediate issues of infertility, such as lack of marital support, answering questions according to social desirability and the exclusion of respondents outside of medical treatment. Questions have also been raised regarding the use of standardised measures that may be more sensitive to the ways in which women characteristically express psychosocial distress (Abbey, Andrews & Halman, 1991; Berg & Wilson, 1991). Meryn (2004, p. 3) therefore argues for qualitative research in the area of male health:

Qualitative research has a particularly important contribution to make where treatment issues involving the quality of life are critical for outcome, as for example in sexual health. Qualitative research is still regarded with scepticism by the medical community ... . But I believe qualitative research can help us increase our knowledge and understanding of medicine. The interpretation of textual material and purposeful samples is different from the calculations of numerical material and random examples. But ... the underlying principles are much the same and qualitative and quantitative strategies should be seen as complementary.

Greil (1997) suggests that it may be relevant to understand the different ways in which men, in contrast to women, feel stressed by infertility. Instead of comparing emotions, he considers it more helpful to understand how the different stages of infertility and medical treatment impact on men. This approach was used by Mason (1993) in her study of 22 infertile men. She reports on the stages of investigation, the impact of the diagnosis and its consequences. Regarding their reactions to medical investigation and treatment, she concludes:

... put in a nutshell, men felt they had been left out and neglected, their problems glossed over or perhaps completely ignored. Valuable time had been lost for some because they had not been checked out early enough. According to others it was ironic that though they had the problem, they were not the ones being treated. ... The medical experiences described to me reflect the earlier discussion about the shortage of effective male treatments. Often, not much was offered. (Mason, 1993, pp. 72-73)

She argues that the lack of knowledge about and/or interest in andrology has contributed to poor quality investigation. In addition to this, seeking a fertility investigation does not seem easy for men. Mason
(1993), along with several writers, indicates that it is often the female partner who initiates investigations and assumes a pro-active role during treatment (Abbey et al., 1991; Newton & Houle, 1993). Riegl & Partner GmbH (1998) found that almost half of the men they interviewed in Germany had to force themselves to consult a specialist. Mason (1993, p. 58) suggests that the active role of women reflects the social attitude that "children are seen as women's business and most people assume the woman is at fault". Men also criticise the lack of adequate facilities to provide semen samples and complain about the lack of individualised care (Beutel et al., 2001). One respondent in a German study expressed how humiliated and compromised he felt when he remarked that having to masturbate "on the loo is simply shitty" (Beutel et al., 2001, p. 199).

Regarding the diagnostic impact, Mason (1993) reports that in her study, men's reactions were dependent on whether they had expected problems. Given that few had symptoms, were not constantly reminded by their body of fertility, as is the female partner, and that there was little knowledge about the complexity of the male reproductive system, she comments that men were "blissfully ignorant of what could go wrong" (Mason, 1993, p. 85). Those respondents who were unaware of their impaired fertility commonly reported feelings of shock, anger, denial, and both a sense of missing out on an important experience and of failure. The severity of the responses, to some degree, was dependent on the time that had elapsed between diagnosis and the interview. The longer the time had elapsed, the less severe these reactions were. Another factor that ameliorated reactions was infertility caused by a hereditary condition as this was a clear-cut situation that men were able to accept more easily and receive support from their wives. However, Mason (1993, p. 90) concludes that "the message that emerges from this discussion is that it would be unwise to assume that men respond in a uniform way to a diagnosis of male infertility".

Mason (1993) also describes the emotional repercussions of infertility as manifold and strong. They include guilt, shame, loss, a sense of personal failure as well as denial and isolation. According to her, these repercussions also impact on the couple's relationship. Men feel guilty because they cannot fulfil their partner's and social expectations. They describe themselves as inadequate as they have failed to get their wives pregnant. Lee (1995) describes men as having similar reactions and found that they blame themselves and feel useless. Derogatory self-attributions such as "loser", "failure", "garbage" and "defective" (Daniluk, 1997) vividly reveal men's lack of confidence. Furthermore, shame results from the
perception that fertility is linked with virility and potency, thus infertility is assumed to negatively affect sexual functioning. Lee (1995) explains that some men suffering from infertility feel their masculinity to be threatened, which can result in impaired sexual desire and/or functioning. This has been confirmed by other researchers who have identified a high number of men or couples with sexual problems. Berger (1980) found that up to 63% of men in his study suffered from temporary impotence lasting between one and three months after infertility had been diagnosed, and Eckert, Sobeslavsky and Held (1998) found that over half of 183 couples in their study experienced sexual problems. Drawing on the notion that fertility is linked to virility, Houghton and Houghton (1987, p. 48) explain that “the man who is seen not to have children is considered [by society as] lacking in masculinity or virility”. According to Lee (1995), men tend to deny feelings of loss of virility and potency but are willing to disclose feelings of loss of self-esteem. Mason (1993) adds that a more general and pervasive feeling of impotence rather than solely sexual impotence, men’s feeling of powerlessness, their inability to achieve something they assumed would be easy to achieve as well as the fact that sexual interactions seem pointless may add to difficulties in men’s sexuality.

In Mason’s study, many men commented on the veil of secrecy surrounding male infertility and their feelings of isolation. They felt lonely because they were not able to share their experience of infertility with other men, which may also result from the perceived link between fertility and sexuality. On the other hand, Lee (1995, p. 69) states that their “overwhelming tendency to deny their plight often [leads to] irrevocable commitment of isolation”.

Regarding the impact of male infertility on a couple’s relationship, several men in Mason’s (1993, p. 87) study felt they “had let their wives down and felt obliged to offer them a divorce”. Similar reactions were found by Snowdon, Mitchell and Snowdon (1985) who reported that the men in their study suggested a divorce to their wives when they were diagnosed with infertility because they could not fulfil their marital obligations. Although these obligations are rarely expressed explicitly, there seems to be the notion that a husband should give his wife a child. Being unable to fulfil this expectation themselves, they want to ensure that their wives have the possibility of procreating with a different man. Goldschmidt, Seikowski, Brähler and Glander (2001) found that couples affected by infertility indicated a difference in the quality of the relationship. Whereas in the group affected with male infertility, women were described as the
dominant partner and the male partner was defined as submissive; in the group of couples where the male partner's fertility was not impaired, this constellation was the opposite with the male partner being dominant and the female partner having the submissive role. They also found a difference in the relationship quality between those groups with male and female infertility; in relationships where male infertility was present the quality was lower than in relationships where there was female infertility. This may confirm the negative impact of male infertility on male self-esteem and indicate that independently of who is physically affected, it is always the female partner who cannot become pregnant. However, this is not supported by other research. Leiblum (1997) points out that some studies indicate that managing the crisis of infertility results in increased couple commitment and closeness, while others suggest the reverse. In his attempt to understand this contradiction, Reading (1991) hypothesised that infertility had an adverse effect on those couples who are already in a conflictual relationship, but a neutral or even positive impact on couples in a stable relationship. In addition, he suggests taking into account the stage at which assessment is carried out, as couples tend to report few problems at the beginning of treatment when optimism is high, but after months or years of treatment, the stress of repetitive failure may erode marital satisfaction.

Differences between men who were diagnosed as infertile, those who have genetic condition they want to avoid passing on to their children, and the group of men whose infertility results from a previous vasectomy have also been described. Baran and Pannor (1989) found infertile men felt more inadequate and powerless, whereas men with a genetic condition were less concerned about their infertility. Men who had had vasectomies and children prior to this tended to regret their decision pro vasectomy but were not concerned about their masculinity.

Social infertility
Traditionally, DI was used by heterosexual couples only. The use of DI by lesbian couples and single women was thought to be fraught with consequences that were detrimental to the children. Children growing up with lesbian parents were feared to experience disturbed gender role development and boys were expected to be rejected by lesbian mothers. Lesbians were also described as emotionally and
sexually maladapted and this was expected to negatively influence their child’s development (Brewaeys, 2001; Jacob, 1999). At the same time, Streib (1996) commented that family building was also viewed with disapproval within the lesbian community. Lesbians desiring children were perceived to “uncritically orientate themselves towards the model of the ‘small hetero-family’ and ... develop a ‘my home is my castle’ attitude instead of considering alternative ways for co-living for adults and children” (Streib, 1996, p. 7). Concerns regarding single women included the view that children need two parents, a mother and a father; children growing up with a single mother were therefore considered to have a less than ideal development. It was also feared that they would not have sufficient time for a child because of their need to work. Last but not least, single women wishing to have a child were perceived to be selfish or emotionally disturbed (Jacob, 1999).

In recent years, the moral climate has become more accepting of lesbian relationships, and doctors have become more prepared to treat these women (Jacob, 1999; Vanfraussen, 2002/2003). Also, the advent of human rights legislation banning discrimination on the grounds of gender or sexual orientation in countries such as the United States, Canada or Australia grants lesbian couples the right to access DI treatment (Blyth & Landau, 2004). For the United States, Patterson (1994) describes how over ten years ago there was a “lesbian baby boom”. However, some clinics or individual doctors continue to refuse treatment to both lesbian couples and single women (Baetens, 2002). Clinical experience suggests that practices have also changed somewhat in Germany. Whereas previously, doctors refused to treat lesbian couples or single women, there are a small number of physicians who grant these groups access to treatment. Most, however, seem to seek treatment abroad.

Writers have increasingly addressed family building using DI by lesbian couples and single women, and the phrase “social infertility” has been developed to point out that these groups access treatment not because of physical limitations, but because of their sexual orientation or their social situation. Commenting on the concerns previously raised, Jacob (1999, p. 278) explains that the literature suggests that children in lesbian and single mother families are not uniquely disadvantaged but that many “of the difficulties ... are due to the breakup of their biological families and to financial circumstances. In planned families [where women have chosen DI], there does not appear to be significant drawbacks for children”. For children conceived with the help of DI growing up in a lesbian household, this was also
confirmed in a review carried out by Brewaeys (2001) and a study conducted by Vanfraussen (2002/2003) (see Chapter 2, pages 27-29, for a review of parent-child relationships and child development in these families).

Although both groups are not confronted with the emotional challenges of infertility, some of the issues they face are similar to those experienced by heterosexual couples. As with the latter, in those countries with favourable legislation, they must decide whether to adopt a child or use DI. Those opting for DI are confronted with the emotional burden of infertility treatment. Given that lesbian and single women tend to be older, they need to be aware that conception may not occur quickly, or that they may have to end medical treatment without having achieved conception. This can be painful for them as individuals and may strain their partnerships. In contrast to heterosexual couples, lesbian couples must decide which woman will be the biological and gestational mother and which the social co-mother. However, they do not need to manage the stigmatising condition of infertility (Boivin, 2002; Jacob, 1999).

Summary

Although male infertility is as common as female infertility, scientific research into both the medical and psychosocial aspects of male infertility has only recently become an area of interest. Two factors are likely to be responsible for this. Being confronted with impaired male fertility has been described as a threat to male sexual identity. Infertility, in addition, is associated with social stigmatisation, as it is perceived to deviate from prevailing norms and codes of conduct. There is agreement amongst researchers that infertility can be a major life stressor, is associated with feelings of loss or depressive reactions, and may require individual and couple adaptation. There is less agreement regarding the impact of infertility on men than there is on the impact on women. Women have been reported to suffer more significantly from infertility than men, but it is likely that the social context, a gender-specific focus on medical treatment, the biology of reproduction, as well as methodological consideration contribute to these differences.
Typical reactions of men suffering from infertility are feelings of marginalisation during investigation and treatment, as well as feelings of shock, anger and denial once infertility is diagnosed. For many men, infertility leads to feelings of guilt towards their partner. As a result of the strong link between male fertility and virility, they often experience shame and isolation. There are conflicting findings regarding the impact of male infertility on the relationship between men and their partners. While some studies suggest negative consequences, others report higher couple commitment.

Lesbian couples and single mothers are increasingly using DI. Although they do not experience infertility, they share the fact that there is no male to father a child and also experience some of the typical issues heterosexual couples face when undergoing medical treatment. Though serious concerns have been expressed for children raised in such families, there is emerging evidence that these concerns are unsubstantiated.
Traditionally, the understanding of family has been based on blood or genetic ties. Drawing on sociological and anthropological theories, this chapter will explore the origins of these assumptions and the implications for families built by DI. It will outline the specific composition of DI families in relation to other family types and describe the challenges of understanding this family type.

Historical and current understandings of kinship

Traditionally, Euro-American notions of kinship have been founded on blood ties and have defined kinship via the process of biological reproduction (Maine, 1907; McLennan, 1876; Morgan, 1871). Family relationships not based on blood ties, such as adoption, existed in previous times; in such cases where a man did not have biological offspring, adoption was used as an “inheritance strategy” (Goody, 1989, p. 86). In classical Greece and ancient Rome, for example, men could only adopt if they did not have biological children and the purpose of adoption was to avoid the extinction of a family line (Krause, 2003). In the 4th century, however, under the influence of Christianity, blood relationships began to enjoy higher priority than social relationships (Goody, 1989). The church was confronted with the need to provide for those who served it. Therefore, it devised strategies to increase its property, such as sanctioning adoption for childless couples and the remarriage of widows, as property left by these couples and widows was often bequeathed to the church. According to Goody (1989) this explains the strong interest and influence of the church on the cultural meaning of kin, the redefinition of which was used as a vehicle to maximise the church’s wealth. He further points out that formal adoption in several countries, such as the United States, Great Britain and France, was not introduced in legislation until the 19th century (Goody, 1989).
In Western societies, blood relationships continue to enjoy stronger bonds and more certainty even today and this is reflected, for example, in the common belief that "blood is thicker than water". Schneider (1980), in his analysis of American concepts of kin, describes the notion of sharing blood ties as having a dominant role in ideas of kinship. Relatives by blood share a so-called "natural" substance while social relationships, such as relatives by marriage, can only share relationships with each other on a social basis. He continues to explain that marriages can be dissolved by a divorce whereas "natural" relationships created by conception become indissoluble. Blood kin are therefore the "real" kin as it is the laws of "natural order" that connect them:

Blood is a matter of birth, birth is a matter of sexual intercourse. Sexual intercourse is an act which is undertaken and does not just happen. Yet as an act, it is natural. Its outcome is conception, which is followed by birth, and these are natural, too. (Schneider, 1980, p. 38)

According to Schneider (1980), it is the legal contract of marriage that leads to the social unit of the biological family. Members become connected to each other by sexual intercourse between the parents and by conception resulting in the birth of biological offspring. He contends that "the family is formed according to the laws of nature and it lives by rules which are regarded by Americans as self-evidently natural" (Schneider, 1980, p. 34). It was the notion of these connections being "natural" which resulted in separating "real" from "artificial" or "fictitious" kin, such as adoption and other social relationships. These separations were based on the premise that "fictitious" kin only mock "real" kin and were therefore considered of lesser significance (Schröder, 2002). Writers indicate that families based on blood ties continue to dominate other family types. In Germany, Krähenbühl, Jellouscheck, Kohaus-Jellouscheck and Weber (1995, p. 12) describe the biological family as the "most common family form". In the United States, Shanley (2001, p. 148) contends that "the only legitimate family is that which is rooted in ‘nature’ or the ‘longstanding traditions’ of society, and that individuals behave ethically only when they conform to that model”.

These historical and current understandings of kinship help to explain the positioning and viewing of such families as diverging from the norm. Deviations from the so-called "natural" composition were previously devalued, disregarded, stigmatised or tabooed, and the notion of "family" was used for the
lasting union of persons sharing blood ties only (Stein-Hilbers, 1994). The traditional family, however, seems to be “losing its monopoly” (Beck-Gernsheim, 2000, p. 20) and new ways of living together are becoming increasingly popular. Types previously referred to as “experimental” families have become “normal varieties” in the family landscape (Simon, Clement & Stierlin, 1999, p. 98). This diversity does not only include families following adoption, families that are reconstituted following the breakdown of previous relationships, families with a single parent and families resulting from DI, but also families with same-sex parents and a multitude of combinations of these forms. Although they do not fit into the social norm of a family based on biological ties, they all enjoy increasing social and legislative acceptance. These changes are also mirrored in more recent sociological definitions of family. Petzold (1999), for example, contends that a family is a social unit of relationships qualifying by extraordinary intimacy and intergenerational responsibility. Sociologists and anthropologists thus recognise that family compositions can be based on “feeling as a ‘family’ although [members] are not biologically related to each other” (Stein-Hilbers, 1994, p. 15) or on ideas and feelings of relatedness (Holy, 1996).

More recently, developments in biology, technology and genetics have impacted on our understanding and valuing of kinship. Scientific developments in the area of reproductive medicine and gene technology have not only made it possible to separate reproduction from sexuality, but also to visualise gametes during their various stages towards conception outside the human body. Anthropologists contend that these advances have resulted in changes in our understanding of kinship, with a higher value being placed on genetic connection rather than on social arrangements (Finkler, 2001; Franklin, 1999; Strathern, 1992). As Meigs (1989, p. 36) explains:

... at the moment of conception, it is established who one’s ‘real’ kin are. The use of such terms as ‘real mother’ and ‘real father’ attests to the importance in this ideology of the presence or absence of what is understood as an actual physiological connection, as does the cultural fascination with genealogy. ... Kinship ... is a matter of shared blood (or genes) by which one is eternally and immutably related.

Finkler (2001, p. 239) extends this notion and comments that such “natural facts” can even result in medicalising family and kinship as advances in genetics, and biomedicine, “insist on uniting those” who may have no desire to be linked. This suggests that it is now genetic conception, in contrast to physical conception, which defines kinship. Strathern (1999, p. 14) contends that
for Euro-American culture ... kinship affords a context in which people readily conceptualise the relational dimensions of their lives. It is ... by no means the only one, ... but it carries special meaning within this culture in so far as such relations are thought to have their foundation and rationale in the very conditions of coming into being, the procreation and nurture of human beings, and thus in the facts of life.

This suggests that advances in AHR have actually led to a revival of traditional views, while at the same time they have resulted in an increase in novel family compositions.

Understanding families built by DI

The strong orientation towards the concept of families based on genetic ties explains why, for most heterosexual couples when building a family, DI is not their first choice or their “ideal way of having a family” (Daniels, 2004a). Daniels (2004a) and Schroder (2002) argue that the biological expectation as well as the cultural norm lead couples to want to reproduce with their own gametes. They resort to family compositions of social parenting only when the biological option is not possible. Choices then include adoption, fostering, remaining without children and, in the case of male or social infertility, DI. Currently, there is no prospective data available on couples’ decision-making processes once they are confronted with male infertility. Retrospective studies that include respondents who at the time of being interviewed have already decided to pursue DI indicate that couples do consider adoption but for several reasons prefer DI. These include dissatisfaction with the adoption processes, the desire to experience pregnancy and the possibility of the child being genetically related to at least one parent, and the perception that this biological link would be stronger than the social connection (Czyba & Chevret, 1979; Daniels, 1994; Thorn, 1999; Wendland, Byrn & Hill, 1996). Retrospective studies such as these where respondents have already made their decision to pursue DI, however, run the risk of confirming these decisions rather than providing an opportunity for exploring other possibilities. These studies therefore may have only limited value. No studies have investigated the motivation of couples who prefer adoption to DI. Writing from a clinical perspective, Zoldbrod and Covington (1999) explain that the following factors may be important for couples choosing adoption over DI: the balance of parental status after adoption, the greater social acceptance of adoption, pregnancy considered as unimportant, DI as inconsistent with religious beliefs,
the desire to give a home to an existing child rather than creating another, or one or both partners having a special connection or investment in adoption. The authors’ clinical experiences suggest that greater social acceptance of adoption, along with more legal certainty are additional factors for some couples.

Until now, research has investigated the development of children conceived with the assistance of DI and their families, and the meanings and roles attributed to the semen provider. This research, however, has been carried out almost exclusively on families or semen providers who have not disclosed their use of or involvement in DI.

Research on children conceived with the assistance of DI and their families

Early research in the area of DI focussed on the obstetric outcome, infant development, and parental satisfaction. Writers found no risks of obstetric complications or abnormal infant development, and reported parents to be satisfied with their decision to use DI (Amuzu, Laxova & Shapiro, 1990; Clayton & Kovacs, 1982; Leeton & Blackwell, 1982). More recently, the development of children up to pre-adolescence has been investigated. One of the most comprehensive studies is the European Study of Assisted Reproduction Families (Golombok, Brewaeys, Giavazzi, Guerra, MacCallum & Rust, 2002), which has followed the development of a variety of families built with and without the help of AHR in the United Kingdom, the Netherlands, Italy and Spain; the study included 94 families with children conceived by DI. All of the children were found to have developed as healthily as children conceived by in-vitro-fertilisation (IVF), adopted children or naturally conceived children. The authors conclude that the absence of a genetic link between the father and the child does not interfere with the development of a positive father-child relationship. Similar findings were confirmed in an earlier overview of other smaller studies (Brewaeys, 2001) and a more recent investigation involving younger children (Golombok, Jadva, Lycett, Murray & MacCallum, 2004). It must be noted, however, that almost all children born to heterosexual couples in these studies had not been informed of their DI origins. Golombok et al. (2002, p. 838) explain:

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8 IVF involves hormonal stimulation of the female, oocyte retrieval and mixing the husband’s semen with the oocytes in a Petri dish. Several days after retrieval, the fertilised oocytes are transferred into the uterus.
... in spite of the majority of parents' decision not to tell, it appears that the children aged 12 years do not seem to experience negative consequences arising from the secrecy surrounding the circumstances of their birth. This does not mean that it is preferable for children not to be told about DI. ... Systematic studies of representative samples are necessary to fully understand the long-term consequences of DI for the individuals concerned.

As described in the previous chapter, some commentators have expressed serious concerns about the use of DI in the case of social infertility and more especially for children growing up in lesbian families. Research indicates that this apprehension does not seem justified. A meta-analysis of six studies carried out between 1994 and 1998 (Bremaeyns, 2001) indicated that child development was within the normal range and the quality of family relationships appeared to be at least as good as in heterosexual control groups. There were no indications of emotional or behavioural differences or difficulties in gender role development. The social mothers in the lesbian families, however, showed greater interaction with their children than did the fathers in heterosexual families. According to the authors, this resulted from gender differences rather than from parental sexual orientation. A major difference between lesbian and heterosexual families also resulted from attitudes regarding information sharing: whereas most heterosexual parents did not intend to talk to their children about their biological origins, most of the lesbian parents had disclosed their use of DI to the child. Only a few studies have investigated the outcome for families headed by single women. Referring to a study which has not yet been published, Golombok (2004) explains that single women chose DI because they lacked a male partner, wanted to avoid casual sex or had a strong sense that time was running out. A further investigation of 21 solo mothers with very young children (an average age of 25 months) indicated that "the first cohort of solo DI mothers and their children ... continue to function well as the child reaches 2 years of age" (Murray & Golombok, 2005, p. 4). Solo mothers were no more likely to experience stress associated with parenting than married mothers following DI. The authors conclude that this might be the result of a pro-active decision towards the commitment of raising a child as a single mother and the lack of the traumatising nature of separation or divorce from a partner. Similarly to their lesbian counterparts, most mothers in this study intended to talk to their children about the use of a semen provider. Again, the researchers suggest that these results should be interpreted with care because of the small sample size and the young age of the children.
Research on the meanings and roles of semen providers

For many years, semen providers had little recognition. In 1964 for example, Finegold suggested that “it is generally agreed that the donor’s identity should be veiled in absolute obscurity” (p. 35). Approximately 20 years later, Glezerman (1981, p. 185) wrote that semen used in DI should be considered “material from an anonymous testis” and advised that “the myth of blood and flesh has to be uprooted and a state of consciousness has to be achieved in which the donor, from the psychological point of view, does not exist”. The perception of DI being a morally dubious practice, the association with masturbation and adultery, as well as the legal uncertainties for the semen provider (Daniels, 1998a), particularly in countries which do not exempt semen providers from financial responsibilities, may have been important factors for doctors voicing such views.

Research on the attitudes towards semen providers began in 1980 (Huerre, 1980). Although there has been increasing acceptance of their contribution (Daniels, 1998a), they continue to provoke a variety of reactions. Daniels (1998a), for example, contends that semen providers evoke strong feelings from gratitude to disgust in the public perception; Kirkman (2004a, p. 319) describes them as both “saviours and satyrs” and argues that public narratives of semen provision continue to be sexualised and compared to adultery:

The provider as the epitome of sleazy sex was the most commonly reported public emplotment.\(^9\) ... The jokes and references to adultery suggest the cuckolded husband. When the semen provider is considered in the context of the traditional romantic narrative of conception ... his emplotment as sexual usurper of the husband’s place is comprehensible. Even in the absence of sexual intercourse between provider and recipient, the provider’s sperm has cuckolded the husband’s sperm and attracts the customary ribaldry and condemnation. (Kirkman, 2004a, p. 325)

There has been a lot of speculation about the motivations of men who give their semen to infertile couples. Whereas previously, it was largely medical students who provided semen and it was assumed that they did so for purely financial reasons (Lui, 1998; Sauer, Gorrill, Zeffer & Bustillo, 1989), Daniels (1998a), in a review of 20 studies, found that often altruistic reasons, or a combination of these and

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\(^9\) Kirkman refers to “emplotment” as the conferring of order, sequence, and meaning on a collection of otherwise isolated events and characters: applying the narrative device of plot (Ricoeur, 1980; as quoted in Kirkman, 2004a, p. 333).
The type of provider recruited along with his motivation are influenced by whether or not there is policy of payment for semen. Novaes has said, "The fact that … the donor is almost always remunerated indicates that semen donation is defined in advance as a commercial transaction, when in fact its meaning for the donor – and for society – may be totally different" (1989:643). It is for this reason that the policies adopted by clinics and programmes are so central to the recruitment of semen providers. A recent paper by Daniels and Lewis (1996a) has reviewed the issue of the commercialisation of semen, and in so doing points to the role occupied by health professionals – namely that of brokers or mediators. DI practitioners are, in the commercial model, both buyers and sellers of semen, buying from the provider and then on-selling frozen ‘straws’ to clients, usually with a … profit margin. … In the non-commercial model, the health professional acts as a broker, without payment being made to the provider. Yet another model may operate when ‘personal’ or ‘known’ providers are used and the health professional then fulfils a mediating role. (Daniels, 1998a, pp. 82-83)

In his review of the research, Daniels identified two further trends. One was the fact that age, marital status, presence or absence of children, and occupation were interlinked with the motivation to provide semen: younger students tended to indicate more interest in a financial reward and anonymity than older men who may themselves have had children. Another observation was that commercial models seemed to be more important in the United States than in other countries, such as Australia or New Zealand, suggesting either a cultural difference or a difference in relation to recruitment practices. Furthermore, recruiting anonymous students and offering financial compensation may be viewed as more convenient and would avoid having to manage “the psychosocial aspects of semen provision and their importance in gift dynamics and kin relationships” (Daniels, 1998a, p. 89). In a later study comparing semen providers’ views in two different Swedish clinics, Lalos, Daniels, Gottlieb and Lalos (2003) conclude that men could be recruited within a system requiring them to be identifiable to offspring. Though there were some variations in age and factors influencing their decision to give semen, many of the providers were motivated by a strong desire to help couples experiencing infertility. Financial compensation was not the main motivator, but expenses for travel and loss of income were considered potentially important for those who had to travel some distance to clinics.

The assumption, unchallenged until the 1980s, that semen providers should be persona non grata and that “they were hidden away from public awareness and scrutiny” (Daniels, 1998a, p. 76) also implies that the men themselves do not consider the outcome of their semen provision and consequently are not interested.
in any children that may result from the use of their semen. Reporting on the attitudes and motivations of the men in the studies he reviewed, Daniels suggested that, on the contrary, many of them, over 50% in some studies, indicated interest in knowing about the outcome of their donation. They also attributed significance to the genetic connection between themselves and the children conceived with their semen; and furthermore, as indicated in some studies, many expressed interest in their offspring and felt a degree of responsibility towards them. This trend was confirmed in more recent study by Kirkman (2004b), who added that, despite this interest, semen providers ceded parenthood to the social father.

Regarding the meaning that parents who have used DI attribute to the semen provider, there seems to be a variety of different attitudes and feelings. Snowdon et al. (1985) report that parents in their study had difficulty developing a concept for fatherhood after DI and voiced the fear that the child's relationship with the parents, especially with the father, would be damaged, as the child would consider the semen provider to be the "real" father because of the shared blood ties. The mothers in this same study repressed thoughts about the semen provider "in order not to hurt their husbands" (Snowdon et al., 1985, p. 42). Schilling and Blonski (1994) also examined the meanings that infertile men and their partners attributed to semen providers. They concluded that couples felt ambivalent towards the semen provider and tended to ignore his contribution:

Generally the attitude towards the donor is marked by high ambivalence. Fantasies about him are encouraged by his meaning during treatment and at the same time the lack of presence of his person. [The fact that, from a psychodynamic perspective, the donor is a rival to the husband] may be the reason why fantasies about the donor are difficult to verbalise. All but three couples answered that they had not considered any questions about the donor other than his health. Other couples ... stressed the social reality of the situation and thus minimised the biological/genetic meaning. (Schilling & Blonski, 1994, p. 312)

Similar concerns are described by Lycett, Daniels, Curson and Golombok (2005); in their study of parental disclosure patterns, respondents felt concerned that the relationship between the child and the father may be compromised because of the lack of biological connection.

The lack of appropriate terminology to differentiate between the father and the semen provider seems to add to this confusion. In many studies, books and reports, parents are reported to use notions such as, "a different daddy" (Kirkman, 2003), the "real father", the "actual father", the "biological" or "genetic"
father (Lorbach, 2003; Snowdon et al., 1985) for the semen provider, suggesting that he has a paternal role and is a significant person for the child. In her study of narratives used by parents, children and semen providers to understand their family composition, Kirkman (2003) explains that the role of the semen provider:

... is yet to be explained and [one respondent] is uncertain of the words she should use when (or if) the children begin to ask questions. Other parents choose to use terminology that defines the sperm donor and clearly differentiates him from their father, in the knowledge that their children will not yet fully understand what the words mean. There is not adequate evidence to support one approach or the other as most beneficial to offspring identity, although it is difficult to avoid wondering whether redefining the meaning of “different daddy” may itself be problematic. The pivotal significance of words in the development of family narratives and narrative identity is inescapable. (Kirkman, 2003, p. 2235)

Kirkman’s (2004a, p. 328) observation that “the provider is construed along a continuum from having no parental relationship with offspring apart from a strictly (and almost irrelevant) genetic one, to being in danger of usurping the social father’s connection with his child” summarises the tension both mothers and fathers experience.

Furthermore, there are indications that men perceive the semen provider differently from women. As Daniels (2003) points out, it is the female partner who carries the semen in her body and gestates a child from the semen provider. This signifies a close physical connection to him, which is not shared by her male partner. Thus her role can be viewed as collaborating with the semen provider, which may also explain the sexual connotations Kirkman (2004a) found in her study. In contrast, the male partner’s ability to father a child is replaced by the semen provider’s ability, which, as stressed by Schilling and Blonski (1994) can result in feelings of competition between the male partner and the semen provider.

There is emerging knowledge regarding the offspring’s perception and definition of his or her genitor. Turner and Coyle (2000) studied the experiences of teenagers and adults conceived by DI and found that some offspring referred to the semen provider as “my donor father” or “the donor” (Turner & Coyle, 2000, p. 2046). Others described him as “the stranger who masturbated into a glass vial” (p. 2047). In other studies, surveys and personal accounts, the semen provider was in some way defined as the “donor father”, although the man who reared the child was considered the father in the true sense (Baran &
Pannor, 1989; Blyth, 2004a; Donor Conception Network, 2003; Kirkman, 2004a; Lorbach, 1997; Lorbach, 2003; Scheib, Riordan & Rubin, 2004). Rumball and Adair (1999, p. 1395), reporting on parental narratives for sharing about the nature of the conception with children, commented on the experience of one mother. She had regretted using the word “daddy” for the semen provider as the child “flatly denied it and said it was not true” that the semen provider had a parental role. According to the authors, this mother intended to pay more attention to the words she used for the semen provider and planned to talk about a donor rather than a second father when she discusses this with her child. Evidently, in this case, the child had a different understanding from the mother and considered her father to be the only male parent. Scheib et al. (2004) examined the perceptions of 12 - 17-year-olds, growing up with heterosexual or lesbian parents, as well as with single mothers. All of the respondents were aware of their conception by DI and had access to identifiable information about their genitor. Despite the ambivalent terminology used for the genitor, such as “biological father”, the teenagers did not appear to be looking for a father in the donor and few identified him as an important person in their lives. However, “the overwhelming feeling [of the respondents] was curiosity about the donor”, indicating that they hoped for more than simply knowing their genitor’s identity (Scheib et al., 2004, p. 244). The findings of this study suggest that teenagers conceived by DI are capable of developing an understanding of the two men and of differentiating between the man who has the paternal role and the man who is their genitor while at the same time appreciating the contribution of both. Nevertheless, they continue to struggle with appropriate terminology.

The above discussion suggests that the blood or genetic connection remains a powerful bond between people, and this is also apparent in families built by DI. Nevertheless, there seems to be a lack of understanding for the role of, and the difficulty of finding appropriate expressions for, the semen provider in these families.

**Terminology used for and by families built by DI**

Many different terminologies have been used to describe families built by DI and the various family members. From the perspective of medical intervention, “AID” (Artificial Insemination by Donor) was the main term used until the 1980s when “DI” (Donor Insemination) was increasingly used, not least to
avoid confusion with “AIDS” (Auto-immune Deficiency Syndrome) or to avoid the impression that the child could be perceived as unnatural. In order to point out that the gametes of a person who does not assume a parental role are used, independently of whether this involves semen donation, oocyte donation or embryo donation, the terms “collaborative reproduction” (Blank, 1990) and, more recently, “third party reproduction”\textsuperscript{10} and “third party assisted conception” (Blyth & Landau, 2004) have been used.

One of the first attempts to systematically clarify terminology for the adults involved in DI was made by Snowdon et al. in 1985. In their book, Artificial Reproduction, they raise the need to establish appropriate vocabulary in the area of AHR in order to be able to “exactly describe the technologies of artificial reproduction, the role of the people involved and the relationships between them” (Snowdon et al., 1985, p. 14). They suggest using the term “artificial insemination” for any methods of AHR where the oocyte of the woman remains within her body and to differentiate between the genetic, gestating, nurturing and complete mother. Within this context, they also propose the genetic, nurturing or again the complete father for men who are the genitor and/or raise the child. They also raise the question as to “who is the real mother”:

... this question, though justified, cannot be answered at the moment. New rules, for which there are no models, are necessary to answer this question. Knowledge from the area of adoption is of little value because there is no separation between the genetic and the gestational mother. ... [The same applies] to the father. In the case of AID, the genetic father is the donor and the social father the husband of the wife who was treated. Which rights and responsibilities do these fathers have in relation to each other, and above all in relation to the child? (Snowdon et al., 1985, pp. 17-18)

How difficult it has been to conceptualise family composition resulting from DI becomes apparent when they describe that, in effect, genetic origin and connection cannot be separated in families where children are the biological offspring of both parents and that defining kin is based on individual and subjective ideas of a family which are commonly rooted in the concept that kin is related by blood (Snowdon et al., 1985).

\textsuperscript{10} The originator of this notion could not be ascertained; it is used for all types of gamete donations (Daniels, 2003; Hammer Burns & Covington, 1999).
The man who provides his semen has traditionally been called the “donor” or the “semen donor”. However, as many men who provide their semen to be used for a woman, either single or in a couple relationship, receive a financial compensation, the term “vendor” (Annas, 1980) and “consignor” (Blank, 1990) have been suggested. In order to include both men who sell and men who gift their semen, Daniels (1998a) suggests the term “semen provider”. However, this term does not seem to be favoured by lay people and the medical professionals who continue to use “donor” (Blyth, 2004a; Borrero, 2002; Frost Vercollone, Moss & Moss, 1997; Lorbach, 2003) and who increasingly differentiate between: “anonymous donors”, “unknown donors” or “no-donors” for those men who are and remain unknown (Noble, 1987); “yes-donors”, “open donors” (Frost Vercollone et al., 1997) or “identifiable donors” for those men who can be identified by the offspring and/or the parents; and “personal donors” for those men who are known to the future parents prior to medical treatment (Daniels, 2004b). This not only indicates a move away from anonymous semen provision, but also an increase in choices both for recipients and semen providers.

Haimes (1998) concurrently summarises and dismisses previously used terminology for children resulting from DI. She criticises terms such as: “donated children”, used by one of the English pioneers of DI, Mary Barton (as cited in Haimes, 1998); “AID children” used by Brandon (1979) and Blank (1990); and “custom-made children” (Holmes, Koskins & Gross, 1981) or “turkey-baster babies” (Stephenson & Wagner, 1991), for two reasons:

The proliferation of labels goes to the heart of the issues of representation. For example, the labelling of such people as ‘babies’ can suggest that they are to be seen as merely the end-product of DI, whereas labelling them ‘children’, ‘offspring’, ‘adults’, ‘people’ can suggest that they have lives and biographies with the potential to extend beyond their origins in DI. I shall tend to use the label ‘people conceived by DI’. Though clumsy, this has two advantages: first, it situates this group in relation to the practice of DI rather than to any other party (recipients, donors etc.); second, it follows the trend of favouring phrases such as ‘People with AIDS’ and ‘people with disabilities’, which are more open-ended and which place the person first before qualifying him/her as a particular type of person. (Haimes, 1998, p. 54)

Other writers have introduced the word “DI offspring” (Daniels, Lewis & Gillett, 1995a) and “donor-conceived people” (Kirkman, 2004b), arguing that “child” may make it easier to adopt a paternalistic position in relation to this person (Daniels, Lewis & Curson, 1997). Haimes (1998), however, has also
dismissed these terms, arguing that they tend to emphasise a child-like status and perpetuate the tendency only to see the DI person in relation to his or her parents.

Only recently have parents who have used DI and people conceived by DI started to suggest their own terminology. Frost Vercollone et al. (1997), in their book, *Helping the Stork*, differentiate between biological and non-biological children, the latter referring to children conceived by DI. Cordray (2000), who was himself conceived by DI, uses the term “DI adoptee” to describe his own position as he sees his advocacy for more openness to be similar to adoptees. Commenting on previously used words, he states:

> All these labels [such as AID children, test-tube babies and spermees] have served to dehumanize us, to make our human condition even more abstract. We have become caricatures, if we are visible as people at all. These labels made us eternal children whose rights are more easily ignored. (Cordray, 2000, p. 11)

The current tentative and diverse terminology used in the area of DI and the lack of a uniform vocabulary confirms that families by DI belong to a novel type of family – novel at least from the point of view that the secrecy about them is lifting and they are increasingly acknowledged – that has yet to be clearly defined. A full understanding of this family type, the meanings and role expectations of its members, especially the semen provider, has not yet been achieved. Some of the suggested expressions such as “complete father” have a negative connotation, as they imply that those men who “only” bring up the child are “incomplete fathers”. Such language also reflects an either/or binary attitude, which does not take into account that for children both men are important, albeit in different ways. Referring to the man who gives his semen as the “biological father” seems problematic, as the notion of “father” is commonly used for the male person who is actively involved in parenting a child. This is not the case for the semen provider. Daniels and Thorn (2001) suggest using the phrase “men who gave the semen” when talking to young children about their genitor and the word “father” for the male parent, so that children gain an understanding of the two different roles. It is possible that such a distinction is helpful for everybody involved in DI. Terminology used for people conceived by DI seems equally complicated. The move away from “DI child” towards “DI offspring” or “people conceived by DI” is understandable, especially as this group is becoming increasingly vocal and speaking out against being paternalised (Franz & Allen, 2001; Lorbach, 1997). The term “DI-adoptee”, however, may blur two different family types, those resulting from adoption and from DI. This may not adequately address one of the major differences for
the adopted person, that is, having to manage the relinquishment by the birth parents. On the other hand, this development indicates an increased differentiation in both the awareness of, and the labelling of, the various actors. The trend is clearly moving towards an augmented recognition of the complexity of the composition of this family grouping, but there seems to be a need to develop adequate language to describe this new family type.

Summary
The Euro-American notion of kinship has been based on blood ties. Although family compositions based on or including social ties have been increasingly recognised, relationships based on blood or biological connections continue to enjoy stronger bonds in most people's minds because they are regarded as more legitimate. Recent developments in reproductive medicine, biology and genetics, while making possible new types of family composition, have at the same time strengthened traditional views and attributed significance to the relationships between people who share genetic ties. Families built with the assistance of DI, although they have existed for over a century, have only recently been the focus of research. Their deviation from the norm resulted in professionals recommending secrecy and this hindered research for many years.

Current knowledge indicates that although parents are satisfied with their decision to use DI and that child development, as far as can be ascertained so far, is uneventful, most heterosexual couples who have used DI do not disclose this to others or to their child. They fear stigmatisation and a negative impact on family relations should the child become aware of his or her biological origin. The disclosure rate for lesbian couples, as well as for single mothers, is relatively high, probably because these groups need to explain how their child was conceived. As with the general secrecy surrounding DI, semen providers as a group were ignored for many decades and this strategy was assumed to be best for the families and for the men who provide their semen. Views regarding semen providers seem to be quite varied, ranging from suspicion and distaste to grateful appreciation. Research focussing on semen providers themselves suggests that some of these men have an interest in the outcome of their contribution, or even feel a certain degree of responsibility towards the children they have helped to conceive, although they cede
parenthood to the father. Studies also indicate that recruitment policies can have a strong impact on the type of semen provider, either altruistic in motivation or with a financial interest, recruited. Studies conducted on parents’ understandings of the meanings and roles of the semen provider indicate a wide range of feelings and attitudes. Many parents seem unable to define the meaning or role of the semen provider and fear that the child may view him as the father in the psychosocial sense. The few studies conducted on children, however, indicate that offspring can have a relatively clear understanding of the differing roles and positions of the two men. A further indication of the newness and uniqueness of the development of DI is the lack of appropriate terminology to describe families resulting from this method of conception. There have been some attempts to develop a language for defining and describing this increasingly visible and acknowledged family type, but this needs further attention.
Chapter 3

Review of German policy and practice of information sharing in DI

As the research for this thesis was conducted in Germany, this chapter will provide a detailed overview of the historical, social, cultural and legal developments, as well as the practice of information sharing relating to DI in Germany.

Donor insemination in Germany

DI has been practised in Germany for many decades but, as in most countries, it has been considered a morally dubious practice. The first written reports about DI were published in the Federal Republic of Germany (FRG) in 1956 (Krause, 1985), and in the German Democratic Republic (GDR) in 1970 (Günther, 1987). In 1959, the German Medical Commission\(^\text{11}\) (Deutscher Ärztetag) sanctioned DI as going against the medical code of practice. In a meeting closed to the public, Fromm (1959) summarised recommendations of several professional bodies, such as the German Society for Psychiatry (Deutsche Gesellschaft für Psychiatrie und Nervenheilkunde), the Germany Society for Gynaecology (Deutsche Gesellschaft für Gynäkologie), the German Society for Psychotherapy (Deutsche Gesellschaft für Psychotherapie) and the German Federation of Female Doctors (Deutsche Ärztinnenbund), who were all supportive of banning DI. According to the German Society for Legal and Social Medicine (Deutsche Gesellschaft für gerichtliche und soziale Medizin):

\[...\text{the consequences of an artificial insemination can present such a great burden regarding social conventions and ethics that there can be no medical justification for heterologous inseminations. We consider any legal regulation as damaging. It is a highly delicate issue in}\]

\(^{11}\) The German Medical Commission is part of the Federal Medical Chamber, which considers itself to be the parliament of all doctors. One of its main tasks is to establish federal regulations for medical practice.
the intimate atmosphere, which should be considered between all parties involved, that is the woman, husband and doctor, in a trustworthy atmosphere. Fundamentally, every insemination should be forbidden, if it should be regulated at all. It is feared that an insemination leads to an unforeseeable chain reaction of legal uncertainties and legal difficulties, which can be solved neither medically nor legally. By introducing legislation, inseminations would be encouraged. We also have the viewpoint that an insemination devalues the sanctity of marriage down to the level of a technical laboratory procedure. (Fromm, 1959, p. 990)

This and similar concerns led to the following decision of the German Federal Medical Chamber during its annual meeting in 1959:

The 62. German Medical Commission rejects artificial insemination for moral reasons. The artificial heterologous insemination goes against the order of marriage. Its introduction has medical, legal and psychological-ethical consequences, which cannot be overseen by a doctor and for which he is responsible. If both wife and husband agree and a doctor carries out the procedure, there are no concerns against an insemination with the semen of the husband. (Fromm, 1959, p. 992)

According to Strunden (personal communication, May 5, 2002), one of the medical pioneers of DI in Germany, this negative attitude reflected not only the moral concerns and the disapproving position of the Roman Catholic Church, but also the fear of Germany being reproached for re-establishing selective procreation practised during the Second World War under the Nazi regime. At that time, ethical, legal and psychological discussions concerning DI were highly controversial (Brähler & Meyhöfer, 1986; Krause, 1985). It was planned to include DI in penal law. Only after foreign experts, including representatives of the Vatican, expressed their disbelief regarding the German moral arrogance and eagerness to penalise DI during the International Legal Meeting in 1964, this plan was dropped (Wille, 1985).

Three physicians were said to practise DI at that time. It was presumably one of these, Gerhard Ockel, a liberal gynaecologist and one of the first authors of books on sex education for children (Ockel, 1960) who was the first medical professional to discuss DI in public when in 1967 he reported on more than 10 years of DI practice (Krause, 1985). Given that the professional body advised against DI, these three physicians had to fear expulsion and therefore provided DI services under strict confidentiality.

In 1970, as the media seemed confused about the decisions of the Federal Medical Commission, the Federal Medical Chamber discussed DI again (Deutsches Ärzteblatt, 1970). During this discussion, Hallermann presented national and international data indicating "that there are no negative results for the
parents or the children if careful indication and just as careful information were provided” (Deutsches Ärzteblatt, 1970, p. 1981). The moral concerns, he argued, were no longer as convincing, either within the medical or within the general society, so that it had become difficult to argue against DI from a purely moral perspective. The legal complications, however, remained, and it was considered problematic that a child conceived by DI had unlimited right to contest paternity. As a consequence of this right, the semen provider would become responsible for alimony payments. A doctor risked being responsible for compensation payments should he not be able to identify the semen provider, or being prosecuted for falsifying birth documents. Other, more general concerns related to the fact that a change of recommendations would mean that the fundamental principle of DI, being immoral, would simply become obsolete within only 11 years. This resulted in the following compromise:

The 73. German Medical Commission considers the treatment with artificial heterologous insemination no longer as going against its code. However, artificial heterologous inseminations lead to many problems and especially to unresolved legal questions. Therefore, the German Medical Commission cannot yet recommend artificial heterologous insemination. (Deutsches Ärzteblatt, 1970, p. 1982)

As a result of lifting the rejection of DI, physicians were able to offer DI without risking professional sanctioning. The disapproving moral attitude, however, changed only slowly and this resulted in few physicians offering DI services. At the beginning of the 1980s, Walter (1983) listed six clinics offering DI in the FRG, including one located within a university provided service (teaching hospital).

In the former GDR, seven hospitals and one institution for marriage and sexual counselling offered DI services (Seikowski & Glander, 2000). These institutions collaborated closely and established the National DI Register (Nationales ADI-Register [NADIR]), in which, in accordance with the political climate of the GDR, all inseminations, pregnancies and births resulting from DI were documented (Seikowski & Glander, 2000; Weller, Sobeslavksy & Guzy, 1989). According to Günther (1987) and Schreiber (personal communication, May 3, 2005), in East Germany, DI could be accessed by heterosexual married couples only. Although Günther (1987) reported that single women could access DI under extreme circumstances, such as physical deformities making it difficult to find a partner, he advised against this as it was not regulated. As far as can be ascertained from conversations with three doctors who practised in the GDR, there were no legal provisions for family building using DI (Günther, personal
communication, May 2, 2005; Schreiber, personal communication, May 3, 2005; Weller, personal communication, May 2, 2005). However, according to them, a directive from the Ministry of Health stipulated that the social father enjoyed full paternity and thus exempted the semen provider from any legal responsibilities. All of these doctors reported that this directive was binding and resulted in feelings of certainty and acceptance of DI. Schreiber (personal communication, May 3, 2005), in fact, reported that DI enjoyed a higher level of acceptance in the GDR than it does currently. The semen provider was given a small financial compensation by the state for his donation (Weller, personal communication, May 2, 2005). Records of the semen provider were kept, but his identity remained anonymous to the children and their families, and there is no indication that this was a controversial issue, either debated or publicly discussed. According to Günther (personal communication, May 2, 2005), it is not known what happened to this register after the Reunification of Germany.

The number of clinics offering DI in the Western part of Germany increased slowly over the next 25 years. Currently, approximately 40 clinics offer DI, including one teaching hospital. The continuing lack of legal clarification has discouraged teaching hospitals from offering DI. Schilling (1995) assumes that this is also likely to have had a negative impact on the quantity of research carried out in this area. Both major religious denominations in Germany, the Catholic and the Protestant Churches, have issued public statements rejecting DI. The teaching faculty of the Catholic Church has commented that DI neglects the bond of conception with personal sexuality and destroys the unity of marriage (Lexikon der Bioethik, 1998) and the Protestant Church described DI as "an incursion into marriage, ... damaging the exclusiveness of marital relationships" (Kundgebung, 1987, p. 12).

As there is no official or compulsory register for DI, the number of treatment cycles and children born as a result of DI can only be estimated. In 1987, Hirsch and Eberbach assumed between 1,000 and 1,200 children were born annually after DI; Katzorke believed in 1989 that 600 to 800 children were born annually; Schilling suggested in 1999 that over 50,000 children had been born as a result of DI since the 1970s. According to a more recent study, a minimum of 500 children are born annually as a result of DI (Thorn & Daniels, 2000a), with more advanced treatment options for male infertility, such as ICSI, likely

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12 There is no official list of doctors or clinics offering DI services. This number was ascertained by adding to the members of the AKDI those who carry out DI known to the author.
to contribute to the decline in DI (Katzorke, 2001). The only accurate numbers available are those of the former GDR, based on their National Register. Weller et al. stated in 1989 that 1,373 pregnancies resulted from DI between 1973 and 1985. From the beginning of 1989, shortly before the Reunification of Germany in November 1989, until mid-1990, the introduction of the Gesundheitsreformgesetz (1989) (Health Reform Act) led to a temporary termination of reimbursement of ICSI in the public health sector. In July 1990, after changes in the Sozialgesetzbuch V (Social Legislation Code V), ICSI was again reimbursed. Since January 2004, reimbursement for AHR in general and ICSI in particular was again limited, this time by health insurances which had covered 100% of four cycles of ICSI, reducing reimbursement to 50% for three cycles. Clinical experience indicates that couples resort to DI if they do not have sufficient financial resources for ICSI. Costs for ICSI in Germany are approximately three times as high as for DI, the number of DI treatments and thus the number of children born after DI may rise when other treatment options become less affordable.

In the last decades, family building options by AHR using the gametes of the couple have become increasingly acknowledged in Germany. Numerous guidance books, both on medical treatment (for example: Köhle, 1997; Strowitzki, 1998; Teut, 2002; Thöne & Rabe, 1996) as well as on psychosocial issues (for example: Schlagheck, 1989; Winkler, 1994; Wischmann & Stammer, 2004) have been published and there are regular media reports on the topic (Hellmund & Rohde, 1998). Family building using DI, however, enjoys less coverage. Medical textbooks on male infertility dedicate only a few pages to DI (Ochsendorf & Beschmann, 1996), or convey ethical concerns:

Ethical concerns [regarding DI] comprise several aspects of the couple relationship: feelings of guilt, long-term implications for the family and the child, the loss of the natural family structure, the development of false moral reasoning about entitlements and also the misuse of technology for the selective breeding of human beings and the manipulation of reproduction. (Schirren, 2003, p. 375)

In the Encyclopaedia of Reproductive Technology, Waldschmidt (1999, p 327) writing on German legislation comments incorrectly that “sperm donation from a third party is not permitted”. Furthermore, many books on medical and psychosocial issues written for would-be parents make only passing

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13 As will be explained later in this chapter, there are no official and regulated treatment costs for DI in Germany.
comments on DI (Köhle, 1997; Schlagheck, 1989; Teut, 2002; Wischmann & Stammer, 2004), omit it completely (Strowitzki, 1998; Winkler, 1994), or comment negatively on this option:

The so-called heterologous insemination, that is the insemination with semen from a stranger, remains as the very last option. However, this is not practised in Germany. Heterologous insemination is no longer considered as going against moral standards, as it was the case for a long time, but it is still fully repudiated. The greatest problem is the fact that the thus conceived child has a right to know his/her biological father and can also make various demands of him. This is especially the case if the ‘social’ father, in case of a divorce, rejects alimony payments for the child he did not father. But one simply cannot demand such payments of the donor. However, according to a current decision of the Federal Constitutional Court, he may not remain anonymous. Should the physician keep the donor anonymous despite this decision, then he himself may be responsible for alimony payments. These complex issues render heterologous insemination unacceptable. (Fechting, 1997, p. 85)

In current sociological literature, authors indicate that “heterologous methods ... apart from specific exceptions, are principally not allowed” (Schneider, 2002, p. 18) or compare them to practices in the United States where “the donor should look as much as possible like the husband but ‘please without the thick nose’” (Beck-Gernsheim, 2000, p. 125, emphasis added), indicating some scepticism or even sarcasm about the possibility of selecting a semen provider.

Hellmund and Rohde (1998, p. 1065), in their survey of media reports on AHR, defined DI as “a marginal issue in media reports” amounting to only 6% of all articles. Even surrogacy, illegal in Germany, had a higher share of media reports and amounted to over 9% of all media reports. They went on to explain that “parents who had decided to carry out DI or couples who had gone abroad for surrogacy are significantly more ... criticised than couples who carry out treatments which are legal and accepted in Germany” (Hellmund & Rohde, 1998, p. 1069), thus comparing DI with surrogacy which may imply to the uninformed that both are illegal in Germany. A current national awareness campaign launched by the German Society for Gynaecology and Obstetrics (Deutsche Gesellschaft für Gynäkologie und Geburtshilfe [DGGG]), the Federal Association of Reproductive Clinics (Bundesverband Reproduktionsmedizinischer Zentren [BRZ]) and the national patient organisation Wunschkind e.V. aiming to inform the public about treatment possibilities for infertility, does not include DI in the information provided on its website (Damit die Liebe Früchte trägt, 2004). Though there have been some media reports on DI in the last three years (for example: Neubeuer, 2002; Nungeßer, 2004; Schieder &
Kaiser, 2004; Spiewak, 2002; Stevens, 2005), family building by DI can be described as marginalised, as well as even stigmatised and tabooed.

**Development of legislation and guidelines**

In West Germany, discussions about a legislative framework for AHR in general and for DI in particular started in the mid-1980s, approximately ten years after the German Medical Commission had accepted DI. Däubler-Gmelin (1986, pp. 38-39), the Minister of Justice at that time, argued that:

> ... an open, meticulous and fundamental exploration of all individual issues relevant for artificial conception – of an ethical, legal, social and medical-psychological nature would have been not only desirable years ago but remains extremely necessary. ... Now we are confronted with the question of whether the possibilities and extent of application have developed so far that legal regulations cannot influence them anymore. ... National state border lines must be extended, as otherwise regulations already agreed upon are an illusion. It will be the task of the Federal Government to initiate steps resulting in the production of ... uniform regulations within the European Community.

In her article, “Fundamental Principles for Legislation”, Däubler-Gmelin (1986) suggested banning the commercialisation of egg and sperm donation and granting offspring conceived as a result of DI or egg donation access to their biological origin by the age of 16 years. Furthermore, she suggested ensuring that the social parent was responsible for alimony, thus protecting doctors from alimony compensation payments. She also contended that it would not be necessary to clarify all of the issues in a punitive act or other legislation as professional guidelines and regulations were sufficient for some of these aspects (Däubler-Gmelin, 1986).

Three years later, in 1989, the first report for the planned *Embryonenschutzgesetz* (ESchG) (Embryo Protection Act) was published by the State-Federation-Work Group “Reproductive Medicine” (Bund-Länder-Arbeitsgruppe “Fortpflanzungsmedizin”). This group was initiated by the Minister of Justice and submitted a comprehensive proposal for legislation for ART. For DI, the following recommendations were issued:
• DI should be allowed under restricted conditions if male infertility is present and cannot be cured otherwise;
• The welfare of the child must be taken into account;
• It should be mandatory for the doctor to give the married couple comprehensive information before starting treatment. In addition, pre-treatment psychosocial counselling should be mandatory;
• The husband must consent in writing;
• One donor should be used for one couple only, mixtures of the semen of several men should be forbidden;
• A central register is to be established;
• The child must have access to his/her genetic origin;
• Financial compensation to the donor should be banned;
• Donors should only be selected according to phenotypological similarity between donor and husband;
• Only specialised institutions should be allowed to carry out DI;
• Only specialised institutions should be allowed to preserve donated semen. Passing on donated semen to others should to be forbidden. Preserving semen should be allowed for two years only, the semen of a man known to be dead should not be allowed to be used. (Bundesminister der Justiz, 1989, pp. 13-17)

These recommendations led to concerns similar to those voiced in other countries. Katzorke (1989) feared that men would not be willing to provide semen if their anonymity was lifted and a central registry established. He was also concerned that sharing information about the conception with the child may lead to “psychological shock and regressive behaviour” of the child and therefore spoke out against “paternalising or even disempowering … the people affected” (Katzorke, 1989, p. 90). In the same year, the Glover Report on Reproductive Technologies to the European Commission (1989) was published. This report was compiled by representatives of several member countries of the European Union, including a German physician. It was much more guarded regarding DI offspring accessing genetic information, as the authors of this report also feared a great slump of semen providers should their anonymity be lifted. The report argued that:

... it can be better for a child to be born without the right to know the biological father than for that child not to be born at all. But, if the donor programmes can be kept up, best of all might be to be born with the right to know. (Glover, 1989, p. 38)

In 1990, the ESchG, a punitive law, was introduced. Under this Act, inseminations are permitted. As it does not differentiate between inseminations with the semen of the husband or a semen provider, DI is a legally sanctioned service. No additional legal provisions or professional guidelines were issued when
this legislation was enacted. Fragmented motherhood\textsuperscript{14} (i.e. oocyte donation and surrogacy) was prohibited. The Federal Minister of Justice (Bundesminister der Justiz, 1989, p. 21) argued that DI was considered only “to mimic a natural process, whereas oocyte donation would be a step away from natural procreation ... and a deep incision into the human and cultural self-image which includes the unambiguous nature of motherhood”.

In 1995, the Medical Association for Donor Insemination. (Arbeitskreis für donogene Insemination e.V [AKDI]) was founded, initially consisting of physicians only. In 1996, the AKDI issued guidelines for medical treatment with DI and the recruitment of semen providers, as well as for semen storage (Arbeitskreis, 1996). These guidelines, however, are binding for its members only. The AKDI remains the only professional body in this area and has recently broadened its membership to include psychosocial professionals.

\textbf{Current regulations regarding access to and funding of DI}

The ESchG does not regulate access to DI. According to the guidelines of the Federal Medical Chamber (Bundesärztekammer, 1998) binding to all medical professionals, access to DI is primarily granted to married couples but requires the approval of the Federal Medical Chamber. Cohabiting heterosexual couples are required to obtain permission from a standing commission of the Medical Chamber. Treatment of single women and couples in same-sex relationships is not permissible, as this is considered detrimental to the welfare of the child, but clinical experience indicates that some doctors provide DI services to these groups and that both groups also seek treatment abroad. These guidelines also stipulate that doctors should motivate couples to undergo “competent counselling with regard to the psychological burden [of infertility treatment] and the welfare of the child” (Bundesärztekammer, 1998, Para. 3.2.2). However, there is no mandatory pre-treatment counselling and clinical experience indicates that very few doctors require couples to consult a counsellor before embarking on treatment.

\textsuperscript{14}Fragmented motherhood is a term used to describe situations where one or more of the three components (genetic, gestational and social) are not present.
Since the *Kindschaftsrechtsreformgesetz* (Children's Rights Reform Act) in 1998, no differentiation must be made between children born to cohabiting couples and those born to married couples. They enjoy the same rights regarding the paternity of the male partner of the mother. In 2002, the *Kindschaftsrechtsverbesserungsgesetz* (Children's Rights Improvement Act) was passed. It provided some certainty for paternity when heterosexual couples use DI; further details regarding paternity will be discussed below. However, clinical experience and comments made at the annual meeting of the AKDI in my presence suggests that cohabiting couples are disadvantaged and clinics continue to prefer treating married couples.

In contrast to other methods of AHR, the costs of DI are not reimbursed by the German health insurance system. According to the *Social Legislation Code*, AHR is reimbursed only if married couples use their own gametes for procreation (*Sozialgesetzbuch V*, Para. 27a (1) 4). Cohabiting and lesbian couples as well as single women are not reimbursed as the German constitution provides special protection for marriage and family (*Grundgesetz*, Art. 6, Abs. 1) and it is assumed that a family is founded on the basis of a marriage (Bundesärztekammer, 1998). Despite the legal changes since 1998, this has not been challenged. In addition, in contrast to other health-related costs not reimbursed by the health insurance system, including inseminations using the semen of the husband, treatment costs for DI are not tax-deductible, as “the heterologous insemination does not aim to overcome the inability of the husband to have genetic offspring” (Bundesfinanzhof, 1999, p XIV). The lack of inclusion of DI in the *Social Legislation Code* or other medical guidelines also resulted in doctors being able to charge fees set individually for DI treatment.

*Legislation regarding paternity*

According to the *Bürgerliches Gesetzbuch* (BGB) (Citizens' Legal Code), any child born to married couples is the legal offspring of these parents. Even if this child is the result of an extra-marital affair, the husband of the wife enjoys paternity if he was engaging in sexual relations with her during the time of conception; this is referred to as “paternity-by-assumption” (BGB, Para. 1600 d). Until 2002, if circumstances became known which cast serious doubts on this paternity, however, the father, the mother and the child had a two-year time span in which to contest paternity. In several cases, after DI, fathers
successfully contested paternity in those cases where consent to DI was legally proven invalid, or doubtfull, or where the parents had separated and a father-child-relationship had not developed (Müller, 1997a). The EschG, however, does not require the husband to consent to DI, which led legal experts to assume that:

... one could be of the opinion that the doctor may not carry out the insemination if the husband has not given consent. Yet the treatment by the doctor without the husband’s consent remains at least without sentence. (Hager, 1997, p. 9)

The guidelines of the AKDI, however, require a legally binding, written agreement from both husband and wife, presumably in order to counteract this legal vacuum for the semen provider and as a safeguard for the doctors themselves. This is understandable as doctors were reported to fear alimony compensation payments if they insisted on maintaining the semen provider’s anonymity or could not identify him anymore (Hager, 1997; Schilling & Blonksi, 1994), therefore this consent did not only protect the semen providers, but also the service providers.

In April 2002, the Kindschaftsrechtsverbesserungsrecht (Children’s Rights Improvement Act) was introduced. This reform was the first acknowledgement of DI in German legislation and stipulated that paternity could not be contested by “the man or the mother if they have agreed to artificial insemination with the semen by a third party donor” (BGB, Para. 1600, Abs. 2). Only children continue to have the right to contest paternity. This solidified the rights and responsibilities of the father and exempted the semen provider from any legal implications, albeit, according to some legal experts, only in the case of heterosexual married couples (Keiper, 2005; Roth, 2003). Keiper (2005), furthermore, assumes that knowledge of the fact that the father is not the genitor may be sufficient for the child to contest paternity. Roth (2003) argues that paternity is invalid in those cases where a man agreed to DI only in the hope that this would stabilise his marital relationship. If the couple divorces prior to the birth of the child, according to Roth, even the consent to DI would become irrelevant and the divorced husband would not be considered the legal father of the child. At the same time, Keiper (2005), Müller (2005) and Roth (2003) suppose that even in those cases where paternity is successfully contested, the husband of the mother would have to bear alimony costs.
For cohabiting couples, Keiper (2005) and Roth (2003) argue that the paternity-by-assumption is not valid as, evidently, the child is not conceived to a married couple. Both argue that paternity in those cases can only be declared after the conception of the child, as paternity declaration prior to conception is legally invalid (BGB, Para. 1594, Abs. 3). However, it can be assumed that recipients clarify and sign such contracts prior to treatment, thus prior to conception. Roth (2003) points out therefore that the legal status of the male partner remains unregulated until the child is conceived and the father has declared his paternity. Keiper (2005) contends that DI for this group is problematic but may be tolerated if an agreement drawn up by a public notary has been signed. Müller (2005), on the other hand, interprets the *Children's Rights Improvement Act* in a more liberal way. According to her, if the male partner of a cohabiting couple consents to DI, he cannot step back from this paternity acceptance even though it was given prior to conception.

There are also differing interpretations of the *Children's Rights Improvement Act* for lesbian couples and single women. Whereas Keiper (2005) claims that these groups cannot access DI as there is no legal regulation and medical guidelines prohibit treating this group (Bundesärztekammer, 1998), Müller (2005) challenges this strict interpretation. She suggests that the spirit of this recent legislative change indicates acceptance of DI. In her view, DI for these two groups is difficult for two different reasons. Children have a right to access their biological origins and have a right to alimony payments. Although, according to current legislation, access to information about biological origin is not certain (see below), both lesbian couples and single women can ensure that the identity of the semen provider is recorded for the child, for example by safekeeping this information with a public notary. Regarding alimony rights, Müller (2005) suggests that the social parent can adopt the child after birth. This would ensure that the child has two parents who share financial responsibility. Single women, according to her, have the option of naming a further person who assumes parental responsibility and to whom custody is extended.

After the introduction of the *Children's Rights Improvement Act*, none of these issues have been challenged in court. It is therefore not possible to say whether the tendency is towards a more liberal or a strict interpretation of this change.
Access to information about the semen provider

As outlined at the beginning of this section, the discussions leading to the ESchG recommended granting DI offspring the right to access their biological origin. However, neither the ESchG nor any subsequent legislation or medical guidelines have regulated this aspect, although some international literature wrongly indicates that DI offspring in Germany enjoy the right to identifiable information about the semen provider. Blank wrote in 1990 (p. 142) that "those countries ... including Germany ... have had major national efforts to frame policy on these issues". Later he repeated that "the Benda (1985) report in Germany conclude that the child conceived through DI should have access to this record when he or she turns sixteen years of age" (Blank, 1998, p. 145). None of the documents referring to this right took into account that, according to current medical guidelines, medical records can be destroyed after a period of 10 years (Berufsordnung, 1998). There are no specific guidelines referring to the documents of semen providers and recipient couples. The guidelines set up by the AKDI adhere to the legal obligation of documentation "of similar medical documents", thus referring to this 10-year period (Arbeitskreis, 1996, Spenderrichtlinie F.1). The Agreements on Heterologous Insemination, issued by the Federal Chamber of Public Notaries (Bundesnotarkammer, 1997, p. 5b), reflected this contradiction when they advised in 1997, the most recent recommendations, that the child born after DI "has a right to knowing his origin. The assurance of the parent or the doctor towards the donor with regard to his anonymity remaining intact does not go against the right [of the child] to determine paternity".

A survey of the medical practices in Germany, carried out in 1998, indicates that approximately 50% of medical practitioners destroyed their records after this 10-year period (Thorn & Daniels, 2000a). This is not only in contrast to a principle decision of the Constitutional Court of 1989, which ruled that offspring must be provided with the name of the genitor if this information is available (Deutsch, 1996), but also in contrast to the guidelines of the Federal Medical Chamber which stipulate that:

... a child conceived by donor insemination has a right to be informed about his/her biological father, as biological paternity is of significant importance, for example in terms of marrying or the health of this child and his/her offspring. (Bundesärztekammer, 1998, Appendix 1.4)

In 2000, a new bill on reproductive medicine was prepared and publicly discussed. This bill was either to supplement or replace the ESchG completely (Bundesgesundheitsministerium, 2001). Many professionals
involved in this new legislation, as well as other medical, legal and psychosocial experts in the area of AHR, have argued that legal clarification of DI should be provided (Günther & Fritzsche, 2000; Katzorke, 2001; Neidert, 1998; Nieschlag, 2001; Thorn & Daniels, 2000a). Under current legislation, Katzorke (2001) claimed that there was insufficient information stored, regulation of the type and period of documentation was not standardised, the question of anonymity was not resolved, and there was not legal clarity for the physician, the semen provider and the couple to be treated. Others encouraged the development of a federal register and a period of documentation of 30 years (Zumstein, 2001). At the same time, several writers spoke out for banning DI. They repeated arguments presented several decades ago, such as fearing that DI promoted eugenic thinking, describing DI as going against biological and social norms, or contending that the welfare of the child would be compromised as children conceived by DI were instrumentalised by their parents (Baumann-Hölzle, 2001; Derleder, 2001; Mieth, 2001). Discussions regarding this bill were discontinued when the Minister of Health at that time resigned. There were plans to resume the discussion, but this has not been the case. The only recent statement on DI by a politician was one by the current Minister of Justice, Mrs. Brigitte Zypries. In a 2003 speech she said:

So far there is no legal regulation for DI. According to current guidelines of the Federal Medical Chamber … the doctor must inform the donor that he has the duty to provide his identity to the child. … The doctor has corresponding duties of documentation. This raises the question of whether according to the Constitution anonymous donors must be banned. According to the fundamental rights of children, the State has a duty of protection, … including access to biological origin. It is mandatory to avoid the donor assuming a legal paternity role. … A further alternative [to the Children’s Rights Improvement Act] is a general exemption of the donor from paternal duties. … For reasons of legal safety, I support a legal regulation which bans conception with anonymous donors. (Zypries, 2003)

Currently, there are no indications of a discussion regarding German legislation in this area. In 2006, however, European guidelines pertaining to tissue and organ donation will come into effect (Europarat, 2004). These guidelines, which also regulate documentation of gamete donation, stipulate that documents must be maintained for a minimum of 30 years in all member states. However, individual states can provide offspring access to these documents in accordance to their legislation. For Germany, this will result in a much longer period of documentation. Given that access to this information has not been codified in law, it remains to be seen how this impacts on medical practice in the area of DI.
Psychosocial counselling

There is no legal provision for counselling prior to or during any infertility treatment. According to medical guidelines, doctors are to ensure that couples can access “competent counselling about the possible burden of medical treatment and conditions pertaining to the welfare of the child”; couples however, are not required to take this up (Bundesarztekammer, 1998, Para. 3.2.3). This pertains to all types of AHR treatment. There is no knowledge as to how many couples are referred to a counsellor prior to or during DI treatment. Clinical experience indicates that only two of the approximately 40 doctors offering DI services require couples to undergo pre-treatment counselling. There may be some couples that consult a counsellor independently, but it seems most likely that the vast majority of couples do not do so. At the time of writing this thesis, these medical guidelines are being revised and it is a matter of debate whether medical doctors are to carry out the initial counselling for couples prior to treatment (Kentenich, 2005).

Infertility counselling has only recently become a specialised field in counselling. In 2000, the German Infertility Counselling Network (Beratungsnetzwerk Kinderwunsch Deutschland e.V. [BKiD]) was founded (Thorn, 2000a). Discussions during the annual conferences of BKiD indicate that in addition to the author there are only two other counsellors specialising in family building by DI. Though a number of books are dedicated to psychosocial issues pertaining to infertility (for example: Brühler & Goldschmidt, 1998; Glogelt-Tippelt, Gomille & Grimmig, 1993; Strauß, 1991, 2000) it appears that this does not always enjoy high priority with translated literature. In the German translation of Imber-Black’s (1993; German translation: Imber-Black, 1995) book on secrets in family and in family therapy, the chapter “Infertility: Private pain and secret stigma” (Schaffer & Diamond, 1993) was omitted. German literature dedicated to infertility counselling in general (Stammer, Verres & Wischmann, 2004) as well as for family building by DI (Thorn, 2000b) to date is very limited.

Research into family building by DI

Although there did not seem to be an infrastructure for counselling, recipient counselling both in the former Eastern and the Western part of Germany received relatively early attention. In the GFR,
discussions on a psychological assessment commenced in 1980. Graf and Glander (1980, p. 774) published a treatment plan suggesting that “only married couples with a stable personality and relationship can be expected to shoulder the burden” of ADI. Explaining their motivation to set up these suggestions, the authors explained that:

... at least some authors have observed negative behaviour of the married couple [such as] realising the intricacy of their decision only after pregnancy was established ... when half of the couples (esp. the male partners) changed their hitherto positive attitude towards ADI and desired a termination of the pregnancy or a separation from their partner. (Graf & Glander, 1980, pp. 775-776)

The authors also issued comprehensive recommendations prior to treatment. Information about the couple’s physical and mental health history was to be collected, an individual and couple exploration was to be carried out and an additional physician was to be consulted. Furthermore, a four-month waiting period for reflection, as well as a written agreement between the doctor and the couple prior to treatment, was suggested. They also recommended three compulsory follow-up consultations of the family, one, three and five years after the birth of the child, and considered it “their duty to be available for consultancy with the couple beyond the phase of diagnosis and ADI (Graf & Glander, 1980, p. 778). In 1983, these suggestions, together with further medical provisions, were developed into “The Suggestion for a Guideline to carry out Artificial Donor Insemination” (Glander et al., 1983). In 1989, Seikowski and Glander published a supplement which included additional psychological screening issues, such as the couple’s quality of their wish for a child, the type of infertility coping mechanisms, as well as general coping abilities, and the couple’s ability to form a compromise and cooperate within their relationship. However, these comprehensive recommendations were also criticised. Hauschild and Schreiber (1985) argued that psychological pathologies may well develop as a result of infertility and may be solved once pregnancy has been established. Furthermore, according to Schreiber (personal communication, May 3, 2005), this assessment was mainly carried out in the clinic where these professionals worked. Other institutions did not endorse such comprehensive screening. In 1990, after Reunification, Seikowski and Glander (1990, p. 168) published a “concept for psychosocial care for married couples carrying out artificial insemination by donor” and considered the following issues to be vital in such a programme:

* Andrological diagnosis;
• Possibility of accessing psychotherapy to manage infertility;
• Medical information about DI;
• Psycho-diagnostic discussion regarding DI including administration of several psycho-diagnostic tests assessing individual and marital stability;
• Interdisciplinary team consisting of an andrologist, gynaecologist, psychologist, geneticists and legal and forensic experts to assess and decide suitability;
• Medical treatment of DI;
• Psychosocial interventions in the case of acute problems;
• Post-treatment care.

Counselling with regard to information sharing was located in the last section of this programme. The authors argued that “the treatment team should always be available for the parents, even after conception, for example if they have concerns that their child may suffer from a disease caused by the donor or if counselling is required in order to decide whether the child will be informed of their use of DI or not” (Seikowski & Glander, 1990, p. 174). They assumed that information sharing was only necessary in those cases where parents with a close emotional bond to the child ran the risk of “sending verbal and nonverbal messages which are not compatible ... and if the child may sense this contradictory behaviour” (Seikowski & Glander, 1990, p. 174). They also hoped that early psychosocial care might result in accepting asymmetrical parenthood and in attributing greater value to social parenting. This was expected to result in non-contradictory behaviour of parents and it implied that information sharing in those cases would be unnecessary. The only study investigating parental attitudes about information sharing was published by Weller et al. (1989) just after Reunification. In accordance with the political climate of the GDR, the authors stressed that their social responsibility, and their specific responsibility as a medical team, was taken into account by administering a psycho-diagnostic test to all couples in order to screen their capability for parenthood following DI. The authors were pleased to report that “after a positive psycho-diagnostic test, the marriages after the birth of DI children showed greater stability than in the normal population” (Weller et al., 1989, p. 90). Regarding attitudes towards information sharing, they found that just under 9% of the 173 parents intended to share the means of conception with their child, approx. 26% intended to keep it a secret, approx. 45% were undecided and approx. 20% had delayed the
decision until having consulted with a doctor or a psychologist after the coming of age of the child. There was no further discussion of these findings.

There is no indication as to whether all clinics approved of or carried out such assessment. It also appears that this type of assessment primarily served clinicians in selecting couples according to suitability, but there was little opportunity for couples themselves to raise issues they wished to explore. The attempt to select suitable, or inconspicuous, couples and the lack of discussion around information sharing may be indicative that DI, in contrast to Schreiber’s (personal communication, May 3, 2005) assumption, enjoyed limited acceptance and that these writers attempted to demonstrate that professional control can contribute to healthy family building even in those cases where family composition deviated from the norm.

In the former Western part of Germany, similar recommendations were made by Brähler et al. (1988). These were based on the results of a study conducted by Brähler and Meyhöver (1986). In this piece of research, 121 couples were examined from a psychoanalytical perspective before embarking on treatment. The authors developed four typologies of couples, all of which were attributed unfavourable qualities. The largest group was considered to neglect emotions and view infertility as individual failure, the second group revealed depressive tendencies and sexual dysfunctions, the third suffered from severe personality disorders stemming from “chaotic families-of-origin” (Brähler & Meyhöver, 1986, p. 166), and the fourth represented themselves “almost like cliché [couples with] the traditional image of maleness and femaleness” with men as “proactive and women passive-receptive” (Brähler & Meyhöver, 1986, p. 167).

The authors concluded that a child conceived with the help of DI might increase couple instability:

In hysterical marriages, heterologous insemination can subconsciously encourage the fantasy that a wife can achieve pregnancy – and thus phallic potency – even without her husband. In such a constellation, insemination with the semen of an unknown man is a weapon in the battle of sexes, which nobody can win. ... With these couples, psychotherapeutical couple counselling is indicated. If such a couple refuses counselling, a longer waiting period until insemination occurs should be mandatory in order for the couple to be able to manage their couple conflict in a different way. (Brähler & Meyhöfer, 1986, p. 168)

As in the GDR such derogatory views were not universally endorsed. Goebel and Lübke (1987) published a study of 96 parents describing marital satisfaction as high and child development as uneventful. In contrast to Brähler and Meyhöver (1986), they stated that “the motivations of these couples to have a
child and not to accept infertility are primarily not in the neurotic area” (Göbel & Lübke, 1987, p. 639). Again, there is no indication that pre-treatment counselling was available or even required by clinics offering DI services. It seemed that the psychological and social issues of DI received attention only within research projects both before and for many years after Reunification.

All German studies examining marital satisfaction and child development before (Brähler, 1988; Brähler & Meyhöver, 1986; Göbel & Lübke, 1987; Hermann et al., 1984; Seikowski & Glander, 1990; Weller et al., 1998) as well as after Reunification (Schaible, 1992; Schilling, 1995; Schilling, 1999) confirmed the international findings, which will be outlined in the next chapter. Parents were reported to be satisfied with their decision to use DI, divorce rates were lower than the norm and child development was found to be uneventful; as in early international studies, however, in all German studies, children were not studied directly, but indirectly through questions asked of their parents. Some of these studies also examined parental attitudes regarding information sharing. Again the views of German couples, both before and after treatment are similar to those in other countries. Until recently, Schaible (1992) and Schilling (1995) found that parents favoured secrecy over information sharing as they feared detrimental effects on the child, rejection of the father, legal problems and wanted to avoid stigmatisation. Disclosure rates in both studies were low; Schaible (1992, p. 65) reported that almost 95% of the 46 parents he studied did not consider it helpful “for the child to learn that he or she is not a ‘proper’ child of their marriage”, in Schilling’s (1995) survey, 34 of 40 parents did not intend to share the use of DI with their children. Schilling (1995) contended that for ten of those couples who did not intend to share, this presented a major burden. Those couples experienced nightmares, missed sharing with significant others, and felt pressured into explaining medical appointments. All others described secrecy to be either a slight or no burden. Despite these negative experiences, Schilling (1995, p. 16) concluded:

... the decision to inform children or not is to be left in the hands of the parents. Even though maximum candidness is considered desirable today, the ‘cathartic’ revelation of family secrets can be as destructive as their conservation.

In 2003, Thorn and Daniels wrote about educational group programmes to prepare couples for family building by DI. These programmes provide opportunities for couples to receive comprehensive information on the medical, legal and psychosocial dimensions of DI by experts in their fields, meet and
gain support and information from other couples, and meet a couple who had children as a result of DI. An evaluation of those attending these programmes indicated that participants' feelings of isolation had diminished, they felt empowered by the information and sharing with others, and profited from the experience of the family whom they had met. Many described a lack of social acceptance for DI; they felt DI was tabooed and stigmatised and spoke out for more media awareness to promote change. In 2000, several of the participants founded the German patient organisation Information Donogene Insemination (Information Donor Insemination [IDI]) which since then has organised regular national meetings for families built with the assistance of DI. In a separate study, Daniels, Thorn and Westerbrooke (2005) showed that these programmes impacted significantly on the levels of confidence of participants: whereas half the 48 respondents felt no or little confidence about DI prior to the programme, only two reported having no or little confidence in DI after the group programme. This increased level of confidence seemed to flow through to the couples' decision-making about information sharing. Whereas prior to the programme, only 42% indicated that they would probably or definitely share the use of DI with their children, 90% felt this way afterwards. Such educational group programmes represent a very different approach than individual or couples pre-treatment counselling or assessment carried out or suggested both in other countries and in Germany. The group approach, in contrast to individual or couple counselling, had empowered participants towards the use of DI, providing them with both the confidence and skills to discuss DI and reducing their isolation.

Summary

DI was considered a dubious practice in Germany for many years. It was only in 1970 that the German Federal Medical Chamber accepted DI and doctors providing this service did not have to fear expulsion from their professional body. In the subsequent years, the number of doctors offering DI rose; however, as there is no official or compulsory register for DI, the number of practitioners, as well as the number of treatment cycles and resulting births, can only be estimated. Currently, approximately 40 doctors offer DI treatment, and it is assumed that a minimum of 500 children are born annually as a result of this treatment.
In contrast to other types of AHR, DI enjoys little public awareness. This is not only reflected in the small number of media reports, but also in the fact that many textbooks and guidance literature only make passing and sometimes negative comments on DI. It is also reflected in the legislative developments. Whereas a comprehensive legal framework for AHR was enacted in 1990, the rights and responsibilities of those involved in DI have only been addressed partially. The only legislation pertaining to DI was passed in 2002, when changes of the Citizens' Legal Code provided some certainty for paternity in those cases where heterosexual married couples use DI. One of the major legal contradictions is the right of offspring to access information about their biological origin and the legal period for medical record keeping. While medical and legal guidelines, as well as a principle decision of the Constitution Court, have emphasised the right to such information, current guidelines also stipulate that medical records can be destroyed after a period of 10 years. Offspring, as a result, have a theoretical right but cannot put this into practice in those cases where records have been destroyed. In 2006, European guidelines will come into effect specifying that information regarding tissue, organ and gamete donation must be stored for a minimum of 30 years. It remains to be seen how this will impact on the practice of DI.

In contrast to several other countries, pre-treatment counselling is not compulsory in Germany. Although several writers both in the former Eastern and Western part of Germany had attempted to develop screening criteria for couples requesting DI, these seemed endorsed neither before nor after the Reunification of Germany. While several researchers described couples using DI as suffering from psychological instabilities, these views were not supported, and more recently, research carried out in Germany has replicated international findings. Marital satisfaction has been described to be high, and infant and child development in the normal range. Infertility counselling, as a specialised area in counselling, has only been a recent development. The national organisation for infertility counselling, BKiD, was established in 2002. Currently, only a few counsellors specialise in family building by DI, and counselling manuals dedicated to infertility or family building by DI, to date, are very limited. In contrast to other countries, educational group programmes for couples have been offered in Germany and evaluated. Such programmes have been reported to result in increased confidence about the use of DI, and thus, not only help to decrease the stigmatising effect of DI, but to encourage information sharing between parents and children.
Chapter 4

Review of international policy and practice of information sharing in DI

For many decades, information sharing in DI was an issue that received little attention – it was simply assumed that parents never talk to their children or others about the fact that they have used the semen of another man to build their family. In recent years, the issue of information sharing has been debated more and more. Legislation in several countries has been changed to grant offspring the right to access information regarding their genitor, and the number of professionals recommending disclosure to parents is rising. This chapter will outline the historical background and current debates regarding this issue.

Historical overview of policy and practice

Since the first reports about DI were published at the beginning of the last century, secrecy has been the prevailing notion around DI. The first report, published in 1909, illustrated that the doctor performed DI without informing the couple that the semen of a man other than the husband had been used. Eventually, the doctor told the husband, but the latter suggested his wife not to be told (Gregoire & Meyer, 1965). In a sense, this first report set the scene for the secrecy surrounding DI and the anonymity of the semen provider. DI remained hidden from the public and beyond public scrutiny until the middle of the last century. By the 1950s, moral concerns were raised about DI (Daniels & Taylor, 1993; Snowdon & Snowdon, 1993). Family building by DI was not only associated with illegitimacy and adultery but it would have revealed the male partner’s infertility, an additional issue which was not publicly acknowledged. In 1948, the Archbishop of Canterbury established a commission to enquire into artificial human insemination. The commission recommended that DI be regarded as a criminal offence (Report of a Commission, 1948). Approximately 12 years later, a committee investigating the legal aspects of DI commented that DI was “an activity which might be expected to attract more than the usual proportion of
psychopaths” (Earl of Feversham’s Report, 1960). Around the same time, doctors in the United States were going to great lengths to ensure that complete privacy of the recipient couple and the semen provider were maintained (Daniels & Taylor, 1993). By the end of the 1970s, this had changed little, and in public debates, reactions to DI continued to range from “disapproval to abhorrence” (Daniels & Taylor, 1993, p. 156). The situation in Great Britain, where the stigmatising nature of DI was associated with psychosocial concerns and legal uncertainties, was similar to that experienced world-wide:

By the late 1970s, DI had been used as a treatment for male infertility for about 40 years in the UK, with little public awareness or consideration. No one ever set out to explain in so many words why this secrecy was the best course of action. The decision to provide and use DI treatment in secret appears to have been based on the unspoken assumption that being open about the subject would be harmful, either to those taking part and/or to the child born as a result of such treatment. Sexual behaviour was then more socially circumscribed than it is today, and the DI procedure was considered to be extremely controversial. There was also considerable uncertainty about the legality of the practice; so it is perhaps understandable that in those early days both the treatment providers and their patients thought it best to say nothing about what they were doing. (Snowdon, 1993, p. 194)

Despite increasing appeals in the early 1980s for more openness, as Daniels and Taylor (1993) note, “secrecy [was] still the guiding principle for many of those involved in DI” a decade later:

Many DI practitioners have maintained no records of the use of, or conceptions by, donor semen. Neither the child nor the parents have any chance whatsoever of finding out the identity of the sperm donor. The donor in his turn has no way to find out the child’s identity. The protection and privacy for the adults involved in DI is complete. (Daniels & Taylor, 1993, p. 156)

One of the most significant reasons put forward for maintaining secrecy was the need to protect the child. Doctors feared that the truth would lead to “insurmountable social and psychological problems both for the child and for the family” (Snowdon & Mitchell, 1981). They expected psychological and emotional trauma and, as a result of the stigma surrounding DI, feared negative social reactions towards the child. In addition, there was concern that the child might want to seek information about the semen provider. As such information was not available in many cases, this would have been a frustrating exercise. Daniels and Taylor (1993, p. 157) state: “secrecy, when it is practiced for this reason, is being advocated as necessary to protect the child from the consequences of earlier secrecy”.

Future parents had several reasons for choosing secrecy over disclosing DI. Professionals raised serious concerns about the couple’s psychological well-being; psychoanalysts, such as Gerstel (1963), considered
the mere use of DI an indication of emotional disturbance. Although by the 1990s, the climate had changed somewhat and there was increasing acceptance for family diversity, as Daniels and Taylor (1993, p. 157) note, “couples themselves feel there is something ‘not quite right’ about using DI”. In those cases where DI was used to circumvent male infertility, the stigma of infertility in general, and of male infertility in particular, was likely to be a major factor in not disclosing the use of DI (Miall, 1986; Nachtigall, 1993). This also resulted in both doctors and women wanting to protect the male partner. Doctors recommended that women should not disclose to their husband the results of the fertility investigations, and should leave them unaware of the fact that semen of another man had resulted in the conception of their child (Snowdon et al., 1985). Women, on their part, often pretended that they were affected by infertility so that others were left unaware of their husband’s inability to father a child (Lasker & Borg, 1989). In addition, parents felt unsure about the bonding of the child, fearing the child would reject the father because of the lack of biological connection. Finally, parents did not have any narratives or “a script” to tell the child about his or her origins (Daniels & Taylor, 1993, p. 158). Some parents found talking about sexuality in general overwhelming, and sharing about DI with the child was considered even more difficult, especially given the lack of resources. Rowland (1985) also suggests that parents feared the child could be stigmatised by the extended family or school friends. Drawing on anthropological studies, Haimes (1993a, pp. 178-179) confirms that central to the idea of family was the view that “family derives its authority and status partly from an appeal to the natural basis of the biological relationship between the generations” and concludes that secrecy thus protects “the idea of the family”.

Given the morally questionable nature of DI, secrecy also served to protect doctors offering this service (Annas, 1980). They had concerns regarding their public image and therefore did not make any public statements about the fact that they offered this service (Haimes, 1993b). In a sense, the stigmatising nature of DI had extended to the professionals. In addition, doctors were described as those “who have contacts with all persons concerned and who control the information that is passed on” (Back & Snowdon, 1988). Their standards represented professional norms agreed upon by society and this status gave them considerable power. Patients therefore were likely to follow their advice. Triseliotis (1993, pp. 196-197) explains that the medical profession exerted their power on two different levels:
First, it controls the research that is being carried out on DI. Anyone who has tried to get access to samples in this area knows that an iron curtain descends immediately. This obstructionism is defended in the name of confidentiality — to protect the donor, 'patient', or 'customer'. ... Second, the power of the medical profession manifests itself in the patient/doctor relationship. It is well known that patients, and particularly those desperate for a child, come to feel grateful and dependent on their doctors. The advice, therefore, that they receive from their physician about what to tell or not to tell the child born through DI is crucial. There is evidence to suggest that most physicians advise couples not to disclose the facts of DI.

The semen providers were also seen to require protection. As a result of the legal uncertainties, the fear that they may have to bear alimony payments and that their offspring could claim inheritance rights, lifting their anonymity and granting offspring access to information was feared to drastically reduce the number of semen providers. Secrecy was also considered important in protecting a possible disruption to the semen providers’ own families should offspring have access to them in the future (Beck, 1984; Rowland, 1985). These same fears were later expressed by authors such as Craft and Thornhill (2004) and Ahuja (as cited in Hall, 2004), as a result of a change in legislation in Great Britain (HFEA, 2004) which took effect in April 2005 (this will be further discussed below).

Last but not least, DI lends itself to secrecy. The woman carries and gives birth to the baby, thus to the public, the contribution of the semen provider is not visible (Daniels & Taylor, 1993).

**Current debates about information sharing and secrecy**

For the last two decades, the number of writers from various professional backgrounds arguing against secrecy has been rising. Arguments have been brought forward from a psychosocial stance focussing on the child and the family, as well as from medical, legal and ethical viewpoints.

**Psychological considerations**

Writers with a psychosocial concern argue that not providing offspring with information regarding their biological origin is keeping a secret. Secrets can have a variety of negative impacts on family dynamics. They can influence the distribution of power (Bok, 1999; Imber-Black, 1995) by adding to the power of
the person concealing information and diminishing that of the deceived; this leads to imbalances and hierarchical orders. Haley (1977) describes this as triangulation: two parties form a coalition and exclude a third or more parties. According to this concept, these structures become pathological if the coalition persists and is not openly acknowledged. Furthermore, Karpel (1980) contends that family relations can suffer from a loss of relational resources as secrets can “contribute to pseudobonds instead of genuine alliances”. He views secrets as harming the balance of fairness and the overall structure of trust and trustworthiness within the family, and violating the trust, which “may constitute the most devastating consequence of secrets” (Karpel, 1980, p. 300). Secrets can also be used to exert pressure by the secret-holders, especially during times of difficulties or crises (Papp, 1995). On a practical level, there is the danger of unanticipated and destructive disclosure by the secret-holder, by others who are aware of the secret or by accidental discovery (Karpel, 1980). Describing common principles in family therapy, in practice in the early 1960s, Sants (1964, p. 140) writes that “a conscious acceptance of the known facts, intolerable though they may appear to be tends to improve rather than worsen relationships”.

Furthermore, family secrets can also result in deception, distortion and mystification, and generate anxiety both for the secret-holder and the unaware:

Secret-holders experience anxiety in their fear of disclosure, their discomfort when relevant topics are discussed, and their attempts to deceive or distort information. The unaware are likely to experience anxiety in relation to seemingly inexplicable tension that develops when areas relevant to the secret are discussed with the secret-holders. They may also experience confusion and a variety of negative feelings in relation to the ‘explanations’ they formulate in an attempt to understand this anxiety. Secrets perpetuate shame and guilt by sealing these feelings up within the secret-holder, out of the reach of others who might help. And they may contribute to a vague but tenacious sense of shame or guilt in the unaware. (Karpel, 1980, p. 300)

In her book on honesty in families, Wieman (2001, p. 14) critically comments not only on the deception of the children but on the parental need to deceive themselves from a challenging reality. She asks, “How much do we as adults want to use the notion of protection in order to protect ourselves, in order to flee from our pain or in order to make children believe that there is harmony and a sugar-coated world?”

Family secrets often concern issues tabooed and stigmatised in our society, such as children born out of wedlock, extra-marital affairs or other events that may be shameful for the family (Bradshaw, 1995;
Imber-Black, 1995; Simon et al., 1999), and the use of DI for family creation (Nachigall, 1993; Schaffer & Diamond 1993). Writers agree that withholding information concerning the birth and/or biological origin of their children is not a private issue for the parents but creates a family secret as this information is considered to "belong" to the children (Bok, 1999; Bradshaw, 1995; Feast, 2003; Karpel, 1980; Papp, 1995). From a family therapy perspective, Imber-Black (1998, pp. 129-130) argues:

Secrets about birth origins (including paternity, adoption, and the new birth technologies) ... involve another person's right to information. While secrets like these have powerful relationship implications, they pertain first to another person’s autonomy. When such secrets are kept from the person whose life they directly affect, the secret-keeper is operating from a position of arrogance, saying, in effect, 'I know what’s best for you to know – even in your own life'.

Bradshaw (1995) differentiates between constructive secrets (such as playful secrets intended to surprise family members), generative secrets (such as the first love of a teenager not shared with the parents) and so-called "dark" or destructive secrets amongst which he includes those concerning the genetic origin of a child and kept after the birth:

One still unknown area of secrecy is the issue of infertility and new reproductive technologies ... All of this advancing area questions genetic origin, which seems a central theme in our society, especially of the men. Infertility is often kept a secret. It is clear that many men and women mourn and feel shame and social pressure if they cannot have children. ... The possibilities of [surrogacy or artificial insemination] pose enormous moral, ethical and psychological problems. ... Most religious belief systems are strict opponents of artificial insemination, and surrogacy and DI are still attacked from legal and moral perspectives. These concerns force couples who use these technologies to secrecy. As with any other secrets, we must also question with these secrets the impact on the actor who the secret is kept from, the child. ... The child may have to carry the heavy burden of a dark secret because of the religious and moral condemnation together with the shame felt by the partners. In the case of ... DI there is a third 'parental figure' the absence of which signifies the lack of a vital person for every family member. (Bradshaw, 1995, p. 69)

Both family therapists and adoption researchers point out that secrets can impact negatively on self-esteem and identity (Bradshaw, 1995; Feast, 2003; Papp, 1995; Triseliotis, 1993). Identity theory is used as a notion which helps in understanding oneself and is based on relative continuity of attitudes and behavioural patterns when observing oneself and others (Fröhlich & Drever, 1981). Erikson (1977) developed the theory of "psychosocial identity", which he defined as the personal coherence of an individual, explaining that it is especially during youth and adolescent years that identity crises can occur. Such a crisis can be the result of subjective affect as well as of objectively definable interruption of
personal continuity. More recent theories have extended Erikson's premise by explaining that identity is not a rigid view of oneself, but is continuously renewed by interconnections with others (Krappmann, 1973), and is thus created and recreated in language, conversation and interaction within changing relationships (Gergen, 1991). Several adoption researchers stress the importance of detailed and accurate information about the origins of adopted people. Even in 1964, Kirk argued that parents who kept adoption a secret and rejected difference were denying a relevant and important aspect of the child's origins, sense of identity and self-esteem. As Triseliotis (2000, p. 85) explains:

Adopted children have not only to know that they are adopted, but also to understand and integrate this knowledge and its meaning into their developing selves. For children adopted when very young it is not apparent until around the ages of 5–7 that they cognitively begin to grasp the meaning... . Even if understanding comes later, disclosure has to start earlier so that children can feel that they 'always knew'. There is no agreement about when telling should start, but most researchers suggest that the earlier the better.

More recently, many adoption researchers have contended that this concept is similar for children conceived by DI (for example: Baran & Pannor, 1989; Feast, 2003, Haimes, 1988, McWhinnie, 2003; Triseliotis, 1993; Wiemann, 2001). However, it is not only the child who is required to adapt his or her identity to new information. For those experiencing infertility and using DI, a similar process of identity adaptation seems necessary (Berger, 1982; Daniels, 1999; Greil, 1991; Thorn, 2000c). Keeping DI a secret may also hinder a successful psychosocial adjustment to building a family by DI for the adult parties.

Growing awareness of the importance of medical and genetic information

As early as 1980, Annas claimed that offspring should have unlimited information about the semen provider so that they can access their medical history. More recently, advances in genetics technology and an increasing understanding of the human genome have led writers to question whether anonymity of the semen provider is appropriate from a medical point of view (Greenslade, 1998). Cooper (1997, p. 47) stresses that access to genetic origins can be vital to those conceived by DI:

Although procreation with known third parties is becoming increasingly more common, especially among couples opting for ovum donation, the vast majority of couples involved in gamete donation use anonymous sperm or eggs. This practice raises an ethical question:
Is it morally acceptable to bring a child into the world with an unknown genetic parent? This question has been historically overlooked, perhaps because until recently, nurture, rather than nature, has been thought to play the primary role in human development. Genetics was thought to be relatively unimportant in determining who a person would ultimately become. Thus if nature was not very relevant, one could argue that it did not matter where one's genes came from, and it could be concluded that it is morally acceptable to bring a child into the world with an unknown genetic parent. The past 10 or 15 years have deepened our understanding of the role of genetics. Although scientists have not finished mapping the human genome, more and more information about biological destiny is unfolding on an almost daily basis. We now understand that genetics play a very large role in determining one's physical and mental health as well as personality. And although no one knows exactly what the nature/nurture equation is, human nature is being weighted much more heavily on the side of nature than was previously assumed.

Our knowledge of genetic heritage has increased even more dramatically in the last few years. Greenslade (1998, p. 23) contends that our understanding of "the place of inheritance in causation of, and tendencies towards, ill health is currently being investigated in a wide range of diseases, from autism to Alzheimer's, from cystic fibrosis to Creutzfeld-Jacob Disease". She believes that having correct and accurate knowledge can not only enable individuals to adjust their lifestyle to risk factors, but also to use preventive measures in order to avoid or minimise the risk of acquiring illnesses with a genetic factor. In 2004, in recognition of these advances, the American Society for Reproductive Medicine (ASRM) issued recommendations encouraging professionals in AHR to provide comprehensive and identifiable information to offspring conceived by gamete donation (ASRM, 2004). The Society argued that it was of fundamental interest to a person to know their genetic origin so that they can make informed health care decisions (ASRM, 2004). A survey investigating the attitude of the general public in the United States confirmed that this was not only a view held by professionals but by the public as well. In the HealthStyle survey conducted in 2004, 96% of respondents believed their family history was important for understanding and managing their own health (Yoon et al., 2005). However, results of a similar survey conducted in Great Britain in December 2004 suggest more varied attitudes. Whereas most of the 202 general practitioners who participated expressed the need for patients to have more comprehensive information about illnesses running in their families, the vast majority of the 1042 members of the public who responded to the survey did not consider this information relevant (Healthcare Heritage Study, 2004). Despite these differences, the results of the two surveys indicate a trend towards a heightened recognition of hereditary conditions.
Until recently, medical arguments mainly revolved around medical issues of people conceived by DI. Semen providers, on the other hand, may also have an interest in learning about genetic diseases they have passed on to offspring. In 2003, Feast described the case of a child conceived by DI who was diagnosed with a rare genetic disease. In this case, the semen provider, who had fathered a total of 43 children, was the carrier of this single gene disorder which had a 50:50 chance of being passed on to offspring. Open access to such information would not only enable the offspring and their families to adjust to such diseases, but may also impact on the semen provider’s decision to father children in his own family. This aspect, however, has rarely if ever been discussed.

**Legal debates**

Whether or not offspring should have the legal right to access information about their biological origin remains a matter of great controversy (Blank, 1990; Blyth & Landau, 2004; Knoppers & LeBris, 1991; Patrizio, Mastroianni & Mastroianni, 2001). One of the concepts applied almost universally is the welfare of the child (Blyth, 1995a; Daniels, Blyth, Hall & Hanson, 2000; McWhinnie, 2001). However, although the notion that the best interests of the child should always be paramount has been described as a fundamental tenet of Western family law (Asche, 1985), the precise meaning of the best interests for children conceived by DI regarding legal access to their biological origin remains a contentious issue. Various legislative frameworks have defined the welfare of the child in this respect in different ways (Daniels, 1998b), and none of the major international human rights codes has attempted to clarify this.

*The European Convention for the Protection of the Human Rights and Fundamental Freedoms* (Council of Europe, 1950) in Article 8 provides for the right to respect for private and family life, and the *United Nations Universal Declaration of Human Rights* (1989) provides for the right to marry and establish a family. The latter also stipulates in Article 16 that the family is entitled to protection by “Society” and the “State”. It regulates adoption in so far as it mandates states to control the process of adoption (Article 21). The *United Nations Declaration of the Rights of the Child* (1959) in Principle 2 states:
The child shall enjoy special protection, and shall be given opportunities and facilities, by law and by other means, to enable him to develop physically, mentally, morally, spiritually and socially in a healthy and normal manner and in conditions of freedom and dignity. In the enactment of laws for this purpose, the best interests of the child shall be the paramount consideration.

The European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (Europarat, 1997) stipulates in Article 10 that “everybody has the right to information regarding all data collected on his health”, and in Article 11 that “any form of discrimination of a person because of his genetic origin is forbidden”. However, with regard to the right of access to biological information, all of these conventions remain vague and unspecific, and this has led to different and contradictory interpretations. The French government, for instance, when reporting on the implementation of the Convention on the Rights of the Child (1990), claimed that anonymity would be in the best interests of the child, as this would avoid the problems of having to manage relationships with both the father and the genitor (Ruxton, 1996). The Australian Human Rights Commissioner, on the other hand, viewed anonymity as a major breach of children’s rights as he considered it vital that children knew their genitors (Harvey, 1997, cited in Blyth, 1999). This wide span of interpretation is also mirrored in legislation, guidelines and practices of DI world-wide. The only change in this respect will be the introduction of the European Guidelines for Tissue and Organ Transplantation, which, as described in the previous chapter, is to take effect as of April 2006 (Europarat, 2004). In 2002, the High Court in Great Britain ruled that Rose, an adult offspring conceived by DI and the mother of a six-year-old child, was entitled to use European human rights legislation to argue for access to information about her and her child’s genitors (Rose v Secretary of State, 2002). It seems likely that similar cases in countries without such legislation will come before the courts.

**Ethical considerations**

In their book *Principles of Biomedical Ethics*, Beauchamp and Childress (1994) identify three guiding principles for moral decision-making processes: respect for autonomy, nonmaleficence or beneficence, and justice. Greenslade (1998, p. 24) argues that withholding information about a person’s biological background does not adhere to the principle of respect for autonomy and violates beneficence:
Putting the two elements [of access to genetic information and the Principle of Autonomy] … together, it would seem that, for an individual to make autonomous choices about her health, she must first be in possession of sufficient information about herself. Given what we know and are learning about inheritance then information about biological ancestry and the biological extended ‘family’ is required. It is not simply the donor who may hold a vital key in a health puzzle, but any one of his or her relatives. Geneticists do, after all, rely on pedigree analysis, or the study of family trees, to counsel their clients appropriately. The proponents of anonymity would counter by suggesting that such a pedigree could be delivered anonymously. However, the pace of genetic science is such that new disease connections are made every year, the information we need today will not be the same as the information we need tomorrow, and we cannot predict what the changes will be. In addition, collecting a complex pedigree of all the information that might conceivably be needed would be an impossible task, and the more complex the family tree the more identifiable the family becomes because of it. The solution would seem to be an open situation in which the child, or his or her carer, has access to the individuals with the answers when the questions arise. Of course, self-understanding relates to more than objective facts about one’s background, but includes a deeper knowledge about how one came to exist.

Feast (2003, p. 85) adds that “it would seem untenable that groups of individuals – children of donor gametes – be systematically denied access to information that may affect their physical or psychological well-being”, and she goes on to describe this as discrimination “because they are currently the only group of people whose need for information is not recognized”. This violates the principle of fairness in regard to other groups of people who are not genetically related to their parents, such as adopted children. However, other writers have argued that access to information limits the semen provider’s and the parents’ autonomy (Pennings, 1997; Shenfield, 1997).

It seems difficult to balance these moral rights, especially given that, prior to and during treatment, there is no guarantee that the child whose welfare should be taken into account will be born. The couples in treatment and the men who provide semen, nonetheless, can actively promote their own interests and may not find it easy to see beyond their immediate needs (Daniels, 1998b). Such a perspective is implied by Pennings (1997) when he suggests a double-track policy. According to this policy:

... a donor has the choice to enter the programme as an anonymous or as an identifiable donor and recipients can choose between an identifiable or an anonymous donor. The details (at what age the child can be told the name of the donor, who the child should contact etc.) may be adapted to the national legislation and can be used to emphasize specific points. (Pennings, 1997, p. 2839)

Pennings (2000) further argues that although prima facie rights, such as granting autonomy to children, are binding and obligatory, they can be overridden by competing prima facie rights. He considers the
right to privacy and the autonomy of parents and semen provider to be such competing rights. However, such a premise fails to acknowledge the power imbalance: the parents and semen provider are active decision-makers in the process of DI, whereas children are forced to live with the consequences of these decisions. Their rights would not enjoy paramount interest, but they would be at the mercy of the adult parties. If autonomy was viewed to be a guiding principle, it should also be this party who should be consulted. Given they cannot be consulted, as the decision is taken prior to their birth, they may be the most vulnerable party in this respect. Therefore, utmost care should be applied in preserving their autonomy.

The meanings of information sharing for the family and those conceived by DI

As a result of the secrecy surrounding DI, research and surveys on the experiences of families and offspring conceived to heterosexual couples to date is limited. Nachtigall, Pitcher, Tschann, Becker and Szkupinski Quiroga (1997) examined disclosure attitudes and family relations after DI. Although they found no differences between parents who had disclosed and those who had not, with respect to parental warmth, fostering of child independence, strictness or aggravation, they noted a relationship between perceived stigma and the father’s warmth and fostering of independence:

[P]erceptions of stigma may affect the father-child relationship adversely. It is possible that fathers who feel greater overall stigma may psychologically distance themselves from their DI offspring or have concerns about stigma affecting their child that differ in degree from the mother’s concerns. Because the perception of stigma may result in efforts to manage or to control the stigma through various social and psychological mechanisms, the child’s independence could be viewed as a threat to privacy or confidentiality. This in turn could translate into parental efforts at stigma control, resulting in practices that curtail the child’s autonomy. (Nachtigall et al., 1997, pp. 88-89)

Lycett, Daniels, Curson, Chir and Golombok (2004) compared child adjustment and family relationships in 46 English families created by DI. The 48 children in these families had a mean age of 6.6 years. Twenty-eight of the parents had decided on or tended towards nondisclosure, 18 had already or planned to talk to their children about their conception by DI. As in previous research, the development of children was found to be uneventful in both groups. However, the authors noted that parent-child relationships in
the families favouring disclosure were more positive than in families favouring secrecy, and they reported fewer difficulties among the disclosers than among nondisclosers:

Mothers who were inclined towards disclosure reported less frequent, and less severe, arguments with their children. They also considered their children to show a lower level of conduct problems and to be less of a strain. In addition, disclosers viewed themselves as more competent parents than their nondisclosing counterparts did. (Lycett et al., 2004, p. 177)

There was no difference in the father-child relationship in these two groups. The authors suggest two interpretations of these findings. Disclosure might have had a greater impact on the mother-child relationship where mothers may have adopted a more relaxed approach to parenting. Also, the number of children exhibiting behavioural problems may have been higher in nondisclosure families. This is also the first study to examine the reasons for parental refusal in participation. As previously speculated (Golombok, Cook, Bish & Murray 1995), a large proportion of parents who declined to participate did so in order not to jeopardise the secrecy about their children’s conception. The results of Golombok et al.’s (1995) study and the one conducted by Nachtigall et al. (1997) suggest that both the stigma and the secret may impact subtly and covertly on family relationships. The fear of stigmatisation may result in curtailing the child’s need for autonomy. Clinical experience of the author confirms such findings. For example, on several occasions, clients have suggested that they need to ensure that children conceived by DI would not study medicine, as otherwise there would be the danger that they find out about the genetic contribution from a third party.

The first survey investigating the experiences of offspring was conducted by Cordray (1999/2000), who, as noted earlier, was conceived with the assistance of DI, and is now an activist for information sharing. He reported data from about 36 offspring aged between 12 and 56 years, most of whom found out about their conception during adulthood. Almost all of those who learnt later in life suspected that there was a secret surrounding their connection with their father. Most also felt that they should have received this information earlier and remembered that others had known about their conception before they were informed. As Cordray (1999/2000, p. 5) explains:
... we feel that information about our genetic history, our genealogy, and the identity of our donor is our right. It is not necessary to protect us from the truth. DI is not merely a medical technology that helps to create viable pregnancy for infertile people. It has lifetime effects on the children conceived. ... We are primarily concerned about our autonomy as adults who view access to information about our identity as our fundamental civil right.

Turner and Coyle (2000) investigated the experiences of 18 people who, similarly to those in Cordray's survey, were recruited through various international support networks. The youngest in this study was aged 16 years. All of them found out about their conception later in life and often under unfavourable circumstances. They reported feelings of mistrust, distinctiveness from the rest of the family, abandonment by the semen provider and professionals who had recommended secrecy, as well as loss and frustration regarding the unobtainable information about their origins. The authors suggested that “these experiences could be postulated as being indicative of a struggle to assimilate, accommodate and evaluate information about their new identities as donor offspring” (Turner & Coyle, 2000, p. 2041). In 2002, the results of another investigation were published (Hewitt, 2002). Like Cordray, Hewitt was conceived with the assistance of DI and her interest in carrying out this project was to find out whether the identity issues she experienced were shared by others conceived by DI. She recruited 47 international participants aged between 12 and 59 years and reported similar findings to Cordray (1999/2000) and Turner and Coyle (2000). Many of the offspring in her survey felt confused about their identity, described feelings of helplessness as they could not access information, and in cases where they were informed late in life, anger towards professionals and parents. Hewitt argues:

... the act of disclosure has the opportunity to be either a positive of a negative experience. The younger the age at which disclosure took place, the more positive the experience was likely to be for the donor-conceived people and their parents. Donor-conceived people who were told about their conception at an ‘older’ age, that being above thirteen, quite often expressed a wish to have been told earlier. (Hewitt, 2002, p. 16)

Many of these offspring voiced curiosity about the semen provider; they wanted to have access to medical information, as well as knowledge about his physical appearance, family history and motivation to provide semen.

Limited data is also available on the experiences of Belgian children growing up in lesbian families. Vanfraussen, Ponjaert-Kristoffersen and Brewaey (2001) examined the views of 41 children aged between 7 and 17 years who were all informed about their origin at an early age. Approximately half the
children preferred information about their genitor, were curious about his physical appearance, and interested in his personality and his hobbies and occupation. Although some referred to him as their biological father, he was only their father in a biological sense and all children described their mothers to be the parents. The authors contend that “loyalty towards the mothers and especially towards the social mother may have prevented some of these children [who did not indicate interest] from admitting that they were interested in the donor” (Vanfraussen et al., 2001, p. 2023). Interestingly, more children than mothers favoured information and registration of non-identifying information about semen providers. The children were interested in their origins, whereas the mothers focussed on building a family; for them, the semen provider was merely a means to an end. Given that semen providers remain anonymous in Belgium, the authors argue for providing children conceived by DI with at least some hereditary information. Similar research for children growing up with single mothers has not yet been carried out.

The results of these studies must be interpreted with care. All use only small samples; in addition, the results of Cordray’s (1999/2000) survey, as well as Turner and Coyle’s (2000) and Hewitt’s (2002) studies, may be distorted because respondents were mainly recruited through support networks favouring disclosure and many were informed under unfavourable circumstances; there may well be a bias towards describing the effect of secrecy negatively or reporting the reactions to such unfavourable disclosure. Nevertheless, they tentatively confirm the view of family therapists that secrets can have a detrimental impact on family relations, and they also suggest that early disclosure can prevent a disruption of the identity process. More research with larger sample sizes is required to contribute towards a comprehensive understanding of information sharing both for the families as a whole and for the offspring.

Policy developments

Until the middle of last century, the practice of DI was largely treated as a private matter between the doctor and the patient (Blank, 1998). As a result, individual practitioners had great power in deciding which groups of patients were granted access to treatment, which recruitment methods for semen providers were applied, and how long records were maintained. In a sense, until then, DI was located in
the arena of private ordering, or, using social work terminology, a “private trouble” (Mills, 1963), in which governments and legislation, responsible for policy development or “public issues” did not intervene.

Blank (1990; 1998) outlines the several stages in policy development regarding DI. An individual clinician’s standards of practice can provide guidance for programme guidelines, which can be developed into professional or association guidelines, and, in turn, can lead to regulatory models. Professional guidelines are valuable and provide some control over the practice of DI; they also offer flexibility, as they can be adapted to changing technologies or social values more easily than legislation. At the same time, they lack legal authority to ensure compliance. Blank (1998, pp. 134-135) notes furthermore that “although lack of compliance with voluntary guidelines by nonmember businesses carries some risk, in the emerging highly lucrative commercial fertility industry, such guidelines might, in themselves, not be a strong enough form of self-enforcement or policing of such activities”. This has led a number of countries to set up further regulatory mechanisms, such as commissions, government guidelines, licensing authorities and legislation. In these countries, the use of DI has moved from the individual practitioner’s model into the public arena. These countries include Austria, Canada, Great Britain, The Netherlands, New Zealand, Sweden, Switzerland and Victoria/Australia.

Although the above countries have all introduced legislation in favour of DI and many countries do not prohibit this way of building a family, it must also be recognised that it is forbidden in some (Blank, 1990). It must also be taken into account that the introduction of legislation does not automatically result in endorsing third party reproduction. This was exemplified when Italy enacted its law on medically assisted reproduction in February 2004 (Norme in materia di procreazione medicalmente assistita, 2004). Until then, Italy was the only country of the European Union that had no legislation in the area of AHR. This law banned any form of third party reproduction, not least because of the influence of the Vatican. Boggio (2005, p. 5) claims that this “raised, rather than solved the debate over complex and difficult issues” and expects that debates around several issues, including sperm and egg donation, to reopen in 2005.

15 According to Blank (1990), DI is prohibited in Brazil, Egypt and Libya. Due to the lack of publications, it could not be ascertained whether this is still the case.
The following will outline the situation in countries which have been at the forefront of legislative development, have enacted legislation regulating access to treatment, clarifying paternity following DI, documentation, access to information about the semen provider and the provision of counselling, and where there is knowledge about how these legal provisions have been put into practice. These include Sweden, Great Britain, Victoria/Australia, Canada and New Zealand. Austria (Fortpflanzungsmedizingesetz, 1992), The Netherlands (Wet Donorgegevens Kunstmatige Bevruchting, 2002) and Switzerland (Fortpflanzungsmedizingesetz, 1998) are excluded, as there is no indication as to how legislation has impacted on the provision of DI treatment. As can be seen, there has been a wide range of responses from jurisdictions on family building with the assistance of DI.

**Sweden**

Sweden was the first country in the world to introduce legislation according to which offspring have the right to access identifiable information about semen providers. In 1985, the Swedish insemination act (Lag om Insemination, 1985) came into force. This granted only heterosexual married or de-facto couples access to treatment after the male partner had consented to the use of DI. Legal paternity is conceded to the husband or partner of the mother. Doctors are required to maintain records with identifiable information about the semen provider for a minimum of 70 years, and offspring have the right to access this information upon reaching maturity, an age which was not defined in the Act. There is no provision for pre-treatment counselling, but the Act stipulates that doctors must ensure that "the medical, psychological and social circumstances of the patients are such that an insemination can be carried out" (Lag om Insemination, 1985, Para. 3). The Act does not regulate the legal status of a co-mother in a lesbian family for those who have undergone treatment abroad, suggesting that this family formation is not desirable in Sweden.

At the time of introduction, gynaecologists strongly criticised the legislation. They contended that the Act was based on:
... a non-confirmed hypothesis regarding the children’s need for knowledge of their biological origin. Moreover they criticized the recommended psychosocial investigation of healthy women prior to insemination and characterized it as unnecessary and humiliating. They called the new legislation a ‘feelingless terrorism’. (Daniels & Lalos, 1995, p. 1871)

Furthermore, there was evidence that the number of children conceived by DI and born between 1983 and 1988/89, and the number of semen providers recruited at that time dropped dramatically and that many couples sought treatment in neighbouring countries (Daniels & Lalos, 1995). Gynaecologists put forward the idea that both couples and semen providers were unwilling to continue under this new legislation, but Daniels and Lalos (1995) argue that it might have been the gynaecologists who were no longer willing to provide treatment under this new legislation. Daniels and Lalos (1995) also provide data regarding the number of semen providers; this indicates that after 1989 (the first year such numbers were ascertained in Sweden) the number rose steadily from 69 to 106 in 1993. Back and Snowdon (1988) note that the type of men who provided semen also changed. Whereas prior to the Act, most semen providers seemed to be students, after the new legislation was introduced, they were mainly older and married men. A study conducted by Daniels, Ericsson and Bum (1998) corroborated this. They confirmed that semen providers tended to be older men with an average age of 37 years, had previously fathered children, had had contact with people experiencing infertility, and provided semen out of a desire to help such couples. The authors also ascertained their attitudes regarding anonymity versus identifiability, noting that although “a considerable number of them (44%) thought that they had or should have the right to remain anonymous … this figure is considerably lower than the percentages of donors answering similar questions in studies in other countries”, such as Belgium or Great Britain (Daniels et al., 1998, p. 127).

There is no data available to determine if and how doctors assess parental suitability required by the new Act. Gottlieb, Lalos and Lindblad (2000) indicate that all of the 148 parents examined in their study had received pre-treatment counselling encouraging openness, but the exact nature of this counselling was not explained. They found the Act to have only limited impact on parental decision-making about information sharing as “only 52% of the parents had told or intended to tell their child” (Gottlieb et al., 2000, p. 2052). They explain that “legislation alone is not sufficient to change personal attitudes in a population. We believe that stimulating ethical discussions within the responsible professional groups is of major importance as a complementary measure” (Gottlieb et al., 2000, p. 2055).
Great Britain

In 1990, the Human Fertilisation and Embryology Act (HFEA, 1990) was introduced in Great Britain, regulating a wide range of AHR treatments, including DI, oocyte and embryo donation, as well as surrogacy for heterosexual and lesbian couples, and for single women. All infertility clinics providing these types of treatments are required to be licensed by the Human Fertilisation and Embryology Authority (HFEA), the statutory regulatory body established as a result of the Act. So-called “do-it-yourself” practices, such as self-inseminations often practised by lesbians (Saffron, 1994), were not prohibited and continue to be practised yet operated outside the regulatory framework. According to the Act, consent of the woman’s partner to DI results in his ability to enjoy full legal paternity. However, in those cases where DI is practised outside the legal framework, semen providers run the risk of being treated as the child’s legal father (Blyth, 2004b).

The Act provided for the anonymity of the semen provider to be preserved, but gathered non-identifiable information to be made available to offspring. Semen providers were asked to give information about their physical characteristics as well as their occupations and interests. In surveys of clinics, with regard to the quality and quantity of information clinics sought of the semen providers, Blyth and Hunt (1998) and Abdalla, Shenfield and Latarche (1998) pointed out that individual clinics varied both in what information and the amount of information they sought from semen providers. One of the key provisions of the Act was to carry out treatment only if the welfare of any child affected by this treatment is taken into account (HFEA 1990, Section 13/5). Commenting on developments since then, Blyth (2004b, p. 228) contends that “in practice, implementation of the welfare of the child requirement has been problematic”, as the meaning of the welfare of the child has not been agreed upon. Until recently, this was also reflected in the offspring’s right to access information about his or her genitor. Offspring intending to marry were able to ascertain whether the register provided any evidence of a genetic relationship to his or her intended spouse. In addition, an individual who had reached the age of 16 in Scotland, and the age of 18 elsewhere in Great Britain, was able to enquire whether the register showed that his or her birth resulted from DI (Blyth, 2004b); no explanation is given as to this difference in age.

There is an active network of offspring of DI and of other forms of gamete donation and their parents (Donor Conception Network), which for many years has been advocating for greater access to
information and for lifting the anonymity of semen providers (Donor Conception Network, 2001; Gollancz, 2001; Hunter, Salter-Ling & Glover, 2000; Whipp, 1998). As noted earlier, a woman conceived by DI and the mother of a child conceived by DI filed a court case to obtain information about her own and her child’s genetic origin (Rose v Secretary of State, 2002). While the case was adjourned pending government consultations, the judge stated that this was, in his view, an essential aspect of their identity and private life supported and protected by the European Convention on Human Rights (Blyth, 2004b).

Several months after this case went before the court, the UN Committee on the Rights of the Child expressed the concern that:

... children ... born in the context of a medically assisted fertilization do not have the right to know the identity of their biological parents. In the light of articles 3 and 7 of the Convention, the Committee recommends that the State party take all necessary measures to allow all children, irrespective of the circumstances of their birth, and adopted children to obtain information on the identity of their parents, to the extent possible. (United Nations Committee on the Rights of the Child, 2002, Paras. 31-32).

The government acknowledged these arguments but decided to defer a decision (Blyth, 2004b). Despite similar fears expressed in Sweden regarding the decline in semen provider, in April 2005, legislation was changed, not least as a result of the above court case. Children born after this date can now access identifiable information about their biological origins (HFEA, 2004).

The 1990 Act placed great importance on counselling. In order to define the nature and role of counselling, the government commissioned a health research institution, the King’s Fund Centre, to issue a report on what counselling comprises (King’s Fund Centre Report, 1991). This Committee stipulated that four elements were integral to counselling: the welfare of the resulting child and any other child who may be affected; the needs of infertile people; the needs of prospective semen providers; and the desire for assurance that infertility services were carried out in a responsible way (Blyth, 1995b). As a result, the HFEA determined that counselling should include the following:
Implications counselling which aims to enable the person concerned to understand the implications of the proposed course of action for her/himself, for her/his family, and for any children born as a result;

Support counselling which aims to give emotional support at times of particular stress e.g. when there is a failure to achieve a pregnancy;

Therapeutic counselling which aims to help people cope with the consequences of infertility and treatment, and to help them to resolve the problems which these may cause. It includes helping people to adjust their expectations and to accept their situation. Therapeutic counselling may be provided within the centre or it may, more appropriately, be provided by an external agency. (Blyth, 1995b, p. 45)

Blyth (2004b), however, criticises this proposal as theoretical only. The Act merely stipulates that clinics must employ or make available a qualified counsellor to patients. Couples and individuals, on their part, are not required to take this up. Studies carried out in Great Britain (Boivin, Scanlan & Walker 1999; Kerr et al., 1999) indicate that the actual uptake of counselling is low, which Blyth (2004b) criticises as going against the intentions of the legislation. Furthermore, when the Act was introduced, there was “only a handful of infertility counsellors, who in the opinion of relevant professional bodies, possess[ed] the necessary experience and qualifications” to offer qualified infertility counselling in Great Britain; training programmes for infertility counselling only commenced at the end of the 1990s (Blyth, 2004b, p. 233).

**Victoria/Australia**

Federal Australian legislation enacted in 1975 recognised the social parents in a donor procedure as the legal parents. Thus, any legal relationship between the semen provider and the offspring was severed. This was followed in all Australian states, which, between 1984 and 1986, introduced similar, or amended existing legislation, to recognise the woman who gave birth to a child as the legal mother and her partner the father (Szoke, 2004). This provided the basis for legislative changes in Victoria. In 1984, a central register was established which recorded all births resulting from third party reproduction. In 1995, the *Infertility Treatment Act* came into force, enabling everybody conceived by third party reproduction to access identifiable information when they attained the age of 18 years. In 1995 and in 2001, registers were established for donor procedures which took place before and after 1988 respectively. Applicants are now able to exchange information on this register and can stipulate conditions under which information can be released. This open attitude was largely influenced by developments in the area of adoption, where legislation in 1984 provided access to information for adopted people. Though the number of semen providers decreased after 1988, this is not considered to be linked with waiving
anonymity but with the advent of ICSI and cryopreservation of semen (Szoke, 2004). Similar legislation has recently been introduced in Western Australia (Szoke, 2004).

The *Infertility Medical Procedures Bill*, enacted in 1988, prescribed mandatory pre-treatment counselling for everybody undergoing AHR, including recipients of DI and semen providers. Such counselling must be carried out by counsellors accredited by the Australian Reproductive Technology Accreditation Committee (RTAC). The RTAC was established by the Fertility Society of Australia (FSA), a professional body representing scientists, doctors, researchers, nurses, consumer groups, patients and counsellors in AHR both in Australia and New Zealand. It stipulates that pre-treatment counselling should be available for recipients and semen providers, and requires counsellors to hold a four-year tertiary qualification, be registered as a psychologist, social worker or psychiatrist, have a minimum of two-years, full-time-equivalent, post-graduate counselling experience, and be knowledgeable about infertility and infertility treatment (*Code of Practice for Centres using Assisted Reproductive Technologies*, 2002; Oke 2004). For recipients, counselling includes information on the legislation, psychological and ethical issues related to infertility and its treatment, and relationship issues for the family, such as the implications arising from using known semen providers and possible contact. With semen providers, counsellors are to explore their motivation, inform them of the offspring’s right to access their identity, and look into the impact of their donation with regard to their current or future family relationships (Blood, 2004). Furthermore, this code of practice has also resulted in infertility counsellors having become integrated members in infertility clinics. Despite this comprehensive legal framework and the pro-active attitude of the Victorian government, a survey published in 1998 indicates that most parents do not tell their children about their birth origins (Blood, 1998). More current data could not be ascertained.

**Canada**

Canada is claimed to have had a “long road to regulation” (Haase, 2004, p. 55). Debates were first initiated by the Royal Commission on New Reproductive Technologies in 1989, and included the impact of reproductive technology on society as a whole and on individuals, the issue of commercialisation, as well as the rights of offspring conceived by DI to access their biological origins (Haase, 2004; Manseau, 2004). Legislation was finally enacted in 2004 (*Statutes of Canada, Bill C-6, 2004*). As in Great Britain,
all individuals, independent of marital status and sexual orientation are granted access to AHR, as it would be considered illegal to discriminate under the Canadian Charter of Rights and Freedom (1982). Haase (2004) notes that although most clinics offer services to single and lesbian women, there is anecdotal evidence that these groups are denied treatment by individual doctors.

In Canada, legal parentage issues fall under provincial or territorial jurisdiction and this has not changed since the enactment of AHR legislation. Although a federal commission recommended clarifying the issue of paternity after DI, as well as the legal status of others involved in gamete donation already in place in 1993, few provinces or territories introduced such legislation (Haase, 2004). In the case of gamete donation, only Quebec and the Yukon have legislation defining the rights and responsibilities of recipients and semen providers, but in Quebec, similarly to Great Britain, legislation does not cover informal arrangements. Haase (2004, p. 62) argues that the “omission of status legislation in most provinces is significant ... [as] it is a necessary protection for donors in arguments endorsing the continuation of donor anonymity”.

According to the recently introduced legislation, a licensing authority, the Assisted Human Reproduction Agency of Canada, similar to the HFEA in Great Britain, is to be established, but this has not yet occurred (Haase, personal communication, April 11, 2005). The Agency is to “maintain a personal health information registry containing health information about donors of human reproductive material ... and persons conceived by means of those procedures” (Statutes of Canada, Bill C-2, 2004, Para. 17). On request, offspring can access “information relating to a donor of human reproductive material ... but the identity of the donor ... shall not be disclosed without the donor’s written consent” (Statutes of Canada, Bill C-2, 2004, Para. 18.3). This represents the double-track policy suggested by Pennings (1997), according to which the semen provider has the right to decide whether he is willing to be identifiable or anonymous, and the recipients can select a semen provider according to their preference; the offspring in cases where parents have selected an anonymous semen provider do not have the option of accessing information about their genitor. Similarly to the situation in Great Britain, offspring who have reason to believe that they were conceived from the same semen provider, can contact the Agency, which is to disclose whether this is the case. There is no provision regarding the preservation of old records some doctors kept prior to the introduction of the new Act (Haase, personal communication, April 11, 2005).
The Act also stipulates that counselling must not only be made available to everybody involved in third party reproduction prior to treatment, including semen providers, but that clinics are to ensure that the person receives it. In 2004, Health Canada conducted a workshop in order to promote a debate about infertility counselling in Canada (Assisted Human Reproduction Implementation Office, 2004). During this workshop, objectives of and qualifications for infertility counselling were discussed, and the Canadian Infertility Counselling Association (CICA) was founded. In 1999, Haase commented that specialised counselling for infertility was limited; it remains to be seen whether the foundation of CICA will initiate change in this area.

New Zealand

New Zealand differs from many other countries in that DI (as well as other forms of third party reproduction) has enjoyed more social acceptance and a larger degree of openness. This accepting attitude has been influenced by several factors. For Maori, the indigenous people of New Zealand, genealogy is an important concept. According to Maori values and norms, *whakapapa* which is “the mechanism by which individual whānau [family] members establish ascent to an eponymous ancestor” (Daniels, 2004b, p. 149), plays a central role. In 1993, a committee was formed to advise the government on developments in the area of AHR, which:

emphasized the vulnerability of AHR offspring when decisions are made about issues such as access to genetic information. ... [A] further guiding principle was the requirement to uphold the Treaty of Waitangi, the 1840 document incorporating partnership between the indigenous people of New Zealand ..., and the Crown. ... As the Committee describe it, in essence this guiding principle means that, ‘developments in AHR must recognise and protect the rights and responsibilities of the Treaty partners’ i.e. of both Maori and non-Maori. Further, they held the ‘right to know one’s genetic origins as a basic principle. ... In addition, as the reports states, knowledge of *whakapapa* is a Treaty right which not only links individuals to tribal lands but also is the basis for such constitutional rights as voting on the Maori electoral roll. Maori currently constitute approximately 13% of the population, but their impact, especially in terms of the Treaty, is much more significant than that figure might indicate. (Daniels & Lewis, 1996, p. 60)

In addition, debates regarding openness in adoption following the introduction of the *Adult Adoption Information Act* (1985) contributed to more openness in the area of DI (Daniels & Lewis, 1996). Also, since the 1980s, when the first literature on the psychosocial issues of DI appeared, there has been a
strong call for openness (Daniels, 2004b). It was especially the involvement of social workers applying a biopsychosocial perspective to AHR, that increased the understanding of the needs of the children and their families, as well as the long-term implications of DI (Daniels, 2004b). Last but not least, in 1993, a National Ethics Committee was established; one of the Committee’s tasks was to ensure that the rights of the people, especially children, involved in AHR, are protected (Daniels, 2004b).

Similarly to Australia, infertility treatment in New Zealand, with and without donated gametes, is open for anybody, irrespective of sexual orientation or marital status (Daniels, 2004b). Although legislation regulating AHR has only recently been introduced (Human Assisted Reproduction Technology Act, [HART] 2005), legislation regarding the legal rights and responsibilities of the parties involved in DI has been in place since 1987. The Status of Children Amendment Act (1987) stipulated that the couple treated would be the legal parents of the child, while it protected the semen provider from legal responsibilities towards offspring conceived with his semen, thus protecting him from the threat of being sued for alimony or inheritance demands (Daniels & Lewis, 1996).

According to Daniels (2004b), clinics have recruited identifiable semen providers for the last ten years. Offspring can access information about the semen provider via the clinic, and clinics are prepared to trace and establish contact with semen providers on behalf of offspring, even if they were recruited under the promise of anonymity. In addition, the recent legislation also provides for the establishment of a voluntary register, such as that in Victoria/Australia.

New Zealand infertility clinics have voluntarily sought accreditation by the Australian Reproductive Accreditation Committee (RTAC); this has resulted in counselling being carried out both with recipients and semen providers on a regular basis (Daniels, 2004b). It is likely that this social acceptance and the legal certainties for parents and semen providers have resulted in the high number of parents favouring disclosure (Rumball & Adair, 1999).
Summary

This chapter has provided an overview of historical and current factors influencing the practice of information sharing. When in the middle of last century, first comments were made and then reports were published about family building by DI, the secrecy surrounding DI stemmed to a large degree from its morally questionable nature. DI was not only associated with adultery and illegitimacy, but its use would have also revealed male infertility, a highly stigmatising condition. All actors involved in DI had reasons for adhering to secrecy. Parents feared stigmatisation for themselves, especially for the male partner, and for their children. In addition, the fathers feared rejection by the children, should they learn about their biological origin. Doctors also saw a need to protect their public image, while semen providers risked legal liability towards the child if their contribution became known. Last but not least, in contrast to adoption, DI was easy to conceal, as the woman carried out an apparently usual pregnancy and gave birth to a child.

Beginning in the 1980s, writers from various professional backgrounds have highlighted a multitude of reasons supporting disclosure. Secrecy was considered to be detrimental to the well-being of families and children, and access to information was viewed as vital in order to make informed decisions about medical issues and adjust to genetic conditions. Although the question of whether offspring should be regarded as having a legal right to information about their heritage has remained controversial, several jurisdictions worldwide have enacted legislation providing such access. From an ethical perspective, writers have argued that anonymity and secrecy violate the principle of autonomy and justice, especially when comparing offspring conceived by DI to adopted people who are universally granted the right to know the identity of their birth parents.

Research indicates that disclosure rates until the end of the last century were relatively consistent, with only a few parents telling their children about their DI conception. Parents gave similar reasons for secrecy as those voiced by professionals. Over the last few years, an increasing number of parents have favoured disclosing their use of DI. These parents contend that children have a right to know of their origins, they also want to avoid accidental disclosure and do not want to live with the burden imposed by the secret. They also feel that children should have access to information about their genitor, particularly in the case of medical problems. As a result of the secrecy, only a few studies have been carried out
investigating the experiences of offspring. These suggest that disclosure late in life or under unfavourable circumstances can impact negatively on the development of identity. Offspring also voiced mistrust towards their parents and felt frustrated because of the lack of information available on their biological origins. Those who were advised about their DI origins at an early age did not indicate any negative reactions but were curious about the semen provider; some identified him as an important person for them, but did not attribute a parental role to him.

As a result of the controversies regarding DI, it is not surprising that only a few countries have introduced legislation clarifying the rights and responsibilities of those involved in DI. Several countries have been at the forefront of this legislative development for a variety of reasons. In 1985, Sweden was the first country in the world to introduce legislation, granting offspring the right to identifiable information about the semen provider. In Great Britain, legislation was introduced in 1990 and a licensing authority was made responsible for record keeping; however, offspring could only access non-identifiable information. After controversial debates at the beginning of the new millennium, and a court case in 2002 where offspring fought for the right to access complete information, in 2005, new legislation was introduced. All children born after this change can access identifiable information about the semen provider.

Victoria/Australia is said to have the most comprehensive legislative framework. In addition to having granted offspring access to information about the semen provider since 1995, the Victorian Infertility Treatment Authority has established a voluntary register for those born prior to this date. Developments in Canada contrast those in Victoria/Australian. AHR legislation was introduced in 2004, and Canada is currently the only country in which legislation provides for semen providers to decide whether they wish to be identifiable. New Zealand introduced AHR legislation only this year (HART, 2005). Clinics, however, have been supportive of offspring establishing contact with the semen provider for the last 10 years. The involvement of counsellors, recognition of Maori culture, which places high value on ancestry, and previous legislation clarifying paternity after DI have resulted in greater social acceptance for this family building alternative than in many other countries.

This suggests that policies in several countries have been undergoing major changes, and it is likely that more countries will, over the next few years, start debating regulations in this area. At the same time, it
has to be recognised that several countries, such as France (Bateman Novaes, 1998) and Poland (Bielawska-Batorowicz, 2004), still adhere to strict anonymity, arguing that this provides the best protection and stability for a family created by DI, and that third party reproduction remains banned as it is considered morally offensive (Boggio, 2005). In contrast to the middle of the last century, however, policies now seem to be in a transitional phase. Change is occurring, not the least because it is initiated by parents and offspring who are supportive of disclosure.
Chapter 5
Towards a theoretical understanding of parental information management in families built with the assistance of DI

This chapter will examine theories that contribute to the understanding of parental decision-making. It will outline theory development in social work, the influence of systems theory and the biopsychosocial model developed by Engel. Theories of social stigmatisation, including Goffman's influential work, will be used to draw attention to the function, impact and alleviation of stigmatisation.

A social work perspective of theory building

"There is nothing more practical than a good theory". Einstein’s phrase sums up the value and usefulness of theory and theory development. Theories are based on experience and knowledge on a high level of abstraction, they serve to explain realities and can be drawn on to make accurate predictions in order to enable action-planning (Müller, 1997b). Models, which often precede theory building, are a simplified symbolic representation of a system (Fröhlich & Drever, 1981); the use of a specific perspective refers to a particular point of view, or paradigm from which to make sense of or categorise an experience (Wikipedia, 2004). These various levels of theory building will be used in this chapter to delineate notions that can contribute to an understanding of parental decision-making in DI.

With regard to theory development in social work, two opposing views have emerged in the last few years. Some scholars display a deficit-oriented view and decry the patchy and incomplete development of theory in this field. Mühlum (1997), for example, suggests that there are many diverse concepts and theoretical approaches of various profundities, but argues that there is a lack of a comprehensive scientific theory for social work. Others prefer a strengths-based perspective and comment positively on the ability
of social work to pull together theories developed in other scientific areas. Payne (1997, p. 26) describes "social work practice theories" in his book, *Modern Social Work Theories*, and, similarly to Fröhlich and Drever (1981), refers to various levels of theory building in social work, such as models, approaches or perspectives, and explanatory theories. The practice theories he describes are theories that are applied by social work but originate in other disciplines, such as psychology and sociology. He explains that social work:

... is part of a network of occupations working in a territory or social space concerned with interpersonal and social action. These occupations, such as counselling, nursing, development work, teaching, police work and medicine, have social roles, theories, social, legal and political contexts for their practice, systems of professional organisation and education which may overlap but which also have distinctive features. ... Therefore, related professions are likely to share some aspects of their theoretical base. For each, this may be strengthening. ... The availability of a range of theoretical perspectives in social work enables appropriately trained workers to work in agencies using specialised techniques, and this helps the penetration of the profession into various settings from which it might otherwise be excluded. (Payne, 1997, p. 289)

The strengths-based perspective will also be reflected in this thesis. It will draw on theories from related social science areas and analyse how they contribute to explaining parental decision-making in family building using DI. In Chapter 8 these theories and perspectives will also be considered in the light of the results obtained from the research conducted for this study and tested against the knowledge currently available.

From its beginnings, social work practice has been concerned with providing help and welfare for the poor and needy. This is also reflected in what is considered to be one of the first social work documents. In 1525, Vives submitted his paper *De Subventione Pauperum* (On Supporting the Poor) to the municipality of Brugge/Belgium. The paper "seemed to be popular and was even translated into French and Spanish" (Engelke, 2003, p. 391). At the end of the 19th and the beginning of the 20th century, social workers primarily attempted to counter the socially devastating situation resulting from industrialisation in larger town and cities. At these stages in the professional development of social work, the interrelatedness between individual misery and environmental factors received great attention. Social workers pointed out that deprivation was not only caused by individual or personal factors, but also by social and environmental factors which played a major role. In the 1930s, influenced by developments in psychiatry and psychology, an increasing number of social workers considered psychoanalysis an
efficient scientific theory. Under this influence, the focus shifted from a psychosocial perspective towards a perspective concentrating on the psychological problems of individuals, neglecting the significance of environmental factors (Bock, 1997). Approximately twenty years later, social science theories, and especially systems theory, led to a "rediscovery of the 'social' in social work" (Engelke, 2003, p. 414). These theories also contributed to a greater appreciation of contextual forces and the interrelatedness between people and their social context (Bock, 1997; Engelke, 2003). More recently, constructivism and social construction perspectives have influenced social work theories. Constructivists hold the belief that there is no objective reality apart from the individual's view of it, arguing that "no one view of reality can comprehensively cover what a worker needs to know" (Payne, 1997, p. 31). Social construction emphasises the significance of the social aspects and the influence of cultural, historical, political and economic conditions:

Construcktionist and postmodern ideas ... say ... people understand things by conforming with socially agreed representations of the world which we accept as reality. The constructionist asks who makes the agreement and how it comes about. Many postmodernist and related sets of ideas further emphasise power relations expressed in language which cause ideas about the world to be more or less powerful with particular groups or individuals. (Payne, 1997, pp. 31-32)

The above discussion sets the scene for a consideration of family building with the assistance of DI as an emerging area that has been the subject of limited research to date. This is an evolving area. Given social work's orientation towards private troubles and public issues, analysing the factors influencing parental decision-making regarding information sharing is seen to involve both individual aspects and contextual forces. This thesis will examine parental decision-making using a systems perspective. This perspective allows light to be shed on the micro issues (intrapersonal and family) as relevant factors. It puts equal weight on the immediate meso issues (significant others and professionals involved in treatment), and the larger macro environmental issues (e.g. culture and social policy), and makes it possible to examine interdependencies between these three subsystems. Systems theory is particularly helpful when analysing the micro, meso and macro factors in combination as it demonstrates how each subsystem needs to be understood to enable an understanding of the whole.

16 There seems to be some disagreement on the time when the ideas of the systems theory started to influence social work. Some authors comment that this began in the 1950s (Engelke, 2003) while others point out that this did not occur until the 1970s (Bock, 1997).
In the area of medicine, Engel (1977) developed the biopsychosocial model in order to draw attention to the need to understand not only physical manifestations of diseases, but also the impact of psychological aspects and the social context on the well-being of individuals. Though not used extensively or explicitly amongst non-medical scholars in the area of infertility and family building by DI, this model serves as a means of raising the awareness of and the need for understanding the psychosocial issues individuals and couples experience when suffering from infertility and considering DI. As neither the systems theory nor the biopsychosocial model contribute towards explaining the origin of the phenomenon, other theories have to be drawn upon in order to analyse the reasons for parental management of information sharing.

Social stigmatisation theory, which several scholars have applied to understanding an individual’s reactions both to infertility and family building using DI, is referred to in order to analyse social interaction and understand reasons for parental decisions (See Chapter 1, p. 14 regarding the stigma of infertility and Chapter 2, pp. 24-27 regarding the stigma of family compositions including social ties). Used in the context of a new and emerging field, such as family formation by DI, stigma theory was deemed to serve best in explaining how individuals perceive themselves, how they assume they are perceived by others, and how these perceptions impact on the way they feel in and manage situations.

**Systems theory and its influence on social work**

The origin of systems theory goes back to the General Systems Theory (GST) developed by von Bertalanffi (1968), a biologist, who, according to Payne (1997, p. 137), proposed that:

\[
\text{... all organisms are systems, composed of sub-systems and are in turn part of super-systems. Thus, a human being is part of a society and is made up of, for example, circulation systems, cells, and these are in turn made up of atoms which are made up of smaller particles.}
\]

Though originally formulated in the 1930s as the organismic systems theory, von Bertalanffi (1968) introduced the GST as a meta-theory and a new paradigm to control model construction in all sciences; he also applied it to social systems. One of the major advantages of the GST is its shift away from linear and reductionist models and its focus on complexity and interdependence within and between categories. Its principles have been applied in many different fields, including sociology (Luhmann, 1994), psychology
(within family systems therapy; Simon et al., 1999) and, as described above, social work. However, especially in social science areas, systems theory, as it is now referred to, tends to have the character of a general model more than a theory (Steinert, 1997), or perhaps a perspective, as it provides a point of view that analyses or understands interaction processes within and between social systems, but fails to explain realities or to enable action-planning. For the sake of comprehensibility and consistency with the literature, I will continue to refer to "systems theory" whenever a systems understanding or approach is described.

The main concepts of systems theory are:

- Differentiation: As systems grow larger and more complex, they form subsystems. Family therapists, for example, refer to the parental subsystem of mother and father and the subsystem of the children;
- Homeostasis or equilibrium: Systems can maintain their fundamental nature despite input from outside. A person, for example, remains him- or herself, despite the education they undergo or the knowledge they accumulate;
- Open versus closed systems: All systems and subsystems have boundaries. In open systems, energy is exchanged across the boundary of a system; a closed system does not have any interchange across boundaries. Families can be referred to as having open or rigid boundaries, depending on how easily they accept energy from the outside, for example, in the form of communication;
- Energy: Every system requires energy both that which comes from within as well as that which comes from without these boundaries so that it can flourish. Systems which do not accept energy from the outside and do not have sufficient energy from within experience difficulties sustaining themselves;
- Non-summativity and synergy: Non-summativity contends that the whole is more than the sum of its parts. This means that newly developed systems have a different quality and interact differently from the individual subsystems they are comprised of. Synergy refers to social systems creating their own energy to maintain themselves, for example, groups in which individuals create bonds that strengthen group cohesion. Without this synergetic effect, systems
would require outside energy, as otherwise entropy (a lack of coherent organisation) would occur;

- Reciprocity: If one part in a system changes, all other parts are affected by this change and required to adapt. This can also be observed in families. If one family member changes behaviour, all other family members are required to adapt to this change;

- Equifinality and multifinality: Based on the premise that systems can only be permeated but not instructed, both equifinality (reaching the same result in different ways) and multifinality (similar circumstances leading to different results) can occur. (Payne, 1997; Simon et al., 1999; Steinert, 1997)

According to Payne (1997), Pincus and Minahan’s (1973) change model is considered one of the most widely used conceptualisations relating systems concepts to social work. Pincus and Minahan argue that to lead a satisfactory life, people depend on systems, such as the natural system of family and friends, formal systems of community groups, and societal systems, such as hospitals and schools, in their social environment. Social work must therefore focus on these systems. Though often not explicit, many typical understandings of social work indicate that they are based on such a systems approach. As early as 1963, social work was said to be concerned with the interrelatedness between private troubles and public issues (Mills, 1963). It has also been described as being based on understanding the interaction between individuals and their environment (Bock, 1997), or considering clients and their context (Payne, 1997).

Other scholars refer to “the social system [as] a special order of system” composed of persons or group of persons who interact and mutually influence each other’s behaviour (Anderson & Carter, 1999, p. 4).

Based on the systems theory, Germain and Gitterman (1980) developed a more expansive ecological model for social work practice. Their approach, known as the life model, is widely used in various fields of social work practice (Bock, 1997; Compton & Galaway, 1999; Engelke, 2003; Payne, 1997). Compton and Galaway (1999, p. 34), using the concept of “person-in-situation” as an interchangeable notion for considering the relationship between person and environment, summarise the life model and explain:

In discussing the person-in-situation, we will be looking at environmental demands, internal demands, environmental supports, and individuals’ coping or adaptive abilities. A problem exists when there is not a good fit between the individual’s coping ability and the demands of the environment or between what an individual wants and desires and the supports of the environment. Germain and Gitterman ... suggest that these problems in
living may occur at times of life transitions, because of maladaptive interpersonal processes relating to the individual's coping ability and because of either excessive demands or inadequate supports from the environment. ... Change efforts might be directed toward eliminating environmental sources of stress, alleviating or reducing the stress by reducing environmental demands, increasing the supports available from the environment, or strengthening the individual's coping ability.

With regard to the environment, Compton and Galaway (1999) emphasise that this includes the different levels of the social environment, such as the individual and the family on the micro level; the group, the community and class on the meso level; the culture and culturally supported ways and opportunities to seek meanings in life on the macro level. All of these different levels are considered to influence the individual construction of meanings and choices, and in return, every individual influences the environment through these meanings. Although in social work education and practice, as Anderson and Carter (1999, p. 4) argue, a "duality has emerged as [a result of] the historical distinction between 'casework' and 'community work' ", they also acknowledge that social systems, as any other system, are not linear and, therefore, "causation is multidirectional, multiple, and mutual" (Anderson & Carter, 1999, p. 16).

As with any theory, systems theory has been challenged by some writers. It has been described as expository only and failing to explain why things happen and why connections exist. In the area of social work, it falls short of telling workers which interventions to use (this refers to the concept of equifinality) and it may be over-inclusive, as it does not differentiate sufficiently between relevant and irrelevant issues (Payne, 1997). One of the major criticisms, however, is its neutral and value-free perspective. Steinert (1997) argues that systems theory raises only the formal question of how a system may function or may function best, but does not succeed in questioning who profits and who has to pay the costs in order to maintain any given balance in a system. This highlights the fact that systems theory is a theory for understanding rather than a theory devising interventions. Payne (1997) therefore points out the need to look both at philosophical issues, such as understanding the nature of social work tasks, and at the same time focus on the changes required and what contributions social work can make to such changes.

However, despite these criticisms, social work has embraced the systems perspective as it offers an inclusive understanding of:
... how the public and the private interact, how various change agents might be involved and that workers and their agencies might themselves be targets for change. Together, these sets of ideas enable workers to manage the stress of emotional pressure from their interpersonal work by seeing it in a wider social context. (Payne, 1997, p. 141)

This is also reflected in a recent statement about social work in Germany and the definition of the International Federation of Social Workers which both draw on the systems perspective to describe social work:

Individual and social existence is always subject to challenges .... Social work therefore has the theoretical and practical task to ... analyse origins, connections and to develop solutions for problem solving which aim both at individual improvement of coping behaviour and the ecological context. (Mühlum, 1997, pp. 955-956)

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. (International Federation of Social Workers, 2004)

The biopsychosocial model and sociological perspectives

The biopsychosocial model of medicine was proposed by Engel, an American psychiatrist, who characterises the previously used biomedical model as “mechanistic and reductionist” (Engel, 1977, p. 134). He strongly advocates taking into account the human factors when diagnosing and treating patients. Based on the GST, the biopsychosocial model treats the relevant biological, psychological and social issues in a disease with a systems understanding, thus recognising that biological symptoms are interrelated to a patient’s psychological state, such as his belief about an illness, and the social factors in his life, such as his relationship with his family and others. This interrelationship is illustrated in Figure 5.1.
In medicine, the development of this model indicated a paradigmatic shift away from the dominant biomedical understanding towards a holistic and humanistic understanding. Engel stressed the importance of understanding a patient’s individual perception of their illness in addition to understanding the physical aspects of medically definable diseases. In order to achieve such an understanding, Engel emphasised the importance of communication: he encouraged patients to give as much information as possible, not only about the bodily symptoms, but also about the way the illness affected their individual psychological well-being and their relationship with others.

Though the biopsychosocial model has received some attention (Schmid Mast, 2004), it is not widely accepted in medicine. A recent survey of medical schools in the United States indicated that its popularity has decreased, and therefore the authors spoke out for a more active recognition of the model in teaching curricula:

Further incorporation of psychosomatic medicine in US medical school curricula is critical to the continued transition of the medical field from a traditional biomedical model towards a biopsychosocial model with an increased emphasis on prevention and holistic evaluation and treatment of individuals. (Waldstein, Neumann, Douglas, Drossman & Novack, 2001, p. 342)
In psychiatry, the area in which Engel originally developed the biopsychosocial model, the shift to neuropsychiatry and recourse to biological approaches have also resulted in favouring a biomedical stance (Pilgrim, n. d.). This bears a similarity to the application of a biopsychosocial perspective in the area of infertility and the application of AHR. Both have historically been located within the medical discipline or, as Daniels (1986, p. 55) provocatively suggests, they were “under the control of the medical and scientific professions”. Individuals and couples suffering from infertility consulted a doctor who arrived at a diagnosis and carried out treatment with the aim of conception. Once pregnancy was achieved, the physical problem of infertility was overcome and the task of the doctor successfully completed. This biomedical understanding, however, has severe limitations. It focuses solely on one aspect of disease and its management: its physical manifestation. In the case of infertility, and particularly male infertility, most medical interventions do not cure but only circumvent the problem by bringing together oocytes and semen and thus facilitating conception. In the case of DI, male infertility or the lack of a male partner are bypassed by using the semen of a different fertile male to achieve conception. Despite pregnancy and the birth of a child, the male partner remains infertile. Although research into the understanding of psychological implications of infertility has received increasing attention over the last decade (Boivin, 2003; Greil, 1997), the explicit application of the biopsychosocial model, including the social aspects, has only been suggested by Daniels (2000), a social scientist with a professional background in social work.

From a sociological perspective, it is not only relevant to ask, “who gets sick and why”, but also to question how the experience of illnesses is socially constructed and how formal health care is provided in modern societies (McLeman, Ryan & Spoonley, 2004, p. 213). Sociologists and anthropologists have challenged so-called “medicalisation”, which refers to putting ordinary life issues, such as childbirth, into a medical frame of reference and perceiving it as an area of life requiring medical intervention. Several writers propose that this is occurring in family building using DI as well as in the general area of AHR. Explaining the historical connection between childbirth and reproduction, Bateman Novaes (1998, p. 106) contends:
It must be remembered that, at the end of the eighteenth century, the presence of a (male) physician at childbirth was still a rare event, exceptionally justified by their monopoly of a new instrument, the forceps, designed to facilitate difficult births. Thus the possibility of providing some form of technical assistance with reproductive processes, even if of an experimental nature, may have been perceived outright by physicians as sufficient to justify interfering in their patients' reproductive concerns.

While DI remained an exceptional response to male infertility, secrecy was considered the easiest way of avoiding the social and moral concerns and objections. Secrecy, however, also resulted in a lack of rigorous evaluation of this medical practice normally expected to be performed with new medical technologies. The advent of cryopreservation of semen and semen banking in the 1970s made it possible to receive semen from a provider at a different time from carrying out the insemination of the woman. At the same time, the medical aspect of DI was manifested as it became necessary for somebody, almost exclusively doctors, to act as an intermediary between the semen provider and the recipient. This justified the biomedical legitimacy of the technical procedure and the professional intervention in this scenario. According to Bateman Novaes (1998, p. 114), commenting from a French perspective, this solidified the medicalisation of DI:

DI thus set up as a practice organised around semen banking quickly began to shed its quasi-clandestine and ambiguous therapeutical status, particularly in France. It became a more socially visible and apparently more respectable procedure, now openly mediated by physicians in an institutionally stable management position.

Bateman Novaes, however, criticises the involvement of the medical profession as many of the issues involved in DI are not only located in the technical and medical but also in the social and psychological arena. These include aspects pertaining to the welfare of the child and decisions regarding access for groups not historically demanding DI, such as lesbian couples or single women, as well as also matching semen provider and recipients in heterosexual couple relationships. Especially in the latter case, the medicalisation of DI practice is indicated: both actors are commonly matched by blood type and phenotypological similarity, as the semen provider should resemble the social father as much as possible. Such a selection is carried out to ensure that the offspring is unlikely to discover his or her origin during a medical examination; however, there is no medical rationale for this (Bateman Novaes, 1998).

In her article, “The kin in the gene”, Finkler (2001) went one step further. As described in Chapter 2, page 26, she argued that not only is reproduction medicalised but so is the family and kinship:
To the array of human experiences that have become medicalized, I suggest that we must now add the family and kinship. Understood as biogenetic, they have come under close medical inspection through the prevailing biomedical understanding of disease etiology. Beyond issues associated with gender, family and kinship relations have been given a new dimension that stresses faulty genes rather than social status, position, or even poverty. Cultural significance is given to genetic transmission, for better or worse. ... With the medicalization of family and kinship, a connection must exist irrespective of love and choice. Biomedicine insists on uniting those who may not choose to be connected. (Finkler, 2001, p. 239)

This notion is supported by Franklin (1999, p. 162) who puts forward the following argument:

With the assistance to conception comes also assisted origins, assisted relations, assisted genealogy, and assisted futures. The meaning of such assistance is not merely additive: it is transformative. One does not only derive new relations, but new ways of understanding relatedness, new implications of relatedness, new joys of relatedness, and new fears about bringing the dangers of relatedness, or of bringing new relations into being.

This stresses the importance of applying a biopsychosocial perspective to family building with the assistance of AHR, and especially third party reproduction. Though it is relatively easy to physically conceive with the gametes of a semen provider, Franklin indicates that from a psychosocial perspective, it is not so easy. With the help of a biopsychosocial perspective, these taxing issues can be acknowledged and a framework for understanding the psychosocial implications of this treatment can be developed.

Social stigmatisation – Goffman’s pioneering work

The understanding of social stigmatisation goes back to the influential work of Goffman (1998), an American sociologist of Canadian origin. Goffman’s interest was in social psychology, especially in face-to-face interaction for which he attempted to define a structure and an order. His first wife’s suicide in 1964 (Online-Lexikon Universität Graz, 2004) may suggest that he was not only interested in the theory of social stigmatisation from a professional perspective, but was faced with this in his personal sphere.

Goffman (1998) describes a stigma as a deeply discrediting attribute, marking the bearer as spoiled and reducing him or her from a whole and usual person to a tainted, discounted one. As a consequence of this devaluation, the so-called “normal” people, the non-stigmatised, are justified in positioning the “spoiled”,

stigmatised person as of lesser value. According to Goffman, it is the intricate interplay during the
categorisation of social interaction, which leads to stigmatisation. He contends that a so-called “virtual”
social identity is created by assumptions based on anticipated normative expectations. These can differ
from the actual social identity based on the qualities proven by the individual:

The routine in social interaction ... allows us to deal with anticipated others without special
attention or considerations. When confronted with a stranger, first sight may allow us to
anticipate his categories and his qualities, his 'social identity' – in order to use a terminus
which is superior to 'social status' as it also includes personal qualities of character such as
'honourableness' as well as structural qualities of the type of his 'profession'. We use these
anticipations, which we have by changing them into normative expectations, into justifiable
demands. Typically, we are unaware of having made these demands and unaware of what
nature they are until the acute question arises of whether they have been fulfilled or not. At
this point in time we are likely to notice that we have [merely] been assuming what the
other person should be. (Goffman, 1998, p. 10)

Stigmatisation occurs if a stranger displays qualities that make him different from others. However, it is
not the quality itself which is stigmatising, but the discrepancy between a person’s quality and
stereotypical social expectations. The process of stigmatisation is therefore a relational one: non-
stigmatised people define categories they do not possess themselves as stigmata and ostracise those who
have these qualities. The stigmatised accept this and behave accordingly.

Qualities leading to stigmatisation are not only dependent upon making and accepting definitions of
attributions, but also vary in different historical, social and cultural contexts as these influence social
norms and customs. Therefore, any quality can be stigmatising if it deviates from the ideal of a particular
context. Increasing social acceptance of homosexuality since the 1980s in some countries, yet defined by
Goffman in the 1960s as a stigma, exemplifies this contextual impact, in this case of time, on the
transformations of social norms and stigmata. The less desirable and more extensive such qualities are,
for example, a profound physical or mental handicap, the stronger is the discrepancy between virtual and
actual social identity and the higher the likelihood that this individual is stigmatised. Stigmatisation may
not only lead to a loss of social roles and contacts, but also to isolation and ostracism and the impact of
these on the identity of the stigmatised person. As everybody deviates from social norms in one or more
areas, and is incomplete and inferior, every interaction is subject to conformity and deviance. Therefore,
everybody attempts to control his or her public image and to exert strategies in order to hide their
differences from the norm. In this sense, stigmatisation is a general societal component.
Goffman differentiates between discredited and discreditable forms of stigma. If an individual assumes that others know already of the stigmatising quality or if this is evident, he or she is defined as a discredited person. These qualities comprise physical deformities, such as missing limbs, so-called character deficits, such as many mental diseases and unemployment, or phylogenetic stigmata, for instance belonging to a certain race, nation or religious denomination. Such people can be discriminated against and excluded from social interaction and resources, justified by ideologies or rationalisations explaining their inferiority. Discreditable forms of stigma include qualities not visible or evident to others, such as a criminal background. In these cases, individuals only run the risk of being shamed if others become aware of their deviance from the norm. Both infertility and family building with the assistance of DI can be seen as invisible stigmata (although the absence of children is a visible violation of norms and thus can be thought of as a visible stigma).

During social interaction, every individual is eager to receive information and to control the information about his or her person. Information does not only pertain to verbally communicable facts, but also to so-called “social information” transmitted by cues which Goffman (1998) defines as “symbols”. Depending on their social value attribution, they can be positive symbols of prestige (i.e. the white coat of a doctor) or negative stigma symbols (i.e. the handcuffs of a prisoner). Again, the meaning of a symbol can change depending upon time and context. In addition, meanings of symbols can be misinterpreted or misused. Goffman further differentiates between verbal and nonverbal communication, such as gestures and mimicry, and draws attention to the non-verbal interaction between people with a non-observable stigma (discreditable individuals) and non-stigmatised individuals. He contends that discreditable individuals feel ashamed and fear ostracism. Referring to identity theory, he explains that individuals with discreditable forms of stigma are identified if they violate social norm. This deteriorates their respect for themselves, as their actual identity does not fulfil their ideal shaped by the predominant norms in a certain group or society. Consequently, these individuals need to develop techniques to hide the stigma, such as keeping it a secret or controlling the information about the potentially shameful quality. Goffman describes this as “stigma management”. Extensive stigma management is relevant in the public life of discreditable individuals and in their interaction with strangers. In order to pass as a “normal” individual, associated with great social reward, discreditable individuals disguise their stigma symbols (by covering up scars),
make them invisible (by wearing contact lenses instead of glasses), substitute a quality that is severely stigmatised with one that is less stigmatised (pretending one is tired instead of admitting impaired hearing), admit the stigma to a small circle of trusted individuals who help in managing social interaction (a friend reading for an illiterate so that others are unaware of his deficiency), or avoid intimate social contacts (such as the child of a mentally ill person who does not see friends in order not to have to answer questions about her father).

Management strategies designed to disguise stigmata increase the risk of having to live with lies, and an attempt to “avoid being discovered ... one lie after the other” must be developed (Goffman, 1998, p. 107). In addition to making interaction with others increasingly complex and difficult, individuals applying these strategies run further risks. They deprive themselves of learning what others really think of them, they may become subject to blackmail by those who are knowledgeable about their secret stigma, or the stigma may be divulged by somebody who can read the disguising techniques. This can result in feelings of ambivalence in new groups. The discreditable person cannot fully identify with this group and may suffer from feelings of disloyalty and disrespect for his or her own person as he or she cannot speak out for people sharing his or her stigma if the group disrespects them. Management problems can also arise if previous strategies become inadequate. Disclosing the stigma, or attempting to downplay the effect of it, is an additional management strategy. Goffman describes the efforts of a girl who uses a wooden leg as a substitute for her missing limb in private but uses crutches or a more elegant limb in public. He calls this “covering” and regards this as an acceptable strategy if it is used in the process of disclosing the stigma. Although realising that disclosure of the stigma leads a person from having to manage information to having to manage unpleasant social situations, Goffman (1998, p. 12) values this as a “wise, well-adapted phase ... a [final] state of dignity” and believes that the stigmatised have to learn to admit their stigma in a casual manner until it becomes an irrelevant factor in interaction.

While Goffman did not directly connect his work to symbolic interaction, many of the concepts he uses indicate that this greatly influenced his thinking. Symbolic interaction, also referred to as symbolic interactionism, is a sociological perspective, which examines individual and group-interaction. Blumer (1969) coined the phrase “symbolic interaction” but drew many of his ideas from the work of Mead (1934), his teacher and the originator of this theory. Symbolic interaction rests on the following three
premises (Blumer, 1969), which, similarly to the notions of social constructivism, stress the importance of meanings derived from social interaction:

1. Human beings act towards things on the basis of the meanings those things have for them;
2. Such meanings arise from the interaction of those individuals with others;
3. An interpretive process is used by the individual in each instance in which he interacts with his environment.

According to these premises, interaction is dependent not only upon construed reactions of specific others, but also on the reactions of generalised others (Steinert, 1997), and thus normative social expectations. This helps to explain why infertility and family building by DI can be perceived as stigmatising on both levels. Perceiving one’s identity as “spoiled” is likely to result from the generalised negative meanings. This in turn affects concrete interaction with others. Having internalised this negative view, individuals expect others to react negatively in concrete situations. They therefore avoid disclosing infertility and DI. The non-stigmatised, subject to similar normative expectations, also attribute a negative meaning to these issues and therefore do not raise them themselves. Thus, a self-fulfilling prophecy of these tabooed issues is created. The strong internalisation, however, has an additional negative effect. As a result of the taboo and the lack of communication about both, the negative meaning is not challenged and individuals are unable to adapt their meanings to encompass the issue.

**Recent developments in stigma theory**

More recently, Goffman’s stigma concept has been both criticised and expanded. Kleinman et al. (1995) disapprove of it, as many social scientists who study stigma do not belong to a stigmatised group; they do so from a theoretical perspective, uninformed of the lived experiences of the people they study. This is said to result in a misunderstanding of the stigmatised and the perpetuation of unsubstantiated assumptions (Link & Phelan, 2001). The second critique addresses the fact that stigma has mainly had an individual focus on micro-level interactions, that the literature on discrimination is far less extensive than on stereotyping, and that there is a need to address structural issues. Though Goffman (1998) considers
the relationships between individuals important in stigmatising processes, he seems to perceive a stigma mainly as something in the person rather than a label others affix to a person (Link & Phelan, 2001), thus giving less attention to the sources and consequences of exclusion from social and economic life (Oliver, 1992). Others have expanded Goffman’s theory by contributing to the definition of stigma and by adding functions to stigmatisation and describing its impact.

Many writers refer to Crocker, Major and Steele’s (1998, p. 505) definition of the manifestation of stigma: “Stigmatised individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in some particular social context.” Similarly to Crocker et al. (1998), Stafford and Scott (1986) suggest that stigma is a characteristic of a person that is contrary to the norm of a social unit and define “norm” as the shared belief that a person should display certain behaviour at a certain time. Jones, Farina, Hastorf, Markus, Miller and Scott (1984) view stigmatisation as the relationship between an attribute and a stereotype: linking a person to an undesirable characteristic or stereotype produces a negative attribute or stigma. In addition, terminology describing the actors has moved away from morally laden words, such as “the normal” and “the stigmatised” used by Goffman (1989), to more neutral definitions, such as the “non-stigmatised” (Crocker et al., 1998) or the “target” and “perceiver” (Dovidio, Major & Crocker, 2000).

**Biopsychosocial functions of stigmatisation**

Several writers have attempted to explain the functions of stigmatisation. These explanations include biological, psychological as well as social purposes. Kurzban and Leary (2001) argue that there may be biological and evolutionary reasons for stigmatisation. Contending that “natural selection ... fashion[s] the constraints and limits on sociality that cause one to direct one’s social efforts in productive ways”, they conclude that such constraints may play a vital role in generating stigmatisation (Kurzban & Leary, 2001, p. 192). According to this model of explanation, stigmatisation derives at least in part from the following three elements: dyadic cooperation, coalition exploitation, and parasite avoidance. Under the premise of dyadic cooperation, those who cannot, fail to, seem unlikely or can not be predicted to reciprocate are stigmatised as they “are not a good store of social value for trading relationships” (Kurzban & Leary, 2001, p. 193). When dyadic cooperation is threatened, a typical affective reaction is
anger and these individuals may be socially excluded or punished (e.g. criminals). The term “coalition exploitation” refers to between-group interaction where dominant groups exert pressure and exploit subordinate groups, such as the sexual exploitation of women in subordinate groups by males of dominant groups. This typically results in feelings of fear and hatred. Parasite avoidance explains the stigmatisation of those individuals who pose a threat to the health of others, with typical reactions such as disgust and desire for physical distancing in order to avoid potential contagion. Kurzban and Leary (2001, p. 199) also point out that “parasite detection systems may be biased towards false positive because of the high potential costs of misses”. This understanding can help to explain why members of a particular group or culture tend to agree on which features ought to be stigmatised, and this approach may also explain why many stigmata manifest themselves in most, if not all, cultures. Kurzban and Leary (2001) stress that this evolutionary view should not be construed as suggesting that stigmatisation is genetically determined or inevitable, but that the systems underpinning stigmatisations are domain-specific and designed to solve particular adaptive problems. The design of each cognitive system, they believe, is a critical step in discovering how to effect change. They agree with Jones et al. (1984) that visibility or evidence, as well as social disruptiveness, play causal roles in the severity of the stigmatising process.

Neuberg, Smith and Asher (2000) suggest a similar understanding but apply a different perspective. They focus on the interrelatedness of biological and social functions for stigmatisation. Within such a biocultural framework, they explain that stigmatisation serves to identify individuals who threaten or hinder successful group functioning, such as nonreciprocators (e.g. thieves or people with a physical handicap), treacherous (cheaters), or those who counter-socialise by possessing views that challenge core values of groups (e.g. sexual behaviour or group safety). This perspective is supported by Stangor and Grandall (2000) who believe that various forms of threat, either symbolic or tangible, must be present, such as health or moral danger (e.g. homosexuality) in order to result in stigmatisation, and by Pfuhl and Henry (1993), who emphasise the importance of social norms. They also argue that deviance, unusualness or violations of social customs are contributing factors for stigmatisation.

The psychological and social functions of stigmatisation have been revised by Crocker et al. (1998). They contend that the enhancement of self-esteem or social identity, as well as justifying a particular social, economic or political structure, is the main purpose of stigmatisation. The enhancement of self-esteem
and social identity imply that stigmatisation is used in order to compare oneself to others and to put oneself into a superior position. However, although self-esteem seems to play a role in stigmatisation, both from the perspective of the stigmatiser and the stigmatised, the link is not a straightforward one. Kurzban and Leary (2001, p. 189) argue that “our view is that although self-esteem and stigma are intertwined in some fashion, these theoretical perspectives do not provide a satisfying account of why individuals discriminate against particular others”. The view of justification of the social structure as a function of stigmatisation suggests that people in a particular culture are believed to be members of a subordinate group because of certain qualities attributed to them, such as laziness or lack of initiative. This approach, however, does not explain why certain stereotypes, such as those concerning the handicapped or the diseased, are relatively consistent across cultures and history. Therefore they put forward the evolutionary model described above.

Jones et al. (1984) in analysing the functions of stigmatisation address the issue of the severity of stigmatisation. Similarly to Goffman (1998), they argue that the following dimensions determine the degree of stigmatisation:

- Visibility versus concealability;
- Disruptiveness, or the degree of its negative impact on social interaction;
- Controllability, referring to the degree with which the stigmatising condition can be changed. However, some stigmatising conditions that are preventable are more highly stigmatised than others which are beyond individual control, but incontrollable conditions can also lead to harsh stigmatisation;
- Aesthetics, or the degree of an unpleasing feature;
- Peril, the degree of danger the stigmatised condition poses.

Link and Phelan (2001, p. 367), analysing the nature and consequences of stigmatisation, argue that the dimension of social power is vital:
In our conceptualisation, stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics – to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them”. In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatisation is entirely contingent on access to social, economic, and political power that allows the identification of differences, the construction of stereotypes, the separation of labelled persons and discrimination. Thus, we apply the term stigma when elements of labelling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold.

In order to avoid obscuring the fact that stigmatisation is a social process, Link and Phelan suggest using the term "label", rather than "attribute" or "mark" which tend to locate the quality referred to as lying in the stigmatised person. A label, in contrast to this, is a social construct affixed to a person or a group by another leaving the validity of the word open. Stigma involves a label and a stereotype "with the label linking the person to a set of undesirable characteristics that form the stereotype" (Link & Phelan, 2001, p. 369). From the perspective of the stigmatised, labelling and stereotyping result in almost immediate loss of social status and discrimination, as well as in individual and/or structural discrimination. Structural discrimination refers to social structures resulting in disadvantaging individuals or groups, such as black Americans who are stereotyped as lazy, which results in a loss of status and thus in difficulty in finding employment. Once stereotypes are in place and socially accepted, this can lead to individuals falling into these categories and to expect stigmatisation to occur in their individual case. If an individual constructs his understanding around this expectation, this can entail negative consequences, such as a decrease in confidence, increase in defensive behaviour or avoidance of social interaction. Goffman (1998) called this a dilemma, as the mechanisms are interchangeable and mutually reinforcing. Link and Phelan (2001, p. 375) suggest that both individual/personal/micro and structural/political/macro stigmatisation are affected by this reinforcement:

If a stigmatized person cannot be persuaded to voluntarily accept their lower status and inferior rewards, direct discrimination can be used to accomplish the same outcome. If direct discrimination becomes ideologically difficult, sophisticated forms of structural discrimination – such as tests that induce stereotypical threat – can achieve some of the same ends. ... To the extent that stigmatized groups accept the dominant views of their lower status, they are less likely to challenge structural forms of discrimination that block opportunities they desire. Further, direct discrimination reinforces the belief among stigmatized groups that they will be treated in accordance with stereotypes and therefore reinforce processes like those explicated in the context of modified labeling theory and the stereotype-threat concept. From this vantage point, stigma is a predicament in the following sense – as long as dominant groups sustain their view of stigmatized persons, decreasing the use of one mechanism through which disadvantage can be accomplished simultaneously
creates the impetus to increase the use of another.

In order to analyse the power component of stigmatisation, they suggest asking a number of questions:

- Do the people who might stigmatize have the power to ensure that the human difference they recognize and label is broadly identified in the culture?
- Do the people who might confer stigma have the power to ensure that the culture recognizes and deeply accepts the stereotypes they connect to the labeled difference?
- Do the people who might stigmatize have the power to separate ‘us’ from ‘them’ and to have the designation stick?
- And do those who might confer stigma control access to major life domains like educational institutions, jobs, housing, and health care in order to put really consequential teeth into the distinction they draw?

To the extent that we can answer yes to these questions, we can expect stigma to result. To the extent that we answer no, some other of the cognitive components of stigma might be in place, but what we generally mean by stigma would not exist. (Link & Phelan, 2001, p. 376)

**The impact of and response to stigmatisation**

Goffman (1998) describes keeping the stigmatising condition a secret as one way of managing it. This supposedly ensures that others remain unaware and that interaction between the stigmatised and the non-stigmatised remains unaffected by the stigma. More recently, several scholars have challenged the assumption that secrecy has no impact on either the non-stigmatised or the stigmatised. They describe micro as well as meso and macro effects of not disclosing a stigmatising condition.

Using the perspective of symbolic interaction, Crocker and Quinn (2000), for example, argue that stigmatisation has a negative impact on an individual’s self-esteem:

One’s position in the social order, and particularly, having a devalued social identity, might affect self-esteem. ... [S]ymbolic interactionists such as Mead ... and Cooly ... proposed that the self is a social construction, and that we humans develop our sense of who and what we are from our observation and interpretation of the responses we receive from others. According to this view, we cannot understand the self without understanding the social context in which it functions. This viewpoint is articulated in the ‘looking-glass self’ hypothesis, which argues that one of the most important ways we come to know ourselves is through the reactions of others [either concrete individuals or a generalized view] to us. (Crocker & Quinn, 2000, p. 155)

They contend that self-esteem is not a stable trait across social situations and contexts but is constructed at a specific moment, in a particular situation and dependent upon the function of the meaning that
individuals attribute to such a specific situation. Thus it is necessary to understand the collective representations that the stigmatised bring with them to a particular situation (i.e. their expectations of others’ reactions). In situations where evaluation by others is particularly salient, the self-esteem of stigmatised individuals will be lower than in circumstances where others’ appraisal is less important or irrelevant (Crocker & Quinn, 2000).

Smart and Wegner (2000) describe unconscious management strategies of secrecy and their impact on individual functioning and their physical health, contending that individuals keeping their stigma a secret pay an emotional and physical health toll. In attempting to conceal their stigma, individuals become preoccupied with them. The secret, as a result of this apprehension, becomes highly accessible when one tries to suppress it most. This preoccupation can result in what Smart and Wegner (2000, p. 224) define as “deep cognitive activation”, a state during which “stigma related thoughts are accessible and influential over behavior and judgement, although they are not currently conscious”, and they contend that:

... in the process of trying to hide stigmas, people may be cognitively affected in ways that are subtle and seem only loosely linked to the activated thoughts of the stigmas themselves, but that may still cause a great deal of distress. Furthermore, there may be times when such people are not even consciously aware that they are preoccupied with their stigmas. They may consider their attempts to suppress thoughts of their stigmas to be successful, although these thoughts may still be influencing their behaviours and judgements. (Smart & Wegner, 2000, p. 225)

Unable to control such intrusive thoughts, individuals are plagued by mental control problems, which their interaction partner may sense and, consciously or unconsciously, react to. Regarding physical health, Smart and Wegner (2000) refer to studies on HIV-positive people, indicating that those who do not disclose their status to significant others are likely to show higher levels of social isolation, depression and anxiety. They conclude that expressing one’s thoughts and feelings about a stressor can help to diminish the deep cognitive activations of the stressor and thus eliminate the preoccupation and reduce its toll.

On an interpersonal level, Hebl, Tickle and Heatherton (2000) suggest that secrecy of the stigma results in interaction difficulties. Regarding the mixed interaction between stigmatised and non-stigmatised individuals, they maintain that so-called “awkward moments” can occur. These episodes indicate that
both stigmatised and non-stigmatised perceive anxiety in mixed interaction. Non-stigmatised may experience threat and fear, as well as a lack of scripts for interaction with stigmatised. They attempt to navigate the conversation so that potentially threatening areas are excluded, or they suppress their thoughts, which can lead to so-called “rebound effects” whereby they experience a number of these thoughts later. Communication may remain on a superficial level as non-stigmatised avoid certain topics or sometimes interaction altogether. In addition, they can feel ambivalent, experiencing both guilt and shame towards the stigmatised, as well as hostility and disgust. As stigmatised individuals strive towards “normalisation” and acceptance by the non-stigmatised, in mixed interaction they experience feelings of being “on stage” explaining their heightened self-consciousness and feeling to create the impression of being normal despite their stigma. This can lead to self-loathing and low self-esteem, which is non-verbally transported by clues such as decreased eye contact in interaction or exaggerated expectation to be treated negatively. All of these effects increase the feelings of anxiety in mixed interaction, which “may perpetuate the negativity associated with mixed relations and lead to further misunderstandings between mixed interactions” (Hebl et al., 2000, p. 291).

The link between stigma and self-fulfilling prophecies has already been noted by Goffman (1998). Jussim, Palumbo, Chatman, Madon and Smith (2000) have expanded this notion. They explain that self-fulfilling prophecies can occur if “an initially erroneous social belief leads to its own fulfilment” (Jussim et al., 2000, p. 376). Self-fulfilling prophecies require the following steps: the non-stigmatised develops an erroneous expectation, and this expectation influences how he treats the stigmatised. The stigmatised reacts to this treatment with behaviour that confirms this expectation. Basing their conclusions on the perspective of symbolic interaction, Biernat and Dovidio (2000) also explain that non-stigmatised who know individuals or groups to suffer from “blemishes of the character” (i.e. from psychological disorders) expect them to be avoidant and distant, and therefore behave towards them in a distant way. The stigmatised, in return, are found to be more unsociable and cold and thus, the non-stigmatised feel justified in behaving differently towards them. Self-fulfilling prophecies can also operate on a macro level. Jussim et al. (2000), for example, refer to broad-based oppression of social groups through political and/or institutional policies that limit educational and occupational possibilities. As a result, these groups can be denied access to a wide range of educational opportunities and thus remain oppressed and without resources.
The challenge of changing stigmatisation

Though not all writers have attempted to develop strategies that can decrease or alleviate social stigmatisation, those who have propose addressing the micro, meso and the macro level. On the micro level, Miller and Major (2000) argue for decreasing the psychological stress stigmatisation can cause. For this, they suggest individual coping strategies, such as protecting the self from social comparison to others and thus avoiding the painful upward comparison with non-stigmatised people, eliminating the stigmatising condition, such as losing weight if obese, and avoiding situations which expose individuals to discrimination. Hebl et al. (2000) also suggest interventions that can change the individual’s belief system; these include raising self-acceptance and accepting difference as non-devaluing, and focussing on personality aspects that are positive.

On a meso level, many writers believe that joining support groups can enhance self-image and general confidence (Ablon 2002; Corrigan & Penn, 1999; Hebl et al., 2000; Miller & Major, 2000). In addition, sharing with others provides emotional and instrumental social support and leads to validation of beliefs and attitudes, as well as interaction compatibility (Miller & Major, 2000). Corrigan and Penn (1999), furthermore, speak out for fostering empowerment by establishing contact between the stigmatised and non-stigmatised in order to reduce barriers. Hebl et al. (2000) suggest that such mixed interaction is best achieved by expressing common interests in order to compensate for the difference between these two groups. They emphasise that open acknowledgement and a constructive disclosing process are particularly helpful:

[I]f the stigmatized individual revealed information surrounding the possession of the stigma, recognized that others probably had questions about the stigma, and encouraged others to ask questions that they might have, the stigmatized individual was demonstrating less reactivity and a great deal of openness towards possessing the given stigma. Therefore, an acknowledgement devoid of defensiveness and hints of maladjustment leads to greater acceptance on the part of the other. ... Additional research ... suggests that more interactional success occurs when stigmatized individuals provide a context for the acknowledgement [such as] requesting assistance and then mentioning the stigmatising condition [which] has been shown to facilitate acceptance of the stigmatized individual. (Hebl et al., 2000, pp. 295-296)

However, it has to be taken into account that individuals with a concealable stigma are less likely to engage in contact with peers, as this would require them to reveal the stigmatising condition (Goffmann, 1998; Miller & Major, 2000).
On a macro level, stigmatised individuals or groups can strive to gain political influence so that their civil rights are enforced (Hebl et al., 2000; Miller & Major, 2000). Members of groups can “engage in community and public education” (Ablon, 2002; Corrigan & Penn, 1999) and thus effect interaction to promote a change of public attitudes and beliefs. Miller and Major (2000) suggest making use of the mass media as they believe that making information available about stigmatising conditions can lead to normalisation and the breaking down of barriers. Though deeming collective coping efforts to be most likely to result in long-term social change, they note that “collective actions by the stigmatized individuals ... are surprisingly rare” (Miller & Major, 2000, p. 257). Such actions, they conclude, are met with resistance from non-stigmatised people as they threaten their control over power and resources.

There seems to be some disagreement amongst scholars as to the question of which strategies are best suited for decreasing stigmatisation. Whereas Miller and Major (2000) believe that it is a matter of selecting appropriate measures to suit specific situations and individuals, Link and Phelan (2001) consider single-strategy approaches as ineffective for achieving enduring change. They suggest a comprehensive framework of interventions:

Our conceptualisation leads us to focus on two principles in considering how to really change stigma. The first is that any approach must be multifaceted and multilevel. It needs to be multifaceted to address the many mechanisms that can lead to disadvantaged outcomes, and it needs to be multilevel to address issues of both individual and structural discrimination. But second, and most important, an approach to change must ultimately address the fundamental cause of stigma – it must either change the deeply held attitudes and beliefs of powerful groups that lead to labelling, stereotyping, setting apart, devaluing, and discrimination, or it must change circumstances so as to limit the power of such groups to make their cognitions the dominant ones. In the absence of fundamental changes, interventions targeted at only one mechanism at a time will ultimately fail, because their effectiveness will be undermined by contextual forces that are left untouched by such a narrowly conceived intervention. Thus, if considering a multifaceted multilevel response to stigma, one should choose interventions that either produce fundamental changes in attitudes and beliefs or change the power relations that underlie the ability of dominant groups to act on their attitudes and beliefs. (Link & Phelan, 2001, p. 381)

From a social work perspective, Miller and Major’s (2000) approach fails to acknowledge interdependencies between the micro, meso and macro levels, whereas these are taken into account by Link and Phelan (2001) in their approach. From this perspective, micro level interventions, such as individual confidence-building and the development of coping skills, meso level interactions, such as
facilitating interaction amongst stigmatised individuals themselves, as well as interaction between stigmatised and non-stigmatised, and macro level interactions, such as exerting political influence and educating the public, must be considered as mutually reinforcing and supporting the process of destigmatisation.

Summary

Social work has traditionally drawn on a variety of social science theories in order to analyse situations and develop interventions for practice. This approach has also been applied in this chapter. Systems theory has been explained in order to underpin the importance of complexity and interdependence. For social work, systems theory provides a more inclusive understanding of the interrelatedness between private troubles and public issues and explains the importance of understanding that the environment impacts on individuals and vice versa.

The biopsychosocial model, based on systems theory, was developed in order to expand the biomedical model applied in medicine. This model stresses the importance of understanding psychological and social meanings that diseases have for individuals, and thus contributes to a more holistic understanding of medical treatment. This is especially important in an era of increasing genetic knowledge, which has contributed not only to the medicalisation of infertility and family building by DI, but also, as a result of the importance attributed to genes and genetic connection, to the medicalisation of family and kinship in general.

The theory of social stigmatisation was drawn upon to explain why individuals or groups are discriminated against. This theory has its origins in the influential work of Goffmann who based many of his ideas on social interactionism. He contends that individuals create a virtual social identity by assumptions based on anticipated normative expectations. Stigmatisation occurs when an individual displays qualities that mark him as different from others. However, it is not the quality itself that is stigmatising, but the discrepancy between the person's quality and the social expectation. More recently, scholars have attempted to describe the biopsychosocial functions of stigmatisation. These include
evolutionary reasons, such as discrimination against individuals that decrease the fitness of a group, biosocial reasons, such as individuals who are perceived to hinder successful group functioning, and psychosocial reasons, such as elevating self-esteem or social identity to the cost of those who are stigmatised. Scholars have also used the perspective of symbolic interaction to explain that prejudices can lead to stigmatisation, as in the case of persons suffering from psychological disorders. Such beliefs can result in self-fulfilling prophecies as the non-stigmatised may behave in a distant way towards the stigmatised, who, in return, react unsociably and thus fulfil expectations. Others have stressed the importance of power in discrimination and stigmatisation. Link and Phelan (2001), for example, contend that stigmatisation is present if labelling, stereotyping, separation, status loss and discrimination occur in a power situation which makes it possible for the stigma to develop. Several scholars have also analysed the impact of stigmatisation. Individuals are likely to develop negative self-esteem in social situations, especially in those that are perceived to be particularly salient. Keeping a stigmatising condition a secret has been associated with a negative impact on emotional and physical health. Secrecy in this area can lead to so-called “deep-cognitive activation” (Smart & Wegner, 2000, p. 224), which describes a state during which an individual attempts to hide a stigma, but stigma-relevant thoughts subconsciously remain accessible and influential in his or her behaviour. Individuals are plagued by mental control problems which are sensed by their interaction partners and which they then react to. Similarly, interaction difficulties may occur in the interaction between stigmatised and non-stigmatised. Non-stigmatised may feel uncertain as to how to behave towards the stigmatised, they may attempt to navigate the conversation so that threatening areas are excluded, and this can lead to superficial communication or to a lack of communication altogether. The stigmatised may feel a heightened self-consciousness and a need to create the perception of being normal. This can lead to self-hate and to developing low self-esteem. More recently, scholars have attempted to define strategies for destigmatisation. The most promising approach is proposed by Link and Phelan (2001), who recommend a multi-faceted and multi-level approach comprising changes on the micro, meso and macro levels. They contend that single strategies located on one level are only likely to fail as they are undermined by contextual forces.
Chapter 6
Methodology

This chapter will examine the process involved in carrying out this exploratory, qualitative study. It will describe the methods applied to access participants, develop the tools for the interviews and analyse the data. It will also outline the ethical considerations relevant to conducting research in a sensitive area such as sharing information about the use of DI.

Qualitative research design
As a researcher with a social science background, my aim in undertaking this research study was to explore the issues associated with the management of information sharing in relation to family building with DI through the experiences of people who are considering, undergoing or have completed treatment. I also wanted to explore the meanings they attach to their experiences and understand these in the sociocultural and socio-political context. Promoting understanding and acceptance of families built by DI and raising awareness of the need to openly manage the children's biological origin, both with clients and other professionals, have been my major professional efforts in the last few years. As a result of my involvement in this field, I have become aware that there are many aspects of family building by DI which have not been researched, either in Germany or internationally. One of the major obstacles for such research is the secrecy surrounding this method of building a family (Golombok, 1995; Lycett et al., 2004). Therefore, it has been necessary to consider a study that would be feasible and realistic. Given that new legislation, which was developed either to supplement or replace the current ESchG, was debated in 2000, and that these discussions are likely to be resumed in the near future (Arndt, personal communication, June 12, 2002), it seemed crucial to understand which factors influence parents in their decision either to keep DI secret or to share it with others and/or the child. Several international studies
have looked at this issue from a psychological perspective (for example: Brähler, 1990; Brewaeys, 2001; Goebel & Lübbke, 1987; Golombok et al., 2002; Schilling, 1999), thus examining factors located at the micro level. Based on previous research (Thorn & Daniels, 2000a; Thorn & Daniels, 2003), macro-factor issues, such as the legislative framework as one of the contextual factors, were deemed to be influential. The impact may not be direct, but as indicated in an analysis conducted in 2003 (Thorn & Daniels, 2003), the lack of legal clarity in the area of DI is likely to contribute to the uncertain social status of the practice and thus make parents, as well as doctors and semen providers, feel apprehensive and/or lacking in confidence about disclosing their involvement in DI. Furthermore, on the meso level, family members’ or friends’ attitudes are likely to influence a couple’s perceptions of DI and their views regarding information sharing. Therefore, these political and social factors were considered to be important in addition to individual psychological aspects that have been the subject of earlier research. The aim of this thesis is to explore micro, meso and macro factors influencing parental decision-making and to investigate the interrelatedness of these different levels, thus to analyse this issue from a holistic, systems perspective.

As there is no other research that has studied these aspects, this is an exploratory study, and as such, is less concerned with numbers and figures than with exploring, analysing and understanding phenomena for one stake-holder group, the couples and (future) parents with experiences of DI. The main criteria for selecting a particular research approach have been identified as the personal preference or experience, philosophical and professional orientation, as well as the nature of the research problem (Moser, 1995; Strauss & Corbin, 1998). Strauss and Corbin (1998) argue that a qualitative design best captures complex details about any phenomena, such as feelings, thought processes, affects and perceptions which are difficult to extract or learn about through more conventional research methods. Although still regarded with scepticism in the medical community, qualitative research has been described as having a particularly important contribution to make in this area (Meryn, 2005). As an inquiry process of exploring and understanding a social or human problem, researchers apply it to build a complex, holistic picture by analysing words and meanings, reporting views and conducting studies in a natural setting (Creswell, 1998). In relation to qualitative research on the social psychology dimensions of infertility, Greil (1997, p. 1682) explains:
... one of the strengths of much of the qualitative literature on infertility is that it analyses the experiences of infertility within its social context, paying special attention to gender roles, family structure and couple relationships, the effects of medical institutions and the importance of reproductive technology in shaping reactions to infertility.

Such an approach was deemed most suited to exploring the multi-faceted nature of parental decision-making. Having decided on this approach, there were several alternative methods to select from (Creswell, 1998). A biographical method which attempts to reconstruct the history of a life, such as life or oral histories, was considered too extensive and unlikely to capture the specific issues relevant to this study. Similarly, an ethnographical approach using participant observation or immersion into the daily lives of participants was deemed too broad an approach. A collective case study method requiring multiples sources of information such as interviews in conjunction with observations, documents and/or audiovisual material, would not have been feasible because of the lack of such material. A project based on phenomenology describing the essence of the experience of family building by DI would have been interesting, but this approach tends to work with relatively small numbers of respondents (up to 10); this was considered too low a number to capture differences in experiences and attitudes.

After considering the advantages and disadvantages of these approaches, Grounded Theory developed by Strauss (1998) and Glaser (Glaser & Strauss, 1967) promised to be best suited for this study. Grounded Theory aims to generate a theory, an abstract analytical schema describing a plausible relationship among concepts and sets of concepts (Strauss & Corbin, 1998), which is to be expressed in the form of a narrative statement, a visual picture, or a series of hypotheses which contribute towards the goal of a study (Creswell, 1998). With this approach, a researcher typically conducts 20–30 interviews until saturation of categories has occurred. A category refers to a particular unit of information; a category is saturated once further interviews no longer provide additional information. The procedure of working with Grounded Theory is comprehensive, yet well structured. After transcription of the interviews, so-called open coding and microanalysis of the data is carried out. With the process of open coding, initial categories and sub-categories, including their qualities and dimensions, are formed. Microanalysis is the next step. This refers to “the detailed line-by-line analysis necessary at the beginning of a study to generate [such] initial categories” (Strauss & Corbin, 1998, p. 57). Following this, open and axial coding is applied in order to ascertain whether there are relationships between categories. This is then followed by selective coding, which attempts to integrate the categories and to develop hypotheses. Finally, “the
researcher may develop and visually portray a conditional matrix that elucidates the social, historical, and economical conditions influencing the central phenomenon” (Creswell, 1998, p. 57). However, this final phase is not often found in studies applying Grounded Theory (Creswell, 1998). This approach therefore provided a sound structure and yet sufficient flexibility to study an area in which few, if any, preconceived ideas existed. I share Strauss's (1998) belief that social phenomena are complex phenomena and that this complexity makes it vital to capture the many variations and peripheral elements which characterise the central issue of a research question. As this implies, I did not expect to find one single answer to my question, but hoped to be able to describe the complexities parents face regarding the management of information sharing in DI.

Face-to-face, semi-structured, focussed interviews were chosen as the primary medium for data collection. This method seemed best suited to capturing individual experiences with and attitudes towards intimate aspects of a life event, such as infertility and the use of DI to build a family. According to Moser (1995), interviews are not only administered to collect such data, but they are also suited to capture beliefs, feelings and knowledge, as well as demographic information. The semi-structured quality of the interviews makes it possible to focus on areas relevant to the research question. It also provides opportunities to explore individual areas thoroughly and gives sufficient flexibility to ask in-depth questions if respondents want to explore areas in more detail. My previous experience with my MA thesis (Thorn, 1999) provided me with some experience in developing and conducting semi-structured, focussed interviews.

Development of the questionnaires

My clinical and research experience, as well as discussions with medical and psychosocial professionals, and a comprehensive study of literature on the topic contributed to the development of my understanding of the factors that may influence parental decision-making. The following areas were considered relevant in this respect and constituted the main areas in which data was to be collected:
• The experience of male infertility or any other factors leading to family building by DI;
• Respondents' level of information about DI;
• Respondents' understanding of family composition after DI;
• Experienced and/or perceived reactions towards family building with DI by significant others;
• Respondents' understanding of the semen provider's meanings and roles;
• Individual factors regarding information sharing;
• Professional and peer support for information sharing.

As male infertility, the most common reason to use DI, is an intimate and sensitive subject which can impact differently on the male and the female partner, it seemed important to capture both men's and women's experiences and views separately, as well as their attitudes as a couple. Therefore, two separate questionnaires were developed. One questionnaire was designed to capture the male and female respondents' experiences individually (see Appendix B: Individual Questionnaire). This questionnaire contained 40 open-ended questions. The second questionnaire was to be administered after the individual interviews to each couple to enable me to gain insight in the couple's dynamics regarding information sharing (see Appendix C: Couple Questionnaire). This questionnaire contained 30 open-ended questions. Assuming that some respondents would have had limited or no opportunity to discuss information sharing, I expected the interviews to have an impact on their thoughts and/or the discussions they had with each other or significant others. In order to ascertain whether this was the case and to understand the nature of these discussions, all respondents were handed a feedback form at the end of the couple interview and asked to fill this in individually, approximately two weeks after the couple interview (see Appendix D: Feedback Form). In this feedback form, they were asked to report on any thoughts, ideas or discussions they had had following the interviews. This form contained three open-ended questions. It also contained a question regarding respondents' willingness to participate in a follow-up study five years after the completion of this study. This data was included in the analysis.

Based on my experience as a counsellor and researcher, I expected some couples not to have discussed the issue of information sharing at all or to have discussed it only in a limited fashion. In this case, the interviews would possibly be the first time that most respondents would have shared their views not only with a researcher, but also with their partners. Should respondents voice their need to explore this issue
further, referrals to counsellors were considered to be helpful and would have been provided; however, this was not necessary. Nevertheless, in some cases respondents indicated the wish to use my expert knowledge regarding DI during the interviews. In these cases, in agreement with my chief supervisor, it was considered ethically appropriate to answer any questions after the research interview was completed. These sequences of the interviews were included in the analysis of the data and in the description of the results. I had not anticipated that respondents would request me to help them establish contact with others pursuing DI. The need to get to know others, however, was voiced by several couples and I fulfilled this request.

University of Canterbury Ethic Committee’s approval was applied for and obtained for this study on July 31, 2001. There is no ethical review required for a study of this nature in Germany.

Pilot study

A pilot study including three couples was conducted between August and November 2001. Respondents were recruited through the German patient organisation IDI, a publication I had written on family building with the assistance of DI (Thorn, 1997) and an information evening on DI carried out in autumn 1998. The individual interviews for the pilot study lasted between 70 and 90 minutes, the couple interviews between 30 and 60 minutes. The interviews of two couples were carried out in their homes, the interviews with the third couple were carried out in their friend’s house as they lived in a different country and were in Germany on holiday. In addition to answering the interview questions, respondents of the pilot study were asked to comment on the following four areas:

- Comprehensibility of the questions;
- Comprehensiveness of interview;
- Timing of the three interviews;
- Any additional comments.
With the first couple, these questions were incorporated in the final part of the couple interview. This procedure turned out to be confusing for the participants. It became apparent that both participants were still reflecting on the content of the interview and it was difficult for them to shift the focus towards giving feedback on the interview process. This section therefore was avoided in the next interviews, and instead the following two couples were handed an evaluation form at the end of the couple interview and requested to fill this in and send it back to me.

Analysis of the pilot interviews indicated that some of the questions that were in both the individual and in the couple questionnaire were redundant. The major change was therefore a more suitable division of those areas covered in the individual and the couple questionnaires; this resulted in a shortening of the individual questionnaire. Respondents replied positively regarding comprehensibility and comprehensiveness, as well as the timing of the interviews. They did not indicate that any additional areas would have been relevant. Regarding demographic information, only the religious affiliation of respondents was added to the questionnaires for the main study.

Main study

Sampling and recruitment

For the main study, a total of 46 respondents representing 23 couples were interviewed. Sampling criteria included: respondents living in Germany and considering DI treatment, and who had had a minimum of one consultation with a doctor, were undergoing or had completed treatment. In addition, respondents had to have sufficient German language skills to understand and answer the questions, and they had to be prepared to be interviewed individually and as a couple. It was considered irrelevant whether they were in treatment for their first child or for further children, as independently of the number of children, they would have had to consider how to manage information sharing. Also, as with the pilot study, only couples who had had no previous contact with me in my role as a counsellor or a group facilitator were accepted. Thus I attempted to limit as much as possible any influence on my part on respondents. It must
be acknowledged that those who had had contact with me at other functions, such as during the information evening in autumn 1998, or those who had read my publication (Thorn, 1997) had been subjected to my ideas. However, given the recruitment difficulty, these couples were included as my influence was deemed to be less significant in these cases than if I had been in a counselling role. There was no age restriction and no restriction in terms of sexual orientation. Therefore, the sample included one lesbian couple but regrettably no single female respondent. The latter is not surprising. As a result of legal uncertainties, the number of lesbian couples and single women undergoing DI in Germany is likely to be low (See Chapter 3 for a detailed outline of practices in Germany and the groups that can access DI treatment).

Initially, I attempted to recruit all respondents through doctors offering DI services. During the annual meeting of the AKDI in February 2001, participating doctors were informed of the plans regarding the research project, and they agreed to pass on information about this study to their patients. In August 2001, these doctors were informed that the pilot study would soon be completed, and in December 2001, they and any other doctors who to my knowledge carried out DI (a total of 39 at the time) were sent invitations to give to couples in treatment with them (see Appendix E: Recruitment letter to doctors). Four doctors indicated in writing and by telephone that they would attempt to motivate couples to participate, and one went to great lengths and sent the invitation to all 17 patients pursuing DI at that clinic. In March 2002, during the next annual meeting of the AKDI, doctors were informed of the progress of the project. By April 2002, this recruitment method had only yielded two couples willing to participate, and doctors were therefore sent a follow-up letter designed for those patients who had received the first invitation (see Appendix F: Follow-up letter). As no further respondents were recruited this way, further possibilities were explored by my chief supervisor and myself. I contacted two infertility counsellors known to carry out pre-treatment counselling and asked them to pass on the letter of invitation to their clients. This strategy yielded three more couples. At the same time, I sent letters of invitation to those couples who had in the previous months ordered my publication on DI (Thorn, 1997) (see Appendix G: Letter of invitation). Six couples were recruited with this method. In June 2002, couples who had indicated interest in attending a preparation seminar were sent invitations; this method yielded three couples. In addition, the invitation (see Appendix G: Letter of invitation) was posted in an Internet chat forum on infertility
supervised by a physician; this led to six couples offering to participate. During a meeting of IDI in June 2002, I was able to inform participants about the project; as a result, three couples who had not had any previous contact with me, as they had only recently joined this group, volunteered to participate. Altogether, these recruitment methods yielded 23 couples.

Several women interested in participating had to be declined, as the male partner was not willing to be interviewed. One couple from Austria and a German woman living in Asia contacted me, both were declined, as they did not fulfil the criterion of living in Germany. In addition, one woman who indicated she was single contacted me. During the interview, she revealed that she was in a stable relationship with a male but that he refused to carry out DI. She had hoped that she would be able to use the interview to explore and clarify her attitude regarding his rejection. She had wanted to pretend to be a single woman in the hope that a doctor would consider her for treatment. The conversation with her continued but tape-recording of it was stopped once I became aware of her situation and needs. She was recommended to consult a counsellor and the material from this conversation was not used in the analysis. One couple was not willing to be interviewed personally, but they sent an email describing their experiences with DI. This was not included in the analysis, as it did not cover all the themes included in the interviews with other respondents.

The difficulty in accessing respondents indicates that it was not possible to select a random sample of couples undergoing DI. Respondents were self-selected as only those who were willing to disclose their use of DI and share their experiences were eligible to take part. Naturally, as in other research in this area (Nachtigall et al., 1997), the majority of participants coming forward to be interviewed favoured information sharing. Therefore, this study is not representative in a statistical sense. Nonetheless, it is representative in that the factors raised by the respondents are based on the current social and cultural context in Germany and the responses given are very likely to be typical for couples undergoing DI in Germany.

17 This Internet chat forum can be found under www.wunschkinder.de. There is a chat forum for those interested in discussing issues related to DI, but registration is required to access this forum.
All individuals who indicated interest in participating were sent a description of the research project containing contact details for myself and for both supervisors, one in Germany and one in New Zealand, as well as a consent form assuring confidentiality and describing the possibility of withdrawing from the project at any time (see Appendix H: Description of the research project; Appendix I: Consent form). Realising the sensitive nature of this project, respondents were assured once more that they could talk to a counsellor should they wish to explore any issues arising from talking about their decision process in DI. Participants were also offered telephone consultation should they have further questions; however, this was only used to clarify dates and times. Before the interviews, they were again advised about the purpose of the study and assured of confidentiality. They were also advised that the interviews would be tape-recorded and transcribed for analysis. Participants were offered transcripts of the interview and the possibility of making comments and indicating any changes they felt necessary. All but one couple asked for and were provided with transcripts; none of the respondents asked for any changes. None of the respondents who agreed to participate withdrew their consent at a later time. All respondents were also offered publications resulting from the PhD thesis; most welcomed this opportunity and wished to be informed of any such publications. Some, however, because they were not able to read English, restricted this request to publications written in German. Participants were also informed that they could access the complete thesis at the Protestant University of Applied Sciences Darmstadt, Germany, where the second supervisor is located.

Carrying out the interviews for the main study

All but one couple wished to carry out the interviews in their homes. The couple, which asked to be interviewed in my practice, wanted to avoid having to justify my visit to family members living in the same house. With most couples, individual interviews with the male and the female partner were carried out on the same day, with one partner leaving the room while the other was being interviewed. With others, because of work commitments, separate appointments for the partners were scheduled. The couple interviews were always administered after the individual interviews. In most cases, the couple interviews were conducted one day after the individual interviews; in one case, a few hours after the individual interviews; and in a few cases, two weeks later. All individual and couple interviews lasted between 60 and 120 minutes. After the couple interviews, respondents were given the feedback forms, as well as a
self-addressed and stamped envelope. All respondents returned the feedback form. In addition to this, a contact summary (Miles & Huberman, 1994) of each interview or any other form of contact (i.e. telephone call) was completed. The contact summary developed for this study included the date of the interview, the code, a summary of the main findings and the interview atmosphere, as well as any new speculations and hypotheses arising from the interview (see Appendix J: Contact summary). The interviews were transcribed and listened to after transcription to ensure complete and correct transcription.

Analysis of the data

The data was analysed with the aid of the computer programme MAXqda (2001). Similarly to other computer-based qualitative programmes, MAXqda provides a systematic and simplified means of analysing the transcripts. MAXqda was selected for several reasons. In comparison with other programmes, it offers more flexibility in transferring transcribed interviews into the programme, there is no restriction as to the lengths of coded segments (from one word to several paragraphs), a high number of sub-codes can be developed (up to 10) and visualised, and coded segments can easily be located in the original transcription (Kuckartz, 1999). In addition, I was able to attend a seminar offered by the Protestant University of Applied Sciences Darmstadt on the use of MAXqda for qualitative research in spring, 2001.

A provisional start-list of main codes (Miles & Huberman, 1994) was created according to the research questions and the main areas covered in the questionnaire. These included, male infertility ("Male infertility"), family building using DI ("DI family building"), understanding family composition after DI ("DI family"), reactions and perceptions of others, such as family members and friends ("Sharing DI"), and the meanings attributed to the semen provider ("Semen provider"). Using open coding and microanalysis (Strauss & Corbin, 1998) the themes and phenomena emerging from the data were compared to these main codes, they were then revised and adapted. Microanalysis was also applied to generate further main codes, such as needs respondents expressed ("Needs") or the terminology they used to describe family composition after DI ("Terminology"). Open coding and microanalysis also served to develop novel relationships between categories. For example, the main code "Sharing" initially consisted
of respondents' individual reactions ("Reactions"), current and past attitudes towards information sharing ("Attitudes", including sub-code "Change over time"), as well as "Reasons for sharing" and "Reasons contra sharing", both including several sub-codes. With the help of microanalysis, the relevance of role models and advice by others in the same situation was highlighted ("Other couples/peers"). As a result of the stigma surrounding DI, I had not expected that such a need would be expressed, but respondents described it as a vital factor in influencing their information-sharing decisions.

In the end, a tree with nine main codes, over 60 secondary codes and over 200 sub-codes was developed. In the next step, the process of axial coding was applied to analyse if and how codes could be systematically linked with each other. Since the aim of the study was to explore factors contributing to a decision-making process, emphasis was put on discovering causal, intervening and contextual conditions (Strauss & Corbin, 1998). Many links were found between categories, for example, the quality of doctors’ information and the stigmatising nature of DI. Respondents felt that doctors may themselves have little information or feel stigmatised and thus were not able or willing to provide adequate information. A further link was, for example, found between the impact of those psychosocial professionals who worked in the adoption area and provided information about the current practice of talking to adopted children about their origins. Most respondents who had applied for an adoption drew parallels between the needs of an adopted child and a child conceived by DI and favoured information sharing. Finally, a conditional matrix was developed to summarise and highlight the main factors influencing parental decision-making.

In order to capture the context of the coded material, in many cases, long passages of interviews were coded. This helped not only to be able to analyse the content, but facilitated understanding symbolic meanings attached to the content in statements, such as, for example, the terminology respondents used to describe the semen provider and the meaning of this.

All passages quoted directly and indirectly from the interviews used in Chapter 7, where the results are reported, and in Chapter 8, where the results are discussed alongside existing knowledge of the topic, were translated by myself.
Triangulation describes the application of additional research options, such as other data sources, different research methods or different researchers, in order to validate and confirm findings or condense this material (Miles & Huberman, 1994; Moser, 1995). This study applied several types of triangulation. The interview setting included both individual and couple interviews, thus I was able to monitor whether there were inconsistencies between the individual and couple statements. The feedback form administered to the participants after completion of all interviews allowed them to comment on the interviews and enabled me to understand if and how the interviews impacted on respondents' attitudes. The contact summaries provided opportunities for additional cross-examining of the material. In order to ascertain more comprehensive data for this context, studying the attitudes and experiences of other stakeholder groups, such as professionals, the semen providers, and children could have been carried out. However, currently in Germany, there are very few counsellors offering specific counselling for DI. The results of medical practice and the stance of doctors carrying out DI were previously published (Thorn & Daniels, 2000a), and these are included in Chapter 3 and Chapter 8 of this thesis. This research, however, was carried out in 1999, and doctors' attitudes towards information sharing may have changed since then. Access to semen providers would have only been possible through the doctors. This was deemed unlikely given the current secrecy around DI in Germany. For the same reasons, it would also have been unrealistic to attempt to find several offspring conceived with the assistance of DI and old enough to participate in this research.

Reporting the results

When reporting on the results, special care had to be taken in order not to reveal the identity of the doctors or counsellors with whom respondents were or had been in contact. The number of doctors carrying out DI in Germany is limited; currently there are approximately 40. It is known amongst these doctors, and especially amongst the members of AKDI, that only two of these doctors require patients to undergo pre-treatment counselling. As there are only two counsellors these doctors usually refer to, the identity of both the doctors and the counsellors could easily be revealed. Therefore, not only were the names of respondents made anonymous, but also any references respondents made about the medical and psychosocial professionals they had consulted and the location where this consultation took place.
Summary

This chapter has provided an overview of the methodology applied to carry out this study. It has explained the motivation for using a qualitative study design, the genesis of the questionnaires and the rationale for carrying out individual as well as couple interviews, and for administering a feedback form. It has also outlined the process applied for conducting the pilot study and how the pilot study served to develop the final questionnaires used in the main study. Despite relatively general sampling criteria, recruiting sufficient respondents for this study was challenging. Therefore, the initial plan to recruit via doctors offering DI services had to be modified and other sources, such as the Internet and IDI, had to be included. All respondents were initially administered an individual questionnaire. The couple interviews were, subsequently, carried out. Respondents also filled in and returned the feedback form. The data resulting from the interviews and the feedback form was analysed using Grounded Theory. A computer programme designed for qualitative research assisted this. A tree with nine main codes and a large number of secondary and sub-codes was developed and interdependencies between codes were analysed.

This study also applied several types of triangulation in order to verify findings. These included the various interview settings (individual and couple interviews), as well as the administration of a feedback form. As the number of medical and psychosocial professionals providing DI services in Germany is limited, special care was taken in order not to reveal the identity of these professionals. Therefore, both in the chapter reporting the results and the chapter discussing the results alongside current knowledge, not only has the anonymity of the respondents themselves, but also of the professionals they consulted and the location where these provide DI services been preserved.
Chapter 7

Results

This chapter will describe the results of the interviews carried out with 46 respondents representing 23 couples at various stages of pursuing donor insemination. After a brief portrait of the respondents, relevant demographic information will be provided. The subsequent sections will illustrate respondents’ reasons for pursuing DI and the quantity and quality of information they were able to gather about this way of building a family. Discussions they had regarding other family building options, and their viewpoints regarding the use of DI for family building will also be described. Finally, their understanding regarding the family composition after DI, especially the meaning of the semen provider and the factors they considered relevant regarding their decision for information management, will be outlined. All the sections will not only draw on respondents’ experiences, observations, perceptions, as well as feelings, thoughts and fantasies, but will also include reactions of others, such as family members, friends, others affected by infertility and professionals. Where relevant, differentiations will be made between male and female respondents.

Respondents’ portraits

The 23 couples participating in this study were unusual couples in that they shared their experiences regarding male infertility and their use of DI insemination with me. This is not the norm in Germany. As outlined in Chapter 3, pp. 54-59, most German couples keep both male infertility and the use of DI a secret. Before the thematic analysis of the data, and thus, a “broken-up” and fragmented version of the narratives and discourses of the respondents is presented, this section will provide short portraits of the couples outlining relevant parts of their personal background and accounts. Names have been changed to protect their privacy.
Anni and Adam

As a social worker with a critical/analytical approach towards the use of technology on human beings, Anni said that she had been highly critical of AHR – until the couple found out that Adam had an extremely low sperm count for which the doctors could not give a reason. The couple decided against ICSI because it was too invasive, and they had had several DI treatments, which had all failed. Should they have a child, they were adamant that they would share information about the conception with him or her.

Berta and Brian

Brian was diagnosed with subfertility. The couple was undergoing DI treatment while the interviews took place. They live in the former GDR and complained about the lack of local treatment centres for DI. They had to travel several hundred kilometres to receive treatment. The distance meant that they also missed the opportunity to share their experiences with other couples undergoing DI.

Cathy and Christine

A lesbian couple, Cathy and Christine had a three-month-old daughter, Claire. They were open about their lesbian relationship and about the fact that they had used DI to create their family. They had consulted a Dutch doctor and received the semen of a man who can be identified by Claire once she has reached adulthood. They were the only couple who had self-inseminated.

Dora and Daniel

Daniel’s infertility was due to mal-descended testis. The couple was still attempting to conceive with the help of DI although they had had many failed treatment cycles. Neither talked about DI to others, and Dora did not intend to share this information with her potential child. Daniel’s attitude was similar, but he felt less certain about it.
Eli and Eric

Eric was diagnosed with subfertility. Eli was three months pregnant when the interviews took place. The couple was unsure whether they would share information about the conception with the child and intended to make this decision in the first few years after the child was born.

Fiona and Fred

Fred suffered from mal-descended testis and the couple was undergoing DI treatment while the interviews were carried out. As Fred’s father had had an organ transplantation, Fred was familiar with the concept of donation and viewed DI in this context. The couple openly discussed DI treatment with friends and relatives and also intended to talk to their child about its conception.

Geraldine and Georg

Georg was diagnosed with infertility resulting from mal-descended testis. The couple had had several inseminations using DI; conception was difficult as Geraldine suffered from endometriosis. Georg’s brother was the only person aware of Georg’s infertility. Neither Geraldine nor George intended to share any information about DI with the child, but felt uncertain about this. They were the only couple who asked to be interviewed in my practice. They explained that they share a house with a relative to whom they did not want to reveal that they had taken part in a study on DI.

Helga and Herbert

Herbert had suffered from testicular cancer, which resulted in azoospermia. The couple had received treatment from a doctor over 150 km from their home. They also attended a local self-help group where other participants underwent DI treatment. Helga was born out of wedlock, had known about this from an early age, but had only met her father when she was an adult. This impacted on her attitude towards sharing information about DI with the child, and she, as well as her husband, intended to openly acknowledge DI to the child. They had also talked to relatives and friends about DI treatment.
Ida and Ian

Ian also suffered from testicular cancer and the couple planned to start DI treatment one month after the interviews took place. They live in the former GDR. Many of their friends and relatives were aware of Ian’s infertility and of their interest in DI treatment, but the couple was unsure whether their child should learn about its conception.

Jessica and Jan

Jan was paralysed as a result of a motorcycle accident and requires a wheelchair; this was also the reason for his infertility. He was very active in several patient organisations. The couple had a one-year-old daughter, Jenny, who had been conceived with DI. They openly discussed DI with many friends and relatives and intended to share this information with their daughter. The daughter was present during all three interviews.

Karola and Klaus

Klaus had been diagnosed with subfertility and Karola underwent several treatment cycles with ICSI and suffered from severe physical complications. The couple had not yet started treatment but had consulted several psychosocial professionals about DI and received contradictory information. As a result, they felt extremely uncertain about DI and welcomed the opportunity to explore some of their concerns during the interviews. Should they decide to carry out DI and conceive, they intended to share information about the conception with the child.

Maren and Markus

Markus was diagnosed with azoospermia. He and Maren had completed their first cycle of DI treatment without success. Markus, self-employed in the transport service, gave a very confident impression. The couple had actively sought contact with others experiencing infertility. They were open about DI and intended to share information about DI with their child.

Nadia and Norbert

Norbert was also diagnosed with azoospermia. Nadia found infertility very difficult because of her strong wish for a child. This was also difficult for Norbert and had apparently led to marital difficulties for the
couple. They had found out about Norbert’s infertility after they had built a house with several rooms designated for children. They sold this house after several ICSI treatments had failed and lived in a flat in Norbert’s parents’ house. They had completed one cycle of DI treatment without success.

**Olga and Otto**

Otto had suffered from severe testicular cancer, the treatment for this left him infertile. The couple had not yet started DI treatment. They had not talked to anybody about their intention to use DI and did not intend to share this information with their child.

**Pat and Paul**

Paul was diagnosed with subfertility. Pat had had many DI treatment cycles, which had all failed. Both had shared information about their use of DI with many others and also intended to share this with their child, should treatment be successful.

**Ruth and Rob**

Rob was diagnosed with subfertility and the couple had not yet started treatment. They welcomed the interviews as an opportunity to explore DI and asked whether they could establish contact with other respondents in order to discuss DI with them and decide for or against its use. They were unsure whether they would share information about DI with a potential child.

**Sonja and Stefan**

In addition to Stefan suffering from infertility, Sonja was diagnosed with uterus myomes. The couple had undergone several treatment cycles with DI, but without success. Sonja had attended several meetings of a self-help group and both she and Stefan intended to share information about DI with their potential child.

**Tina and Theo**

Theo was diagnosed with mal-descended testis and the couple had undergone several treatment cycles with DI. They had talked to some friends about treatment and intended to share this information with their child.
Ute and Uli

Uli was diagnosed with cystic fibrosis and the couple decided to use DI in order to prevent a child suffering from this genetic disease. The couple has a 6-month-old son conceived with the assistance of DI, and were thinking about undertaking more treatment for a second child. They openly discussed DI with friends and relatives and intended to share information about DI with their son.

Vera and Valentin

Valentin was diagnosed with azoospermia. The couple had carried out several cycles of DI, which had not been successful. The couple was unsure whether they would share information about the conception with their potential child.

Wally and Walter

Wally and Walter were both diagnosed with cystic fibrosis and decided to pursue DI in order to avoid passing on this disease to a child. Wally is Irish and had worked and lived in England and in Germany. She described infertility in England as more openly discussed than in Germany and this seemed to have had some impact on her and her husband’s open attitudes. They had talked about DI with some friends and close relatives and intended to share this information with their child.

Zarah and Xaver

Xaver was diagnosed with subfertility. Zarah was pregnant while the interviews took place. Both had talked to many people about DI and also planned to share this information with their child.

Zinnia and Zach

Zach was diagnosed with Klinefelter Syndrome. The couple had completed four cycles with DI but had not yet conceived. They intended to share information about DI with their child.

It will be observed that interview material from some couples will be more extensively used than from others. This is because of the variation in the length of the interviews and the way in which ideas were expressed.
Demographic information

For this study, 23 couples were interviewed. Twenty-two couples were heterosexual and married. As noted above, one couple was in a married lesbian relationship. All respondents were German, apart from one female respondent who was Irish and married to a German. The couples were recruited from all over Germany, but there were only three couples from the former German Democratic Republic. Table 7.1 shows the age distribution, the professions and the religious denominations of the respondents.

<table>
<thead>
<tr>
<th>Age</th>
<th>female</th>
<th>Mean age</th>
<th>Range</th>
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<td></td>
<td>31 years</td>
<td>26 – 41 years</td>
</tr>
<tr>
<td>male</td>
<td>Mean age</td>
<td>36 years</td>
<td>31 – 43 years</td>
</tr>
<tr>
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<td>Professional certificate</td>
<td>University degree</td>
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<td></td>
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<td>20 (43.5%)</td>
<td>17 (37%)</td>
</tr>
<tr>
<td>Religious affiliation</td>
<td>Protestant Church</td>
<td>Catholic Church</td>
<td>no affiliation</td>
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<tr>
<td></td>
<td>19 (41%)</td>
<td>20 (43.5%)</td>
<td>7 (15%)</td>
</tr>
</tbody>
</table>

Table 7.1. Demographic Information

Respondents were in different stages of pursuing DI treatment. Those in treatment, pregnant or with a child amounted to 19 couples; four couples had not yet begun treatment.

Impact and management of male infertility

This section will outline the various reasons respondents gave for using DI to build their families. As this was due to male infertility in most cases, the section will describe the reactions and the ways in which men and their partners managed male infertility. It will also describe how, from the perspective of these couples, male infertility is perceived in public, and how family, friends and others reacted when
information about male factor infertility was shared with them. All of these factors impacted on the respondents’ management of male infertility, including their decisions regarding information sharing.

**Reasons for pursuing DI**

As Figure 7.1 shows, there were six factors which led respondents to consider using DI. The most common reason for using DI was subfertility of the male partner for which no specific cause was identified. In addition to male infertility, for five couples, the female partner was also affected by infertility.

![Reasons for pursuing DI](image)

**Figure 7.1. Reasons for pursuing DI**

**Impact of male infertility**

Approximately half the male respondents sought medical examination before their female partners. As they were aware of factors limiting their ability to father a child, such as mal-descended testis or previous testicular cancer, they expected their fertility to be impaired and sought medical advice relatively soon after they had unsuccessfully tried to conceive. Similarly to Fred, they described undergoing the examination as their own choice:
Fred: It was before we got married ... I said I definitely wanted to know before. ... I think we have an open and honest relationship, and I wanted to clarify [my fertility status] beforehand.

The second group comprised men who had no prior indication of any factors limiting their fertility. In this group, it was the female partner who was the first to have her inability to conceive investigated. In many of these cases, men had to be talked into consulting a doctor. Pat explained a typical situation:

Pat: Then I went to a doctor and was examined again and actually nothing was found. ... And she said, Well, now it's your husband's turn. And that took over a year. I think it took one year until I had convinced my husband to go and have an examination.

Her husband Peter agreed, “It was only with quite a bit of pressure from my wife that ... I got an appointment with the doctor”. This also happened with Nadia and Norbert. Nadia had already been examined, and Norbert recalled that he “went to see a doctor because my wife pressured me”. Eric explained why it took some time for him to be ready to undergo an examination:

Eric: And ... male infertility, you don’t speak about it. I can imagine that many men [need] two years, it also took me a while before I was ready to consider that (...) it could be me. I think many men ... are not prepared to do [an examination]. I know from the Internet forum that several women wrote that their husbands would not be prepared to see a urologist to be checked whether they might be the factor. ... I also did not want to know about it for a long time.

PT: In the end, what led you to be examined after all?

Eric: Because we wanted a child. My wife had done all she could. ... And maybe one factor was that women start relatively early to go to a gynaecologist, or that it is simply a normal thing for women, while for men you can only do [health check-ups] when you are 40, I think.

Reactions towards male infertility

The confrontation with male infertility was associated with a range of strong feelings for both male and female respondents. These affective reactions included severe shock, disbelief, denial, powerlessness, and diminished self-esteem.

For most male respondents, the diagnosis of infertility was described as a devastating experience. They used strong and vivid words that, despite any suspicion they may have had, described the emotional
impact of the diagnosis. Eric reported that it was “brutal what happened to me”, Adam explained that “it was a big shock”, Georg recalled that the diagnosis had made him feel “pretty low”, while for Herbert it was “pretty shitty, when in the end we got the results”. Rob considered the result “a blow in your face”, and Brian was so taken aback that he was not able to talk to anybody about his infertility when it was first diagnosed:

Brian: Well, yes, I learnt about it ... from the urologist, he did all the tests and, then the sperm count and four weeks later I had to go again. Yes, and then he told me very suddenly ... that’s the way it is. ... And I was (...) the first moment, first of all (...) quite down, not like (...) well, how should I say, shocked, to put it bluntly (...) I could not imagine it, but (...) unfortunately, that’s what it is like.

Stefan had a very similar reaction:

Stefan: Well, it was pretty shattering. Well, because I never expected that (...) that it doesn’t function or that it doesn’t (...) work (quiet). ... First I thought, No, why me? Or (quiet), we never thought about it before, that this could happen. ... And well, nobody, goodness (...) I never expected that.

Their partners were aware of these strong reactions and recalled that, for their husbands, “a world collapsed”, that they had “rarely seen such a strong emotional reaction” from their partner, that “he was very disappointed” or “extremely shocked”.

Only the three male respondents who had suffered testicular cancer did not share these strong feelings. For all of them, cancer was a life-threatening disease, and this had ongoing significance for them. They recalled details about the medical treatment they had to undergo, their strong emotional reactions and, like Ian, described infertility as secondary and of lesser importance:

Ian: There were differences in my perception. ... [Infertility] is currently certainly the greatest problem, but it is not the greatest problem of my life. This was certainly the cancer. ... There would not be the possibility of fatherhood if I had not survived cancer.

Other reactions of male respondents included disbelief and denial. Similarly to Valentin, several men underwent “not just one but two or three [examinations] and in the end [they] found out that nothing could be done”. Many couples, such as Ruth and Rob, underwent several treatments with ICSI, hoping that this method would enable them to conceive despite a very low sperm count:
Rob: The reason for us was that I was diagnosed with azoospermia. At first, that means of course that you cannot do any ICSI treatment. But then further examinations showed that despite this azoospermia, ICSI was possible. We tried it three times altogether in a clinic in (N-city) ... but without success. ... We just had to find out that all of these nice brochures and statistics, which only talk about success ... were not relevant to us.

Only one woman conceived with ICSI but miscarried. None of the other women achieved pregnancy.

Almost all male respondents expressed feelings of powerlessness. Infertility was perceived as "the fate which one finds difficult to accept" but that could not be escaped, "a blow in your face", "something that was unimaginable", and said they felt "helpless and depressed". Norbert explained his helplessness, realising that there was nothing he could do to restore his fertility:

Norbert: No perspective (...) I was powerless and felt defeated. I could not do anything anyway. It was not like taking the waters, taking medicine, and then it is OK again. ... It takes its time until you have managed it. ... And then there was an evening, we had friends of my wife round for whom we had renovated a flat, and after they had finished, they went away for a weekend and I was to come along. That was when we had the diagnosis already. ... And I said I didn't want to come along, just go alone. ... I was glad to have some peace, then you can reflect a little (...) about the whole thing. And I was glad when the two went by themselves and I didn't have to talk to anyone, didn't have to answer, that I was all by myself. Then I walked through town for an hour and a half. Normally I don't like walking, I drive or go by bike. But then I walked and I was glad the two were gone, that I didn't have to say or hear anything. ... But what can I do? I have to live with it; there is no other possibility.

Being fertile was perceived as natural, normal and desirable. Lacking the ability to procreate was experienced not only as a physical deficiency, but also as a factor impacting negatively on male self-esteem and identity, as well as on the social expectation of a man to be virile and potent. Peter's example showed how problematic it seemed for many male respondents to distance themselves from the perception of virility and fertility as being interconnected. At an early stage in the interview, he considered the thought of men discussing male infertility unusual, commenting that "an interest group for infertile men, that does sound strange ... [men] don't talk about it", that "there are male ideals which are propagated again and again ... that there are perfect men", and that he compared himself to these ideals, which included being fertile. Therefore, infertility was "more painful on the psychological level than normal pain". At a later stage in the interview, Peter showed how difficult it was for him to preserve his confidence in being male:
Peter: Well, when adopting or doing inseminations, I think it is important what others say. Well, (...) maybe also the pain, maybe especially with men. I don’t see myself as a failure (quiet) although I would not necessarily manage by not somehow clarifying for myself beforehand that I could (...) not become a father. That I am not a failure, that’s where I have a problem.

Other male respondents also explained “that one doesn’t feel like a proper man”, and talked of their “self-esteem being destroyed” when diagnosed with infertility, indicating that the connection between fertility and maleness is deeply internalised. Theo, who admitted openly that he “somehow does not feel like a man”, recalled that his colleagues had assumed that men who had undergone a vasectomy or were infertile were not able to have intercourse. He then explained to his colleagues that he “could work, but his work was not productive, other men can work productively”.

Their female partners shared this perception, as Berta explained:

Berta: It doesn’t fit the nature of the man that it is his fault. It is so unmanly. (...) I think for many men, including my husband; he did not find himself anymore at the beginning. A part of his maleness was simply gone. And that’s why I think people don’t talk about it.

Helga commented that her husband “only felt worth half as much”, and even Vera, who described her husband as relatively confident, said that “there were moments during which I had the feeling, he was wondering whether he was a proper man”.

Regarding these emotional reactions to infertility, there was little difference between the reactions of the male and the female respondents. Although most female respondents were not affected physically, they described themselves as just as devastated by their husbands’ infertility, as it also prevented them from having children. Achieving pregnancy and becoming a mother was viewed as something “our origin foresees for us. ... A women is there to have children”, and thus, infertility was like “a wall that you could not surmount”, or “being hit by a hammer”. Some respondents had felt that their “world broke into pieces”, and Maren described infertility “like a wave that rolled on top of me”. Similarly to men, they felt powerless: saying that infertility “shattered your world” and “threw you over”.

Only a few women reported that infertility was “not as harrowing” as they had expected and that it “did not mean the end of the world”. Maren reported that “then we had a look at the world”, indicating that the couple travelled a lot, while Wally started a new hobby:

Wally: I think that was really a good thing as well, because we really tried to make a conscious decision not to get too hung up on this and on having a child, and therefore I threw myself into sailing. I haven't been sailing for many years, and I really, I wanted to enjoy the boat, I wanted to learn about sailing and that was a lot of fun and took a lot of the stress away that we had before, because he was sailing all the time and gone all the time, and I think maybe that was just one of the reasons to get involved in that, so that I have something else.

**Gender differences**

Several gender differences became apparent with the respondents in this study. Most notably, men tended towards pragmatic solutions, such as “giving up [the wish to have a child]”. This was the case for Fred:

Fred: I leave it as it is, and I must (..) well, I think, OK, Fiona also says I managed it very quickly. I ... understood that I was infertile; let's go on, there was a turning point right away, what other possibilities are there, and ... therefore donor insemination.

Like Georg, many attempted to accept infertility “as it is something you cannot change ... and my attitude is a little bit, not to worry too much about what you can't change”, or said they “had to accommodate myself and ask myself what else I can do with life”. Female respondents, by contrast, reported that their inability to conceive with their partners had different dimensions. Dora highlighted the fact that “we are now 35, at some stage the decision has to be taken”, referring to the biological limit to her fertility. Berta said that her cousin’s children “always make me think and make me feel only half”; indicating that she sadly felt the lack of children. Whereas all male respondents displayed very few emotions when discussing their infertility, several of the female respondents suggested that this section of the interview reactivated some of the feelings they had when their partner was first diagnosed. They talked very slowly and hesitantly, apparently emotionally moved again by this challenging experience. This was particularly apparent with Geraldine and Tina who both cried during this section of the interview:
Geraldine: At the moment it is very bad because many of my friends (..) are all having children. And it is difficult somehow; they just get pregnant right away. Also my brother, he will marry this year (..) and [my sister-in-law] got pregnant right away and they live in the same house. And when I heard that, I thought, No (crying).

Tina: Yes, for me it was also very bad. Because (..) well, we both, well it was a wish of us as a couple to have a child. Or to see both parts united in this child, let me put it this way. ... This is why it was very difficult for me to know that this will never be the case, this is very sad (quiet). ... I still don’t think I have overcome this, there is simply something missing (crying). We somehow try to deal with it. ... You pack it all up and put it away, but then when something comes along, then you think about it again and (..) then it (..) is there (quiet).... But we both really suffer.

An additional difference was the degree of depressive reaction by the male as opposed to the female respondents. Although the male respondents seemed to suffer as much as the female respondents, the women in this study described less severe depressive reactions, such as social withdrawal or shattered self-esteem, than the men. The fact that they were not the infertile partner, but also the fact that they more openly acknowledged and discussed infertility and treatment, and shared their feelings, thoughts and concerns with others, may have contributed to this. Berta explained the different reactions that were apparent for many couples:

Berta: [T]he fact that one could not do anything to have a child; that was the worst for me. That was very bad (quiet). ... I think [for my husband it was] just like this as well (quiet), but he did not say as much. He was also sad, but he was sad in a different way. He was (...) I think I showed it more openly, I was more angry. He, I think, he did think about it, but he did not directly (.) say it. He was sad, he was disappointed, and maybe he felt a little ashamed because of it.

Several male respondents, such as Rob, who “crawled back into my cave”, and Peter confirmed these differences:

Peter: Well, while my wife mourned and cried, I probably pushed it aside to some degree, as a means of coping with it. Of course I knew about it and it was sad. But it did not break out so openly with me. I did not really want to admit it myself and just didn't have so much time, either. ... I was interested in what sort of treatment there was and what sort of possibilities.

Most female respondents described their partners as managing well on the observable, outward level, however, there were also some indications that not all the wives trusted their husband’s pragmatic management. Similarly to Fiona, Wally wondered whether her husband was more upset than he actually showed:
Wally: I think ... he felt, not embarrassed by it, but I think he felt disappointed and a little bit surprised as well and (.) but was quite realistic and quite practical about it. But I think there were moments where he felt he would never be able to pass on, well, who he is, his identity, to another, to a child. He didn't cry. When we found out and we travelled in Sweden, we sat down and I just said to him, If you need to cry... And he cried a little bit, but just for 30 seconds or something. And the day after ... he never got upset about it again, we talked about it, and he'd only say, Well, we'll see what we can do, what our options are, and ... make our decision after that. And he's never been really emotional about it all, angry, or... Sometimes I ask, Are you trying to suppress it or what? And he says, No. He is really showing how he is feeling. (.) He is a very sort of practical person, and (.) I don't know.

Only one male respondent was worried about his long-term management of this crisis. Otto feared he might not come to a resolution about infertility as easily as his wife, because he did not share it as openly with others, but instead “bottled it up inside of me and [feared] it could break out at a later stage in my life”.

*Public perceptions of male infertility*

Respondents did not only associate male infertility with negative connotations themselves, but also believed that this was the publicly held assumption. Almost all respondents supposed that men suffering from infertility were considered less virile and potent, felt that male infertility was regarded as a taboo and stigmatised topic and complained that there was little knowledge, awareness or information about male factor infertility.

When asked how he thought others might perceive men suffering from infertility, Herbert, like many men, feared that others would question his maleness:

Herbert: I don’t know. Maybe they think, He cannot father children, he is not a proper man. And I am not sure how they see it, because we did not talk about it to any friends.

Similarly to Theo, Ian also explained that his friends thought negatively about infertility and that they assumed it had an adverse impact on the ability to perform sex:

Ian: Well, in general (.) I think that [others] think negatively about it (quiet). ... I also think that it is often seen as (.) well, as (.) let me put it this way, everything that has to do with
sex or having sex. ... When people talk about impotence, then they do not mean making a baby but having good sex. ... And if this is not possible, then they think derogatively about it. ... And when there were situations when I talked about my disease or the cancer, then there was also the question, Well, what is it like? Then I could always say in a very relaxed way, well, sex itself is not the problem (quiet). This works the way I want it to work and the way it always has. And then there were discussions about infertility, which initially I did not to participate in, because there was (...) no need to, from my perspective back then. And I think most people who think about infertility ... think that one is not able to have sex, and this is why they think negatively about it. It is not about having children.

Other men also assumed that they would be seen as “someone who cannot do it“, “not man enough”, and “that I would be ridiculed because I am not a proper man”. Adam commented that “amongst men, you laugh about it”, and Xaver added that “the larger part [of society] somehow views it as humiliating or that you are not man enough”.

Their female partners agreed. Ruth and Wally explained how strongly in their view masculinity was associated with virility:

Ruth: [B]ecause men have to be fertile. This is their ideal. Men must function. And if this is not the case, I think, this lowers their self-esteem (quiet). Of course, society sees men (...) always as a male ideal. Men must be potent and fertile and function. And everything else is, well, (...) negative.

Wally: I see that there are a lot of jokes. (...) It's very much linked with, I think status in society, and I think the whole issue is seen as an important part of male achievement, if you like, the same way as what car you drive, what job you have, am, yeah, if you are good-looking ... I think, they joke about it, am, but obviously infertility is a whole.... Many people in society, they realise someone is infertile and feel sorry for them, and if you take it away from the joke side ... I think they feel a pity for them and, am, they feel for them.

Other female respondents commented that “fertility is often thrown into the same pot with potency”, that infertile men “are a failure”, that “they are not as accepted”, that “they are held in low esteem ... and ridiculed”.

Male infertility, according to almost all respondents, including Marcus, “is not talked about”, “the topic is probably taboo, ... a difficult topic”, or is simply “not a topic”:

Markus: But I think that in public it is a taboo subject. Because nobody talks about it in public and says (...), well, that I cannot make any children, at least to me nobody has said that so far. The first person that said that to me was in the [IDI] group in (D-city).
As Adam indicated, the fact that few men share their infertility experience openly seems to contribute to the taboo, or even results in a vicious circle of perpetuating this public perception:

Adam: Well, I can't really say how it is perceived in society because nobody talks about it. Well, I don't know anybody. Well, now I know some, of course, as a result of this [IDI meeting]. ... But before that I never met anybody, and of course, you don't just tell anybody and everybody because it is, well, a very intimate problem.

Although Adam talked about it, eventually he, together with many other male respondents, voiced his anxiety about being ridiculed and laughed at because infertile men cannot provide "what they are supposed to deliver".

The perception of female respondents was very similar. They said that there was "silence about it in public", that "it is a taboo subject" which "is not discussed" and that "this is not a topic that is relevant for people. It is still not a topic. I still think that maybe it is pushed onto the wife", showing that infertility was still, if raised as a topic at all, raised in the context of female infertility. Christine, one partner in the lesbian relationship, also commented that "for hetero couples [sharing] may be a problem because they cannot talk about [male infertility] because it is a taboo subject".

Those male respondents who had suffered from testicular cancer, undergone medical treatment and/or psychological group therapy, commented on another dimension of the perception of male infertility in the medical setting. Some respondents recalled that infertility was discussed with them prior to or after surgery and chemotherapy, others reported that this was not the case. For Herbert and Ian, infertility was not an important issue when cancer treatment took place because they were too young. Ian said, "Infertility was not an issue for me as I still had one testicle and ... with my girl-friend back then, having children was not relevant". Asked whether he was informed about the possibility of cryopreserving semen, Ian responded:

Ian: I am not sure whether I was really informed. ... I was operated on in (A-City) and in 1992 [cryopreservation] was only possible in (B-city), so there would have been some effort ... and an effort which back then would not have been reimbursed by health insurance.

Nor was Herbert fully informed:
Herbert: No doctor told me about [infertility]. At the beginning, I didn’t think about it either. I was ill, and I was glad someone helped me to become healthy. It could be that [infertility] was there before, we don’t know. And it was pretty shitty when in the end we got the diagnosis (quiet).

An additional difficulty voiced by several respondents was the low profile of male infertility. They commented that certain medical interventions for male infertility were, in contrast to treatment for female infertility, neither reimbursed nor tax-deductible. In these cases, it was the German legislative authorities that were considered to have granted male infertility a lower status than female infertility. Eric, who had filed a court case in the hope that the cost for cryopreserving his semen would be reimbursed, shared his strong views about this:

Eric: I don’t know whether my wife has mentioned it, I have filed a court case with the Social Court so that the costs of cryopreservation can be reimbursed and the storage fees in (B-City). It is such that male, restrictions of male fertility are accepted as a disease. ICSI therefore is reimbursed by health insurances, no matter whether it is the woman or the man who suffers from infertility. But if it is male factor infertility and you still want to have a child, then this is not bearable financially (quiet). You have no chance for any reimbursement or help or anything. If you think you cannot afford it, you do DI. And the others are left on their own. And I think this is also a reason why male infertility is not discussed.

Some respondents, such as Uli, voiced anger about this disparity, especially couples who had to pay for treatment themselves and who for financial reasons, had to limit the number of treatment cycles, or couples who were not well off and also had to limit the number of treatment cycles:

Uli: We argued for hours about the fact that now you have to pay. I thought it was terribly unfair that health insurances don’t pay for it. ... What I still don’t understand is the fact that they pay for one option but not for the other. ... It was pretty silly that in our case they did not pay for the testicular biopsy ... even when ICSI was reimbursed, again they did not pay for the biopsy because this was a different legal decision. ... That means they paid for the gun, but you cannot have the munitions for it.

Only a few respondents said that male infertility had recently gained more attention. Norbert and Peter explained that “more media presence and many programmes on TV” had contributed to this development. However, all of those respondents who had the impression that acceptance of male infertility had risen, such as Daniel, acknowledged that they had formed this impression after they had shared their experience of infertility with friends or family:
Daniel: Well, [infertility is] certainly [dealt with] more openly than in the past. But I must say that this is only the case since we have dealt [openly] with the topic. ... When you are affected, then you often hear the statement ... Oh yes, it is confirmed that it is not always the woman who is affected ... but also the man. Therefore I would say it is not always pushed onto the woman.

Zarah had had a similar experience:

Zarah: Well, by now, with my current experience, at least since we have talked with friends and family, it is not so tragic. Now (...) both of us think we should have made it more open right from the beginning, should have said that this and this is the case. Then there would not have been any more questions. .... And all of those people whom we told ... they manage it really well ... many say, I also know someone, or a good girl-friend of mine, it is the same with them.

Sharing male infertility with family members

Many male and female respondents had discussed male infertility with at least one family member. Similarly to Markus, who said that "of course Maren’s parents know and of course mine as well“, it seemed natural for most to share this issue with their parents.

Some men, however, seemed reserved and gave the impression that their parents were not fully aware of the extent of their infertility. Stefan’s hesitance indicated this:

Stefan: Well, they know it. Well, yes, I mean (...) quite how severely I did not explain it, only that with a normal procedure, we, well, (...) cannot have any children (quiet).

Others, like Georg, only talked to siblings:

Georg: The only one I talked about it was my brother in [a city 600 km away]. ... We discussed a potential operation and that’s how we started talking about it. ... Otherwise we were very withdrawn because we thought the entire time, How should we do it? And then the doctor said, You should actually not tell the child. And then we also talked to a psychologist or with someone who (...) something like that, we went to a seminar ... and I also talked to her and she also said she would not talk about it. ... And then we said to each other, Let’s not talk about it for the time being. And I don’t have a big problem with that. I can talk to my wife and my brother. ... If I cannot change something, then I don’t worry about it too much; I don’t need to talk about it to everybody.
Helga and Herbert were among the few couples who did not share their experience with both sets of parents:

**Herbert:** My parents are too conservative. That is the reason why I think they cannot manage it.

**Helga:** There is no acceptance, ... Even when a child is there by DI ... they may not accept the child. I would not want to imagine that.

Some respondents realised that parents who were aware of male factor infertility might wonder how the pregnancy occurred and may assume that it was with the assistance of DI. Like Herbert, they feared that their parents might reject the child. Other couples, at the beginning of the interviews, did not make this connection and differentiated between sharing infertility and discussing the type of treatment they undertook.

Independent of whether it was the husband’s or the wife’s relatives, respondents tended to share more with mothers and sisters than with fathers and brothers, and the discussions were often initiated by the female partner. The female family members, they reported, seemed more open, indicated more interest, and were more articulate about the emotional implications. Helga and Herbert explained this:

**Helga:** [We decided] according to our feelings, somehow. ...

**Herbert:** Yes, yes, according to criteria, as I said, my parents are too conservative. ... And my mother-in-law, again, I must say, she is very open and you can talk to her about anything, also as a son-in-law. And I did not know how she would react, but that was not a problem for me because she is so open ... you can simply tell her. She thinks about it very differently.

In most cases, family members showed empathy or at least acceptance. Many respondents recalled that their relatives “were shocked”, others said that “they felt sorry and were sad for us” or that “they were a little disappointed for me because I could not father a child”. Herbert and Otto recalled their mothers indicating that they had wished for a grandchild when they said, “I so much wanted to become a grandmother”, and realised that their mothers “suffered so much from it as well”. Some parents felt guilty because their son’s mal-descended testis was not operated on in time:
Theo: [My mother] reproached herself. She reproached herself because back then with the mal-descended testis it might have been too late. … Why did she notice it so late? Why did I not say it? Maybe it is a taboo topic, and so on. She really reproached herself … because her greatest wish was to become a grandmother at some stage.

For two parents of the male partner, the fear of their sons being left by their partners was an issue. Markus recalled that his father had said that “he could understand if [Maren] would leave him”, and Anni was aware that her parents-in-law “were very much afraid that I would separate from [Adam]”.

Only in a few cases did family members show little or no reaction. Anni recalled that her father-in-law was “difficult to understand” and “bottled up”, referring to his introvert personality. Stefan’s mother “did not react in any significant way”, and Sonja explained that her parents-in-law did not “want to realise that … it was somehow their son” who was affected by infertility. This was also the case for Wally:

Wally: And my family is unresponsive about it, they're Catholic [and live] in Ireland … and my mother is very religious but she had no real comment about it, if it is a good thing or a bad thing. But the fact that she doesn't say anything means whatever you want, or there you are. I take it, as I think she would prefer it if we would drop it.

One couple reported that the female partner’s mother reacted in a very unhelpful way. “After finally having gathered all the courage to talk” to her mother, Ruth said that her mother “very typically turned it immediately into a reproach”, which was very difficult for her to manage.

Sharing male infertility with friends and colleagues

The decision to talk to friends seemed more challenging as infertility was described as an intimate issue, and not all friendships were perceived to be so close that this could be shared easily. Therefore, many male respondents, including Eric, did not share it with anybody:

Eric: Only in the [Internet] forum where I remained relatively anonymous. OK, (.) my mother knows about it, my parents-in-law….

PT: Did you also talk to friends about it?

Eric: No, so far not. As an outlet-valve I have the Internet forum.
Norbert explained that he “must be able to manage on my own, to find my own decision”, and Stefan said that “the friendships are not so deep” that he would share his infertility. Ian, who very openly managed his cancer disease several years back, explained:

Ian: A large part of my immediate fellow students knew. ... In May 1993, I had the last chemotherapy treatment, and I noticed that talking helped a lot, that I talked about it and dealt with it quite openly. I probably also got on people’s nerves ... but I simply told many people because I felt better afterwards. ... Most of my colleagues do not know about [my infertility], but my boss knows ... because I want to accompany my wife [during treatment]. And I told him that my health and our marriage are the most important things for me. ... At the moment, only two or three people know about [my infertility].

Only a few men managed infertility relatively openly: Xaver, Adam, Klaus and Daniel talked “to good friends”, to “family, friends [and many] acquaintances”.

In contrast to their husbands, almost all female respondents had shared their husband’s infertility with friends. Many, however, like Olga, carefully selected their conversation partners:

Olga: My criteria are simply, hm, (...) well, a friendship that has been going on for several years, and (...) simply people where I know that I can trust them, they don’t go to the next person and tell them. If I know that I can tell them and they will keep it to themselves. Yes, this is the certainty I need. I don’t want to be asked by somebody whom I don’t want to talk to. ... I have had that a couple of times and I felt cornered, and I might tell more in a situation like that than I actually want to. Yes, I want to select for myself, this is my issue.

Other women felt pressured to admit infertility because their age and length of marriage was commented on. Some of these remarks were perceived as relatively neutral, others, however, appeared to be painful, and several women, like Berta, felt the need to justify why they had not yet had any children:

Berta: Because we had also reached the point where we could not be silent anymore. Because there were always such remarks from others, like, Isn’t it about time? Or, Do you need some instructions how to do this? ... That’s when we started really talking about it, because we simply did not want to listen to these remarks anymore. Because they did hurt, somehow. When we started talking, we noticed that it was not so bad after all, because it was not our choice, we would have preferred it differently. But now, this is the way it is.

Ida and Ian married so that they could undergo ICSI treatment. As it was not reimbursed at that time, they asked their friends to give them money instead of wedding presents, thus making everyone aware that Ian’s cancer had resulted in infertility:
Ida: Our best friends knew it, I think, and they also asked a little. But the whole issue became public when we got married. We had to marry [because of ICSI treatment], so that we could do it. We went to the health insurance [people] and they said that we had to contribute [financially]... and we had to be married. ... And then we found that it was not reimbursed. ... And then we said, We will get married and we would like to have money [as a wedding present]. ... And thus, it was very open, that we collect money ... so that we can pay for treatment.

Several respondents, such as Vera, initially denied having discussed infertility with others but realised during the interviews that they had indeed shared it:

Vera: [We do] not really [discuss it with others]. Because we are not (.) yet in agreement about what we really want. Not being in agreement does not mean that we are of different opinions, but we simply don't know [whether we want to tell the child]. We don't know what is right and what is wrong. ... We are unsure, and we more or less said that we do not say anything until we know 100 percent what we want. Because otherwise we cannot keep it a secret anymore. ... And [some time ago] I met somebody I knew from earlier days, a school comrade who has the same problem. I had no contact with her for many years; every once in a while, Valentin bumped into her. ... She is the only person to whom I really talk about it. And (.) my father, I told him, when the diagnosis [was made] back then. I had the need; we did not yet know what we should do. ... And then I told him. Hmm, for him this was a little, well, he is a different type of man, I think it was a bit difficult for him, to have such a son-in-law. But the second time we talked it was different already, he must have given it some thought. ... I never got round to telling my mother [because my parents separated and there was little contact]. ... I wanted to, but the situation just was not right.

Asked whether she had talked to the other women in the support group she had attended, she replied that they did know, but “they knew that no one else knows”.

In this passage, Vera commented on several other issues. She and her husband were still undecided about whether they would share information about the conception with their child, and this seemed the main reason why, initially, Vera indicated that they had not talked to others about her husband’s infertility. Vera was one of the few respondents who, at that stage, talked about the risk that children may learn from others about their conception if the parents had shared infertility or DI with third parties. She considered this risk minimal as the couple had moved away from where the friend lived and where the support group took place. Vera was confident that “they would not tell anybody else and I don’t think there could be a leakage there”. This only left her father who knew about his son-in-law’s infertility and would probably be surprised should Vera become pregnant. Vera, however, did not raise this in the interview. Others
consciously tried to limit the number of people they talked to, and Pat, who had shared her husband’s infertility with many people, recalled how she changed the way she managed sharing:

Pat: Well, we talked about [male infertility] and what options there are and why. ... I have a large circle of friends ... and many people I can talk to, and I made use of it. ... and then it was a problem for me when we started with DI. [According to the doctor] we should tell the child once the child gets married ... . And I knew how many other people already knew ... and that was a problem ... I was a bit worried, realising ... everybody knows but not my child. And then I started becoming a bit more careful ... not telling any more people or saying they should keep it to themselves.

As women reported a greater need to share, they usually initiated talking to others with their husband’s implicit or explicit agreement. This different coping style did not lead to any disagreement within the couples, although for some women, such as Pat, the need to share was so immense that they were not able to control this:

Pat: I simply had to share. I really told very many people. I think now I have counted 18 people.

PT: Have you counted again since yesterday?

Pat: This morning in bed. Maybe I don’t even remember all of them. But (.) I needed to somehow talk ...

Peter: Well, and I knew about it. I knew that she had told 18 people and you always tell it again.

Pat: Sometimes I had a bad conscience ... without my husband knowing. I have just told someone else or ... colleagues with whom I have talked before (quiet). Well, we are not friends, but they felt with me and I asked them not to tell anyone else. ... But they were all people you could trust.

At the same time, as a result of the fear of stigmatisation, several women mentioned the need to protect their husbands. This was the case for Geraldine, who also suffered from endometriosis:

Geraldine: [T]hen I always pretend that somehow (.) because I have regular pains when I have my period, well, that permanently with me (.) and well, I somehow push it a little towards that the problem is with me. And I always say it takes a bit longer [to conceive] because of my [endometriosis] ... the others know about this [but nothing about my husband].

Maren’s concern was also for her husband:
Maren: I always had the feeling that we were both affected. ... And for outsiders I always had the impression I was a second-class person.

Markus: That’s right, you never said, You [Markus refers to himself] can’t have any children; but always ... We can’t have any children. ... Which from my side, of course, is better. If the man can’t have any, there is DI. If a woman can’t have any children, it’s over. From that perspective, there is at least some possibility.

Similarly to the reaction of family members, most friends’ reactions were described as supportive and empathetic. Respondents commented that “they accepted it”, “they managed it in a very positive, nice way”, and that “they supported us a lot”. Several respondents realised that for most friends, male infertility seemed an unknown territory. This unfamiliarity had apparently contributed initially to awkward or even painful comments. Once they, like Klaus, had talked to their friends, they seemed to be more at ease with the subject:

Klaus: No, not really. ... There was lots of [insecurity] at the beginning. ... People asked us many questions, like, When will we become grandparents? When will you have children? And so on. Afterwards, these questions were not asked anymore. ... Then, different comments were made. ... But there was nothing that was a burden for me.

Rob explained that others needed time and an explanation so that they could process the information and react in a helpful way:

Robert: Yes, I talked to almost everybody. ... Even my colleagues knew from the beginning, something that made it much easier for me because you cannot simply expect others to understand. You first have to open up yourself in order to create understanding. And I really had two colleagues who were there for me in this difficult phase. And for me, this was the first real indication that I simply understood, when one opens up and talks a little bit about oneself, then [people understand]. This has also contributed to me thinking very differently, the last three to four years after the diagnosis. ... If I put myself in the shoes of the person I am talking to, and somebody suddenly confronted me with something like this, then I would also have to learn how to manage it.

Only in a few other cases did friends make negative and painful comments about male infertility, such as Tina’s friend, who suggested “that I should consider whether I wanted to stay with my husband, which was dreadful for me”. Otto was confronted with being a “single-balled man” referring to his single testis and was under the impression that “most people are shocked about it and in most cases they only talk about it once they have drunk some alcohol, when they have some courage“. Two couples reported that friendships broke apart, as some friends seemed reluctant to discuss infertility. Nadia and Norbert’s experiences were very similar to Maren and Markus’s:
Markus: [Our friends] have two children now, and we don’t have any contact anymore. We were together very often before. And I think this situation is really shitty, I must say, sorry for saying it like this, ... but I cannot understand their reaction, and I don’t want to understand it. ... We just could not [talk about our infertility] to them.

Apart from these two couples, and despite many worries and concerns, none of the other respondents experienced on-going negative reactions. In this context, respondents did not comment on the subject of infertility being taboo. Maren and Markus, who had talked to nieces and nephews, remarked that it seemed much easier to talk about infertility to children. They seemed more direct and spontaneous and asked many “good questions”, were “candid” about infertility and seemed to accept it more than adults.

Several respondents felt the need to explain absence from work and therefore talked about infertility to colleagues and bosses. Though they reported that “colleagues reacted positively” and were “supportive during this time”, they also indicated that they were fearful of informing colleagues and especially bosses about infertility treatment. Maren, who worked in a Catholic hospital, worried that she would be made redundant if her employer found out that she had undergone AHR. She said that “having children is OK [with the Catholic church] but please, the normal way”, indicating the church’s negative attitude towards AHR. Retrospectively, she recalled her fears were unnecessary as her boss reacted in a very understanding way.

Sharing male infertility with others experiencing infertility

A number of male and female respondents had attended self-help groups or had sought contact with others affected by infertility. For some women, like Vera, the need to, “talk, talk, and talk” was the motivation to seek this contact. Others, both male and female, reported that it was normalising and healing to share with others in the same situation. Tina and Theo met a woman in the clinic where they underwent AHR and stayed in touch with her:

Tina: I am very grateful that I have the possibility to share with someone ... who has the same problem, with someone who has the same problems and with whom I can simply talk, I can get information.

Theo: And that was also very important for me ... that one is not alone. Because you always
wonder why, I mean, you don’t know it. ... And then at first you feel a bit strange, but I was happy that there are others and that you are not alone in the world. And that other men have the same. It is a little bit of a pleasure, but as I said, actually sad for all of us. ... But it was a small confirmation that I was not an only case.

Herbert explained how difficult it was to find a group and the importance of this for his wife:

Herbert: We found the group relatively late. We searched and searched, God knows where, ... and then my wife rang [someone] in Berlin14 and from Berlin to (O-city) and God knows where until we had their address. ... And then my wife told me about the self-help group. And yes, that was very interesting for me, or for both of us, the way the others manage, it helped me a lot.

Information about donor insemination

Respondents expressed a variety of experiences in relation to gaining access to information about DI. Several respondents, such as Georg, “had heard from somewhere” that DI was carried out and, similarly to Adam, had a vague notion that DI was carried out in Germany:

Adam: I think ... I read about it in some paper heading somewhere, without any background information. Well, it could be that I somehow knew about it, in general. ... Well, I knew about all these other possibilities [of AHR], which now, of course, I know much better than back then.

In addition, Adam and Anni, like other couples, were advised about DI by the doctor who diagnosed Adam’s infertility:

Adam: Well, the doctor told us straight away about this option. During the second consultation, when ... I had given the second [semen] sample, that’s when Anni came along and then we discussed it together and explored it. And afterwards, as Anni said, we were very thankful that he told us this way straight away because we heard from couples that it can [take a long time] until you get to this idea [that DI exists]. Not everybody tells you, and we were lucky, in inverted commas, that there was a clinic here in (D-city) which offered it.

Other respondents had heard or read about DI in the media. Rob had read about DI in a women’s magazine:

14 The head office of Wunschkind e.V., the German patient organisation for infertility, is located in Berlin.
Rob: How did I learn about it? It is actually embarrassing. By accident I read about it in a women’s magazine, I think it was called Lisa or Laura, exactly, this is when I read about it the first time. Before this, it was an absolutely taboo subject for me.

Eric, who was aware that DI was practised in America, was informed by a friend that it was also carried out in Germany.

Eric: I think I learnt it from [a friend]. Well, the friend who (..) who told us about it. … When we came back with [the diagnosis] she told us that there is the possibility of DI treatment. That was the first time that someone in our closer social network talked to us about it. … Well, I don’t know whether I would have suggested trying to do it this way.

Several respondents had established contact with other couples suffering from infertility. Markus, who had also heard about DI before, said that it was another couple who had informed them that treatment “with the semen of another man is possible”. Vera recalled that the participants in the support group she attended had informed her of DI. Christine, although she described her knowledge about DI as “common knowledge”, used the lesbian network and attended a workshop designed to inform lesbians about DI, in order to find addresses of clinics abroad that would treat her and Cathy.

The Internet was a resource used by several respondents to find information and addresses of doctors, sometimes, as in the case of Ian, in conjunction with other resources:

Ian: Well, I knew that [DI] existed because a friend, well, who attended university in (F-city) was a donor himself as a student. Yes, you can make money with it. Therefore it was always in the back of my mind, that there is something like that, that there are sperm banks. And now, in this concrete situation, we listened around and then we found this brochure, and then came across an article in the Internet and a tip so that we had the addresses of clinics offering this, those which have sperm banks. And this is how, slowly but surely, we got the information. The doctors, well, they were very reserved.

Like Tina, many respondents explained information about DI, in contrast to other options, was difficult to gain:

Tina: We had heard of this possibility, that before we did not know anything about. Well, I think, when you talk about [male infertility], or you find out a little bit about it, then adoption is always the topic. And we didn’t know about DI.
When she and her husband sought help from a doctor, Theo recalled that their doctor said, “Well, to say it explicitly, you won’t get any further information [about DI],” which confirmed how difficult it was to gain any information about DI. Otto also said that “you can do ICSI and things like that, it was always about adopting children and that was it”, and Berta stated very bluntly, that “you simply did not learn anything [about DI].”

Many respondents were frustrated at this lack of information in general, and others were annoyed with the medical professionals who seemed reluctant to provide information. Zach said that he had had to be very insistent, and that in his case, it was the patient that provided professionals with new information:

Zach: In (D-city), [the doctor] always likes to listen. Well, ... he wants my wife to fall pregnant ... and when you read something new in the paper, you have to be really insistent with the doctor [and ask] what sort of possibility this is. And sometimes the doctor does not know himself, he must be glad that we provide him with the new information.

Zarah, who learnt about DI through the Internet, also recalled that it was she and her husband who initiated a discussion about DI with their doctor; they found it annoying that as patients they had had to be proactive.

Zarah: No [we did not receive any information by the doctor], only afterwards. And we were in treatment with Dr. (M) because of ICSI, and then we asked her about it, and then, of course, she talked, how they manage it in their clinic, and that they actually do it ... but before nothing was said.

PT: What was it like for you having to ask the doctor yourself?

Zarah: I don’t know. I did not think it was very bad. But my experience was that you simply always had to ask the doctors. ... You had a list of questions with everything that was going through your mind, and they themselves never thought of it. ... You always had to take care of it yourself. ... When there was a new problem, you had to run after them to make appointments. They themselves never thought of it.

Geraldine and Georg’s experience was similar. They said that DI was not taken into consideration by the doctors they consulted, and that they even commented on DI being out-dated:

Georg: [A]nd [the doctors] never talked about the issue of DI, only once we started talking about it.

Geraldine: The doctors....
Georg: Neither the doctors in the normal clinic nor [the doctors] in (D-city) took this possibility into consideration. My urologist, it was more that ... well, you don’t really do this, something like this.

Geraldine: Yes, this is how he commented.

Georg: Or the doctor says that, nowadays, you don’t do that anymore.

Geraldine: Because the possibilities are so great somehow, you can do something [with your own semen] these days.

Georg: Yes, and [DI] is not done anymore, you do ICSI straight away.

When starting to research into DI, many respondents commented: “It is simply difficult ... finding literature”. Daniel said that he had found several books, but “of 300 pages, only about two were on DI”, Otto commented that “there is not much [literature on DI], as far as I know”, and Valentin said, “It would have been nice if one was given something [to read] in advance without having to make enormous efforts [to find something]”. Others said that they had found one newspaper article and were aware of English books but, because of language difficulties, only two respondents had read some of them. Like Peter, several respondents compared the number of books on adoption to the scarce amount of literature on DI and said, “With adoption, you get a bundle of information ... and this does not exist for DI”. Many respondents raised the need for literature describing the experiences of other couples and families. As Valentin expressed it, this was considered important for their decision-making process for or against the use of DI:

Valentin: [M]aybe more literature, where you can [read] such questions, like the ones you have just asked at the very end (.) so that you have something to compare ... Yes, that would have helped us.

As a result of the lack of literature, Anni had considered “researching myself, as a social worker, and arranging interviews. ... I missed ... reading about the experiences of others”. Almost all respondents voiced a need for more general information and literature on DI. Others considered “a group that you can attend, ... where you can share information” and more information “regarding the psychology [of DI]” as helpful. Ruth wanted to have “literature on those couples which manage it openly, which may have children that are a few years older”, and Zarah, similarly to Daniel, simply “got annoyed because we hardly found anything. I went to the bookshops, but ... in all books on infertility, there is only a small
section on [DI]”. Her husband Xaver agreed and commented on his need “for more literature with such questions ... like you just asked”.

Contributing to increased knowledge about DI and lifting the taboo were motivating factors for many couples to participate in this study. Ida explained that she wanted “support [from me] very much in shedding some light onto this”, Karola “wanted to make a beginning” with more openness, Xaver wished to contribute towards “reducing the unfavourable conditions ... and discuss [DI] more openly”, and Adam hoped that my “work may be successfully published and then may somehow result in a major change, ... lift the taboo and make [DI] more transparent”. Many hoped that research projects, such as this, would result in a guidance book for couples considering DI.

**Information about legal aspects of DI**

In line with current practice in Germany, most respondents were asked to sign a written agreement according to which the husband assumed paternal responsibility for the child. Almost half of the couples were asked by the clinic to consult a public notary or a lawyer, others signed the contract directly with the clinic. Only in two cases did couples not sign any documents. Despite the high number of respondents who had consulted legal experts, almost all indicated confusion about the legal aspects of DI. Several respondents’ comments were similar to Fred’s:

Fred: The legal situation in Germany is zero. ... The legislators say nothing. DI is put into the drawer ... and there is more or less no legislation. ... I think it would be important that a child resulting from DI has the same status as a child born in wedlock.

Many respondents were under the impression that the legal experts they consulted “did not know” about DI and seemed challenged by the legal complexities of it. Only a few couples had current and correct information, such as Herbert, who had read about it in my booklet; he and Helga had signed a contract with their doctor. I asked Herbert what he knew about the legal situation in Germany:

Herbert: Actually, only what there was in the contract and from your book, that’s where there is also some information. ...

PT: And what exactly can you remember?
Herbert: Well, that the child has the same status as a child born in wedlock. Well, that I (. ) have the same duties as towards a genetic [child], if it were from me, the duties and responsibilities and everything, able to inherit and all of this. And I think that's good, that it is legally clear.

PT: Did the doctor talk to you about this again?

Herbert; No, only once he gave us such a (. ) sheet of paper, this form, and there was a consultation [and the advice] to look at this in peace. And when we came back, he said, Read it through again in peace. And for me, the legal things were clear.

There was a tendency for respondents who had consulted lawyers or public notaries or had read my booklet to have more accurate information than those who signed an agreement with the doctor only.

Legal status of DI

Several respondents feared that DI was illegal, or bordering on illegality. Adam, although he was informed about DI by his doctor, said that “it was probably on the edge of legality”, Fred commented that he “would not have thought that you could do it in Germany”, and both Helga and Ruth recalled that they initially thought that DI was illegal, and therefore Ruth believed she had to go abroad to carry out DI:

Ruth: I did not know anything specific about it before (quiet), absolutely nothing. Before I actually (..) thought it was only possible in Holland19 and that it was illegal here. Because before I never dealt with it, and I was very surprised that there was so much about it in the Internet. That such Pro Familia30 women dealt with it in such a natural way. No, before I thought it was illegal in Germany (quiet). ... [I] probably [thought so] because it is such a taboo subject. Because for me it was so far away (..) that I never had to deal with it. Or because internally, I felt it was something illegal. ... Because you always thought either it works or it doesn’t work. Well then, God didn’t want it to work, then I don’t want to go beyond what He foresees for us.

Karola, although she had read in a brochure that DI was carried out in Germany, was under the impression that DI was very difficult to carry out and only allowed in exceptional cases:

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19 Holland, the country where DI was assumed to be legal, is the country many women travelled to in order to carry out a pregnancy termination in the 1960s and 1970s, when this was illegal in Germany.

30 Pro Familia is a large national family counselling institution.
Karola: We were given a brochure by my husband’s urologist. And it informed us about ICSI (...) and on the last page there was something that in certain cases, but you need the approval of the ethics committee, well, it said that DI is possible. But it was worded in such a way that it (...) sounded to me that actually it is not possible. Only in exceptional cases and (...) after long waiting, somehow. Well, it didn’t sound to me that a nearby doctor would do it, it was very far away. When I read it again, then I somehow (...) had a soothing feeling that somewhere there was another possibility, although ... I had not yet familiarised myself with the thought. But somehow, ... there was something else. And then my husband read it and said, well, for him (...) there would not be any problem, he would even prefer this treatment.

Like Nadia, several respondents explained that their doctor had informed them that DI was illegal:

Nadia: And then we asked the doctor, and we were given the answer: No, this is not allowed in Germany. I think the reason we did not stay in [this clinic] was that afterwards I found out that it is allowed in Germany. And, I don’t remember how I found out, whether I read about it, or maybe I asked Wunschkind e.V., ... but we somehow had the information that it was allowed in Germany.

Although several couples assumed that DI was illegal or bordering on illegality in Germany before they had started exploring the possibilities, most couples, once they had commenced treatment, were aware that DI was permissible. However, they continued to believe that DI was a dubious practice. The fact that oocyte and semen donation are not inherently different, and that to Anni’s knowledge, oocyte donation in Germany was penalised, as well as a statement by a friend explaining the lack of funding for DI, contributed to her confusion:

Anni: I know that it is legal, but also that it is in a grey zone. Hm, I know that this grey zone also has something to do with the question about why costs are reimbursed or not reimbursed. But I am not so sure about this. This is where I feel a little confused. ... I know it is a gamete transfer and this is actually illegal in Germany. Well, egg cells (...) are not allowed to be transplanted. And basically sperm donation is the same. [A girl-friend] also explained to me that health insurance cannot pay for anything illegal.

Other respondents were concerned that the lack of legislation contributed to dubious practices. Adam described DI as a “shady area ... at the edge of legality” and feared that “everything was possible”. Zinnia voiced similar concerns. In addition, she remembered her doctor “advising us that we [were] not allowed to talk about [DI] at all”, and she and her husband Zack had signed a contract agreeing to this. When asking her during the interview whether this would mean that she would not be allowed to do the interview, Zinnia went quiet and said, "Actually not, no".
Interestingly, Zinnia and Zack signed an additional contract with a public notary, but, as with other respondents, they were the first couple that had consulted him and his knowledge about DI was very limited. Although by the time of the interviews, respondents were aware that DI was permitted, comments, such as DI being “nothing illegal. ... Yes, I know what we are doing is not illegal, that’s what I thought at the beginning. ... But otherwise we, well, I don’t know”, still conveyed feelings of uncertainty and emotional confusion about the legal status of DI for some respondents.

Paternity

A second area of doubt was paternity following DI. Respondents had received differing and sometimes contradictory information. Both Markus and Valentin were under the impression that they should adopt the child after birth. Markus said how uncertain paternity after DI seemed both in his eyes and in the eyes of his lawyer:

Markus: My lawyer advised us to adopt the child. [He said], Adopt it once it is there, then you are on the very safe side. I had not yet considered it from that perspective. Because he said that if there is an argument, usually with the wife, I could contest [paternity]. Because legally it is not my child, I don’t have anything to do with it. I did sign it, that I would bear all the consequences, but if you have a clever lawyer, then there are ways out. That’s very easy today. ... So adopt the child, then you are the father, that’s it, no way against it. That’s why I think you need to get advice from others rather than just asking the doctors. Because they said we should sign, the contract has to be made, the one we did in (L-city). ... It is not properly safe, but if there is an astute lawyer, then there are ways out, clearly ... there are always possibilities.

He also revealed his relief that he had consulted a lawyer independent from the clinic, indicating his fear that the clinic may primarily serve its own needs. Other respondents, such as Georg, were given contrary legal advice:

Georg: I asked whether it would make sense to adopt the child before it is born, just to be on the safe side. And [the lawyer] said, No, you don’t need to do this because.... How did he put it? I am practically the father and that I have the duties and that I cannot shy away from them. ... And that’s what we agreed upon with a public notary when he informed me of all these issues. ... It was interesting knowing all of it (quiet). And I also think it is good that you have to do this, I don’t think it was mandatory to [see a public notary] in earlier days.
When discussing with respondents the legal status of a father after DI, it was conspicuous that several men described that they were "practically speaking the father and have all the duties", explained that "if it is successful, it is as if it was my child", or even said that "I am practically not the father" (author's emphasis). These phrases described paternity in relative terms, indicating that paternity seemed uncertain for some male respondents.

Contesting paternity was another area of uncertainty and confusion. Some respondents were under the impression that full paternity was only granted after a certain period, such as Geraldine, who said that "after two years it is automatically accepted, that's when the father gets [full paternity]", and Sonja, who with her husband signed a contract with the clinic and understood that her husband could "contest his paternity within one year". Others again thought they needed to undertake additional legal measures, such as adoption, as described above. Daniel, in his hesitant statements, clearly showed the general confusion many felt:

Daniel: Well, this is a relatively complex issue. ... The precondition is that the couple is married. ... We had to make a contract with a public notary and the clinic that provided the semen. I didn't mind that. ... Well, I know that if it is born within the marriage, it is something like a biological child, no matter who the father is, except if I contested paternity. Well, and this really surprises me a little, that I could theoretically contest paternity retrospectively. ... I would have thought that the contract with the public notary was exactly so that you would actually commit yourself in advance to accept the child as your own. ... But I was surprised that you still have this possibility (.) to refuse paternity. ... Whatever, when I think about this, ... theoretically [the semen provider] could be the father of 50 children, and he could actually be responsible for 50 children. Whether it is exactly like this, I don't know. But with the public notary contract, at least, this is how it could be. And then it is not without risks [for the semen provider, either].

For Cathy and Christine, as a lesbian couple, the legal parenting rights were even more complex. They believed that "in Germany it is not possible to have DI as a lesbian couple because the doctors are afraid that, well, the acceptance of paternity. ... I think if there is no real man in Germany who accepts paternity, then the doctors are not allowed to give the semen". Both were aware that Christine, as the social mother, would not have any legal rights, and therefore they had to resort to other measures to provide some certainty for her. Christine commented on the rights for Cathy:
Christine: Because legally, initially [Cathy] has all the rights. But in the meantime we asked a public notary, a lawyer to issue a general warrant of attorney so that I would have this warrant of attorney for the child. I don’t know how much it is worth, but we somehow have equal rights.

In addition to this, the couple intended to place a declaration of their will with the relevant Department of Youth and Welfare so that Christine would be granted parental responsibility in the case of Cathy’s death.

*Record keeping and the offspring’s rights*

Many respondents had no information as to how long medical records of the semen provider and their records as the recipient couple would be documented. Anni was aware that “some clinics keep the records for 10 years. I know this is legal but it is also in a grey zone”. Her husband, Adam, “was reassured that our records would be kept longer than those 10 years”. Peter seemed very confused and commented that it was the semen providers who would be interested in the records being destroyed, so that there would not be the risk of the semen provider having “to pay alimony”. Helga commented that “the records can disappear, the doctor can destroy them ... after 10 years”. Zarah recalled that her lawyer could not provide any information about this and raised the possibility of contradictions between the right of the child to access his genetic origin, and the right of doctors to destroy medical records:

Zarah: Yes, not even the lawyer knew this (laughing loud). Yes, that is difficult. What would be great is if the child some time really, well, one always says that the child will have the right to access to documents at some stage. But we also read that the documents will only be kept for 10 years. And I think once the child is 16, then the documents are gone. And then the child does have the right, (,) but whether the doctor will then give him the documents, because it also protects the donor, who definitely wants to remain anonymous. And that makes me a little angry, that we have little means at the moment.

Other respondents were also aware of the connection between the length of record keeping and the possibility of accessing information about the biological origin of the child. Eric, who considered sharing the origin with his child, had already found out about the necessary legal steps:

Eric: If I want to give the child the possibility to get to know his genetic father, then I have to ensure a legal order before the 10 years are up. I have already read into this, this is what I have to do. At the latest after eight years, I have to hassle the doctor and say, Well, provide the information or let’s clarify it legally. That is the only possibility, because I think telling the child that she is from a donor genetically, and not giving her the possibilities to get to know him, that is a hot issue, then I only shift the problem away from me onto the child.
Then I don’t have the problem anymore that donated semen was used, but the child has the problem that she has to deal with who is actually my genetic father.

PT: So if you shared with your child, you would also attempt to ensure that the child can access this information?

Eric: Then I would ensure that there is a legal order, which is deposited with a public notary or a court. Well, I have already got a very clear concept of what to do. I would file a court case. Well, maybe we are lucky and by then the files have to be kept for such a time that when the children are 18, they can decide whether they want to meet the donor. At the moment, this unfortunately is not the case, there is this court order by the Federal Constitutional Court which clarifies the right to access one’s genetic origin. But on the other hand, doctors can destroy the records after 10 years and this doesn’t fit together.

Several other respondents also raised the issue of the right of the child to access this information in this context. Some respondents, such as Ian, assumed that “the child has a right to get to know his genetic father once he or she is 18“. Berta was also positive that the child has “a legal right to find out about the genitor”; Norbert, however, when adding, “if one can still find out about him”, indicated that the documents may not be available anymore. Other respondents, such as Fred and Daniel, believed that it was mandatory for the parents to tell the child of its conception:

Daniel: Well, what initially bothered me was ... well it bothers me, but I accept it. Well, that I have the duty if the child wishes to have the information about who is the biological father, I have the duty to tell, even against my will. If I had the will not to tell him, mmh, how to manage this, I don’t know. First of all, the child has to be born. Well, that was actually something that always bothered me, that there is a legal duty to tell. ... Apart from this I know very little.

Fred: The child must be told [his origin] and this is also my opinion.

Rob had similar information from his wife’s gynaecologist and was told of “a law according to which you are forced to tell the child about his origin.” Several passages later, however, he commented, “According to my knowledge, the donor will never be known, not even upon demand”. Ida assumed that the semen provider remained anonymous but said, “The child can find the donor, of his own will. And I think that this period in which the donor can be found will be extended. I think to 20 years or so”. Wally was also advised that the child “would have the right to know at the age of 18 the name and address of the donor, and that was a legal requirement for the sperm bank, we have to make this information available, and that was a surprise to me".
Cathy and Christine were the only couple certain that in their case, records were to be kept indefinitely.

Cathy was asked whether she knew how long the doctor would keep the records:

Cathy: As far as I understood, well, forever. Yes, forever, because it was very important for [the doctor] that we would call him once Cynthia was born and he congratulated us but also said, Send me a copy of the birth certificate. That was very important for him, that he has those documents. ... We also agreed ... when our daughter is 16, she can come to him and then she will get a letter with a copy of the passport and a letter from the donor. But you don't get that, only she does. That was important for him. I think he has a soft spot for children, well, I think he is for openness and he sees it positively to have transparency.

In the view of several respondents, legal clarification was important. Helga said, “I think it would be nice if the whole issue was regulated a bit differently regarding legislation, if a child, like in Holland, from a certain age on, like when it is 18, can undertake something, that would not be bad”. Klaus also supported this. He said, “It would be one of our greatest wishes ... if the period for keeping the records would be increased to at least 20 years”. Peter thought, “The files should be kept for more than 10 years, at least until the child is of age, and the child should be able to decide himself; with the destruction of the files, the taboo is created”. Christine’s wish was “for equal rights and acceptance of motherhood, and the same rights ... otherwise my position is very bad”.

In several cases, respondents asked me for legal information during the interviews. Ida wondered whether “it was correct that it would be our mutual child and we would both be responsible in case of a divorce”. Zarah wanted to find out whether “it was possible for the child to have access to the documents”, and Helga and Herbert wondered whether the records could be accessed if the child had a genetic disease and “bone marrow of the genetic father would [be required]”.

Information about medical aspects of DI

In contrast to the lack of clarification and access to legal information, many respondents reported that information concerning the medical procedure was adequate and sufficient. As described in the previous chapter, many female respondents had undergone ICSI prior to deciding to pursue DI, thus, they were familiar with treatment modalities and, like Olga, said that they were aware that it was less invasive than ICSI:
Olga: If everything is OK with me, then it is not such a big thing as with [IVF] because there is not such a strong hormonal stimulation ... there is little drug treatment and then it can be carried out with an injection and a tube somehow. ... It was the university clinic [that gave me this information] and I also read it in your book.

It was explained to other respondents that treatment was not complicated and they said that they felt “relatively well informed”.

The fact that DI is not reimbursed by the German health insurance system, nor regulated by medical guidelines, which means doctors can set fees individually, led to some concern. Maren and Markus shared their uneasiness regarding doctors’ fees for DI:

Markus: And when there is someone who says, Good morning, and smiles at you, and then asks you how you are and so on. And in (L-city), he says, Good morning, my name is …. and this and that, and that’s what I will do and so on. And if you have questions, I will charge € 30\(^{21}\) extra, and so on. And then I pay another € 30. Do you want to know more? Then go ahead and ask. And that is absolutely ridiculous ... it is only money-making in my view.

Maren: That was clear from the beginning.

Markus: Yes, it was clear.

Maren: They do everything that is medically possible, they do everything, that’s the way things are.

PT: What did it mean to you that you had to pay for the treatment but that other treatment is reimbursed by health insurance?

Markus: That’s bad. ... Certainly, as I said yesterday, what I find disturbing is that others jump into bed, have a child, yet I can pay for it, that disturbs me, but I cannot change it.

Zach criticised the lack of consistency in that “every doctor charges different prices” and also commented how bizarre it was having to pay for this treatment at all:

Zach: What disturbs me a little with (.) DI is that it is like (.) buying a child. ... And somehow it is like ... getting a slave. ... It is strange, somehow. I also know people who have children the normal way, and they don’t think of something like that at all, they don’t know how others feel and so on.

\(^{21}\)The interviews were carried out just after the currency conversion from DM to Euros (€). Several respondents still used DM whereas others used Euros. For the sake of consistency, all prices have been converted into Euros.
Eric assumed that "doctors do not want to go public [with DI treatment] because they would be perceived as money-grubbers". Several couples were strained financially as a result of the treatment. Anni and Adam were given money for "two treatment cycles" by Anni's mother, and Theo and Tina had used their savings for a house to pay for DI treatment:

Theo: Well, I can only say (...) that when we do this treatment with blood tests, and paying in advance and afterwards, and so on. I can only say in DM-prices, mmh, with the drugs, it depends, between DM 1500 and DM 2000 (€ 750 and € 1000). We had injections that were € 25 ... and we had savings for a house and that's gone now. It is a financial issue. And that's why, when I look into the Internet, all the people, there are hundreds, yes. And if you don't have money saved, then you cannot do it.

Only one couple voiced concerns regarding the medical aspects of DI. Tina said that she had only recently learnt "that there are different possibilities" regarding the form of insemination, and Theo commented that, in general, "doctors should be a little more proactive and give more information ... because the problem is that we don't even know ... which questions to ask". Peter and Uli criticised the fact that there was little time "to explore all the questions", and Theo described treatment as "a little bit like mass processing".

Several respondents indicated a desire for more information about doctors who carry out DI. Zach would have liked to have information about doctors who offer DI services in his area, and Berta commented that "there are so few doctors who do [DI]" and that the nearest DI clinics for her and her husband were over an hour's drive away. Eric also suggested that "the doctors of the [AKDI] ... where the most important doctors have united, ... should tell the public that we do this in Germany". Several respondents were surprised when they found out that there were more doctors offering DI near their home town, and commented that "we were not aware of that ... and considered [the doctor we had consulted] as the only possibility for us".

Other comments, such as Uli's, were related to medical treatment, referred to the costs and the general atmosphere in clinics:
Uli: It would have been nice if our health insurance had covered ... all these costs ... and if they had given more detailed information. I thought it was terribly unfair that health insurances didn’t pay it ... I don’t mind if they don’t pay at all, but what I don’t understand is that they pay for one method and not for the other. That is unfair. It was pretty silly that they did not pay for the testicular biopsy ... even when they started paying for ICSI again, [apparently] because this was a different legal decision.

Tina agreed and compared DI to inseminations with the husband’s semen where “couples get reimbursed for four cycles” and commented that “this would have helped us a lot”. Zinnia indicated some irritation when she recalled that “one doctor asks for € 5.000, the other demands € 1.000 or € 1.500, the next one € 300, there is no limit”. She felt pressured by the doctor who charged € 5.000 as he said that “he would not get anywhere with us, but I cannot simply pay € 5.000 [as it is a lot of money].” Zach described the clinic as “a through-road, grab the money, done”. Maren and Markus commented that it was “not so much the money but the injustice” that they felt frustrated about.

Information about psychosocial aspects of DI

From their comments, it is clear that respondents lacked information regarding the psychosocial aspects of DI. Respondents often raised the issue themselves, and found that doctors were less inclined to provide information than counsellors.

Psychosocial information provided by doctors

Only a few respondents indicated that doctors had given them any psychosocial information regarding DI. Adam said that the doctor he had consulted “did not say anything regarding what it was like. And that there are some who are more silent [about DI] and others who manage it in a more open way.” Daniel remembered asking the doctor whether he “should ask my brother [to donate]. And then the doctor said, in a very superficial way,... Often the psychological side is very important. But I would say [the information he gave us] only scratched the surface, but at least he said he would not recommend it.” Daniel’s current doctor, and a doctor he and his wife had consulted several years prior to the first treatment, did not give any information on the psychosocial issues of DI, either:
Daniel: Well, with Dr. (B) this was never an issue. ... She said, When you have done it 12, 15 times, then you know the entire issue. And with ... Dr. (K) ... we did talk about it, but, well, ... he actually neither advised against nor for [DI]. It is a few years ago ... I think he presented it as a possibility that he could carry out and that we had to make the decision ourselves. And that you had to be aware of what it means in advance, all the consequences, that the child was only from one parent. ... I don’t think that there was any great counselling.

As will be reported below the only psychosocial issue mentioned by a few doctors was the question about whether parents should share information about DI with the child.

Similarly to other female respondents, Ruth described in a very detailed way her need for information about the semen provider, but this information was not given to her. Asked whether the decision for or against DI would have been easier had she had more information on the semen provider, she replied:

Ruth: Yes, I think this would have been easier for me. ... It is not that I wanted to meet the donor, but if I knew a little about his social environment, about ... his education. If I had more information than what you are normally given, then I think this would have calmed me down. Simply to know that the child is not from a prisoner or something like that. ... Those are the fantasies you have, and of course I am scared that there is something in the child that I cannot control. Those are the usual questions you ask yourself in a situation like that. ... It is something completely unknown ... that will be transferred into my body.

PT: Did you also raise these issues with the doctors, with whom you discussed DI?

Ruth: No, the discussion was not so detailed. The questions were only: Should you do it? What would treatment be like? What doctors are there? And then briefly the legal questions. Maybe a discussion of 15 minutes, 20 minutes. We did not discuss the more detailed questions.

Psychosocial information provided by counsellors

Six couples in this study were required by the doctor to consult a counsellor prior to treatment, seven did not see a counsellor, and ten consulted a counsellor because of their need to explore issues related to infertility and/or DI. The couples who were required to undergo pre-treatment counselling, had not expected this, and therefore some couples were initially hesitant. Uli commented that this was like "another paragraph somebody had thought of", and Theo recalled his concerns:
Theo: I was a bit worried before the appointment, Oh my goodness, oh my goodness, what will be the result of this? But afterwards I must say, it was OK. Yes, I must really admit it [was OK]. ...You couldn’t start treatment unless you did it. It also depends on the psychologist, how he does it. But I must say ... I liked it. ... At the beginning, it was a bit unpleasant but then (.) it was OK, I thought it was good. And I also think that it should really always be done, although I did go there with mixed feelings.

Anni and Adam were also critical of the mandatory pre-treatment counselling requirement. Adam said that the counsellor “only signalled [the doctor] if yes or no, if this is OK or not”, referring to the couple’s suitability for DI treatment. Anni confirmed this in the couple interview:

Anni: Well, before we did not know, we had no idea why we had to go and see this counsellor. And then I thought in my imagination, that it might be a possibility for us to ask all the questions we have and to get some advice and recommendations, how it works, what can happen to us, what risks there are and so on, and some sort of factual information. ... This is what we didn’t get from Pro Familia. And then we thought, wonderful, this is where we have a psychologist in such a practice. If she cannot provide this, then where else would we be able to get it from? ... But this was not the case. She very clearly represented the interests of the clinic ... maybe to ensure that the couple or the marriage is stable enough for such a burden, in order to avoid an alimony struggle. That could, of course, be a motivation as well. ... Because she kept insisting that there is no (.) possibility somehow to get money from [the donor] if we, if our marriage fails and the husband (.) well, refuses to pay alimony.

For Anni and Adam this was especially disappointing because they had consulted a different counsellor prior to this who was not able to provide any psychosocial information about DI, either. They had hoped that they could raise these issues in the counselling prescribed by the doctor. Other respondents, such as Uli, also felt ambivalent about the fact that doctors insisted on pre-treatment counselling:

Uli: It doesn’t help, in the end it has to be the right thing for both. And I think we would have done it, I think it was right that we did it, but the fact that it was mandatory.

PT: Were you annoyed about that?

Uli: Well, it makes me wonder, does everything have to be regulated by law?

In a later part of the interview, however, he stressed that “it would be a bit one-sided if you would pretend that it was only my wife who needed the ... talks with this psychologist. Retrospectively, I am aware that they were good for me, as well”. All of the counsellors consulted as a result of a doctor’s requirement were reported to have discussed strategies of sharing with the couples; details of this aspect will be reported below.
Several other couples had also sought counselling during their infertility experience, most, however, independent of DI treatment, and in these cases, DI was not referred to during counselling. Only a few explored their decision to undergo DI. Jan recalled that the counsellor was “a little reserved, I had the feeling that she had not yet had many couples where [DI] was an issue”, and Jessica said that the counsellor “did not say anything about it”. Olga and Otto were informed by the counsellor “that Dr. A and Dr. L did things a little differently, and things like that”, referring to medical doctors and the variations in medical treatment, and Rob was provided with addresses of clinics and recalled that there had been some exploration of DI:

Rob: We initially talked to the psychotherapist about infertility. And then, when we asked for addresses of doctors who do this treatment ... you could notice from the behaviour of this woman, (...) initially, we were not given any addresses, not until half an hour later, (...) after a discussion, so that the woman could judge who was sitting opposite her, we were given the addresses. And that’s good, I think, because there should not be any tourism, according to the motto, (...) well, you look for the doctor who does it. That would only create problems (quiet). We thought the woman was very accommodating. We got lots of tips and in the end were surprised when we were given a list with five doctors. ... The psychotherapist also tried to explore issues a little, of course. That’s what she is there for. ... That means that everything that was said about this topic was, it was not questioned, it is not about good or bad, but she asked why you had taken this decision, or (...) what the consequences of this decision could be. That was simply good. ... It was good that an outsider asked certain questions, even if you think you know it all, you can’t have it, you are so caught up in this issue that often you don’t see the trees in the forest you are standing in.

Cathy had extensive counselling prior to the decision to undergo DI. She referred to her lesbian status:

Cathy: I would not have gone this way ... and I would not have had the courage to live in a relationship with a woman and to become pregnant. ... To go beyond the opinion of other people, like psychoanalysts and other professional people who have different opinions, to look at that from a therapeutical viewpoint was important for me, to look at these old voices within myself which say, Well, that you had bad luck (quietly), or you shouldn’t do that. ... And of course [being lesbian] we are regarded with a different public perception from other couples that become pregnant with DI, and [DI] is visible with us.

In the couple interview, she also remembered exploring her attitude towards raising a child without a father and stressed that “this was very important ... without therapy I would not have managed [deciding pro DI], certainly not”.

Only one couple reported negative comments from psychosocial professionals. Karola and Klaus consulted several counsellors who all advised against DI:
Karola: We were there for less than 5 minutes, mentioned the topic (...) and he looked at us and then he said, (...) You had better not do this. And then I was, I was so shocked. I only cried there. ... My husband then asked him why he simply said something like that. ... And then [the psychologist] said, Well, (...) people who do something like that only think of themselves and forget the welfare of the child. Whether I wouldn’t want to know how I was conceived. And if he could recommend us anything at all, it would be a foster child who could go back to his mommy anytime.

This psychologist also warned the couple that DI would lead to separation. As Karola assumed that this psychologist was experienced and knew about DI, she felt very distressed after these sessions as well as bewildered and fearful of DI. However, the couple had the courage to consult yet another counsellor, initially to learn relaxation techniques. Karola said that this counsellor “also tried to talk me out of it ... but she also helped me to find my own way. She did not talk about [DI] negatively ... and didn’t push me into a certain position like the first psychologist did”.

Many couples did not receive any counselling prior to or during treatment, either because it was not offered or they did not deem it necessary. Several respondents considered the interviews of this study to have provided them with a possibility of exploring some of the psychosocial issues associated with DI. Markus took part in the interviews because he had “never had such an opportunity to talk about this issue.” Ida and Helga also commented about the interviews:

Ida: [The questions] were well asked ... because you did not go into such details, and because the questions are like some self-awareness that ... explored the structure in my head. I do have my own thoughts, which I had to put into words. And by putting them into words, I notice whether I made sense or not. If I put them into unclear words, then my thoughts are unclear. ... And when I use clear words, my thoughts are clear. You will notice where I answer immediately and where I have to think first. ... And that is, that is good for me. And to participate in this study I had two reasons: number one is, because I really ... liked it, and I thought, if you want to make such a study, I really want to support you; and number two is, I really ... had the need to be asked.

PT: Were those the questions you expected?

Ida: Yes, roughly. ... I thought there would be more details. But now I realise that I have already reflected a lot.

Helga: This is why we were so eager to [do the interviews]. Because I think, that then, when you have questions, well, I feel that you know about DI. You have met other couples. And therefore I think that this may even be a sort of help, if I may express it like this.
Rob felt more ambivalent but also admitted that he wanted to benefit himself from participating:

Rob: My wife and I also wondered whether we should participate in these questions. She thought it would not be so good because it brings the whole thing up to the surface again; you have to deal with it again. But I said, OK, what do I have to lose? And of course we also looked for our own benefits in these discussions. We also wondered if you could help us in any way with your questions so that it is worthwhile taking part in this discussion. Everybody wants to benefit somehow.

Other respondents such as Ruth, Daniel and Rob commented that they “simply wanted to talk about [DI] again”, and that they hoped that the interview “would bring [us] a bit further” because they “wanted to have a contact person. ... When you have an experienced person in front of you, also to say, Now what would you do?” They wanted to use my experience and “hear what other people say about it”, or they participated because “we have a thousand questions”.

Several respondents voiced different needs for psychosocial support. Klaus said that he was “not happy with what the psychologist was saying, because he felt he was being manipulated. He also commented that he would have preferred sessions together with his wife, as infertility “is a mutual issue but they always split us up, my wife was with the man and I was with the woman”. He would also have liked to meet “other couples in the same situation ... and people who are experienced with DI, not psychologists who have no experience in this area”.

Jessica and Jan would have preferred more detailed discussions with the doctors and had some information about the seminars I offer:

Jessica: I would have preferred it if the clinic itself had offered a discussion. ... Yes, if there had been anything, I was glad when I found the notice about you.

Jan: But I think we only found it there once.

Jessica: Yes.

Jan: At the very beginning it was in the clinic, and we said, Let’s take it along for the child.

Jessica: Yes.

Jan: Well, we never thought that it could become important for us [to attend this seminar].
Wally's comments suggest that she would have preferred some counselling right from the beginning:

Wally: I think what would have been really helpful is right at the very beginning, when I went to my gynaecologist and said, We are trying for a child…. I think at that point it would have been very useful to learn a lot of the things that we learnt on the adoption course, what it means, and also from [the psychologist] what it means, what it is like when you have a child and Walter comes home from work and you’ve had a baby there all day, and just to see it as a more real thing, not just a sweet, cuddly, fluffy thing, to really understand what is involved, the responsibility, what changes in your life. And also then to say, to have a lot of talk about infertility and at the beginning, before you even know you are infertile, someone to say: Be careful what you tell other people and think about how you can handle it if it turns out that you are infertile. Because once you start on the train of telling people … it is very hard then to start telling lies. And that would have been the only option, right at the beginning, some kind of parenting course, where you really start to think about having a baby.

Viewpoints regarding the use of DI to build a family

Family building by DI was not the first choice for most respondents. Several couples underwent treatment cycles with IVF or ICSI using the semen of the husband but without success. Others considered this treatment too invasive, such as Ian, who was concerned because of “all the side effects for my wife”, or unrealistic financially as it was “too expensive”. Every couple in this study had considered adoption, and many had applied for adoption with an adoption agency. Though some female respondents would have preferred sharing the same parental status, all couples considered adoption “highly unlikely” because of the low number of children available for adoption in Germany. As they had with AHR treatments, some couples also felt they did not have sufficient financial means for adoption, and others considered the adoption process humiliating because of the intimate issues raised. In addition, many female respondents wanted to experience pregnancy and their partners wanted to accompany their wives in this phase. Adoption therefore was not a choice for them. Living without children had been considered as a possibility by most, but only one couple, Wally and Walter, had drawn clear limits regarding any medical treatment and adoption. For all respondents, family building with the assistance of DI seemed physically less invasive, financially more feasible and therefore a path which promised to be more successful.
It was clear that there were different reactions between the male and the female partners when respondents initially considered family building by DI. The following section will first report on the reactions of the male respondents and then describe the reactions of the female respondents.

As with male infertility, many men recalled reacting pragmatically when they learnt about the possibility of DI. This was reflected in comments they made, such as, “personally [I] had no problems with [DI] and would not know anything that speaks against it”, DI was a “very simple issue. I have no other choice”, “either I do it or I leave it ... and therefore I don’t have any problems with [DI]”. Marcus commented that he had “to live with [male infertility], which does not burden me anymore ... and DI I think is a good possibility”. These statements indicate that the men were able to accept DI once their diagnosis of infertility seemed to leave no other option and/or they had unsuccessfully undergone other AHR treatment. As Rob stated, they “simply had to rethink” and then were able to accept DI.

Other men had more reserved reactions. Peter said, “I was not excited, and this was reflected in the fact that I did not accompany [my wife to treatment]”. Brian admitted that at first he “was sceptical because you think you can have [your own] children ... but then I got used to the thought”, and Herbert recalled his initial fears thinking he “could not manage it, I didn’t want it at all, I really was against it”.

For several men, family building by DI raised questions or even anxieties, which Xaver outlined vividly:

Xaver: And I said [to my wife], I first of all have to read into [DI] and have to try and imagine it, what it is, would this be a possibility for us, what happens inside of me, and these things. And your booklet helped me a lot. ... And then I thought, What would you do if? ... And there was a little uneasiness I must say, the fact that one knows so little and that I have never dealt with it. What will we be confronted with? And then there were the questions, like, you are not the daddy and you are sort of on the side, you are, so to speak, well, next to the wife and the child, standing there like someone who doesn’t belong there.

PT: You are also expressing this with your gestures. ... You showed with your hands, wife and child very close together and then the husband, or you in this case, ... a little further away.

Xaver: Yes, maybe because I am a little afraid. You know that in a relationship, you make a lot of effort, and you know what the other person is like, but at the beginning, things might happen you cannot control. ... And that’s where I am a little afraid ... that somehow I stand there on my own. Will such a child say later on: Gee, you are not my father. ... And how will this make me feel? At the beginning, I also thought we would not talk to anybody about it ... and I think that was my fear of standing on the side. ... That took a while. ... For me, this topic used to be an absolutely taboo topic, because if you wanted to have
children, of course you wanted your own child. And then we were confronted with this situation. And I had to think again, No, I don’t stand on the side. And I talked a lot to Zarah, because I think it is also an important task for her ... to integrate me again, because I think there could be situations when the child says, I am now projecting into the future, but ...I think we should tell the child and then there could be a situation. Or maybe someone says, Gee, just like the father. Or maybe the other way round ... He doesn’t have your nose at all. All of this could happen, where you think, I cannot accept it, it hurts.

Brian had similar fears and was afraid that, as the social father, he may be “the only loser ... as you never know how [the child may react], what will happen. ... This would be ... the foremost worry I would have”. Herbert, who attended a self-help group and had talked to other men about DI, also voiced these feelings of anxiety. Admitting that he “was afraid at the beginning [and] all men feel this, I have found out”, he indicated that in his experience this reaction seemed common for men.

The genetic connection to the child had an important meaning for some men and they explained that they had to adjust their values. Jan explained this, also commenting on cultural traditions:

Jan: Well, ... I keep wondering myself. It is not yet a completed process (quiet). The first image with which I could live quite well was (.) if I had met Jessica with a child from someone else, then I would have also wanted her. ... To see her pregnant was nice, but I already had the feeling that ... the child is a little more distant for me than a genetic child would have been. ... I don’t know, maybe such old male semen constructs, feelings, like, This is my semen, my child, [they contribute to this thinking]. ... Our whole society works according to this, inheritance laws are always according to the male members. ... And I also like to read old myths, and I know that men used to hunt and the women used to protect, and back then inheritance was different. You could associate each mother with the child, but not the father. And then when people became stationary, then this was a possibility to demonstrate power, I am aware of these issues. And well, today it is similar, you also don’t know who the father is. We know several [women] in our circle where they say, I have a child but the father doesn’t know about it, and so on (quiet). ... But in terms of our society, this has been the orientation for (.) 3000, 4000 years, the father, the male line of inheritance.

In order to ensure a genetic connection between the child and their own family, Daniel, among others, had considered asking a male relative to donate semen:

Daniel: Well, my first spontaneous reaction was that I wanted (.) at least some genetic material from ... my family. And that I thought I would ask my brother. But then the doctor said, The psychological side is very important. ... He only scratched the surface, but he did say that he would not recommend it. And I must say, I would also not do it anymore.

Similarly to Norbert, several men compared a child conceived with DI to their wives “having had a child from a previous marriage”; Herbert, for example, used this metaphor to construct his narrative:
Herbert: It is OK for me, if this is the way it is meant to be (.) and as I said before, I think there are many [men] who don’t know whether it is their child or not. And there are many where the wife has a child from a previous marriage, by divorce or so, whatever. And (.) therefore I think it is not so bad. The only thing (.) Well, how does Helga manage it? She somehow has an unknown child, unknown semen. It is not a totally strange person who wakes up next to her. And I think that was the important issue for me.

In this passage, Herbert also commented on his wife’s feelings regarding the conception with an unknown person, and he was worried, like several other men, if he could manage the involvement of another man who remained unknown. Another metaphor applied by a female respondent in order to understand family building by DI was the notion of “a semi-adoption”, referring to the genetic link between the child and the mother. By contrast, men, such as Brian, compared DI to a full “adoption ... as it is like accepting [somebody else’s] child”. A third comparison used by Rob was made to so-called “cuckoo’s eggs” where the husband was consciously deceived by the wife who makes him believe it is his offspring, but the child is actually conceived with a different man”.

In contrast to their partners, none of the female respondents were able to view DI pragmatically. Most women initially felt unsure or even negative about DI. Similarly to Dora, they explained that they had “a negative attitude because I had never dealt with such a subject”, they “were afraid”, “had a problem with it”, or “quite a few doubts” when they learnt about DI. Other women, such as Olga, reported that their initial positive attitude changed once they realised that this type of family building raised many questions:

Olga: Yes, in the first instance, it was a great possibility. And Otto was even more euphoric. And then we talked a little to [the counsellor], because we wondered whether there were other couples, and what exactly would happen, and whether it remained anonymous, also later on. And, well, you noticed more and more that there were very many problems and questions. ... And when you deal with it a little more, and not just superficially, well, it is complex, so that in the meantime I thought, Maybe it is better to adopt a child or have a foster child. Then both are at the same point. ... It can work ... but it can also be difficult.

Anni and Zarah voiced similar concerns:

22 German expression for children conceived by an extra-marital affair of which the husband remains unaware.
Anni: At first, I think it was just a variation, just like adopting a child or no child. ... [My reaction was] neutral, I think. ... And then very quickly I had this thought, while I was drinking a cup of coffee, I had this thought, Well (.) I don’t want a child from a blue-collar man, with a golden necklace. Which is basically pretty bad, because this is the group of people I work with and I know that they are very normal people. Well, there was immediately the question, Who is the donor and does he fit to us?

Zarah: First I wasn’t so negative, maybe that’s funny, but there is a possibility to really have my own child. And then the questions and doubts came when I read your booklet. Shall we really do it? And what will it be like for the child? And all of these questions. ... That’s when the first doubts came, shall we really do it.

Several women showed concern about family dynamics resulting from this family composition, indicating, like Tina, that they were worried that “[DI] might become a problem for” their husbands:

Tina: I am a little afraid that there may be situations where my husband says ... it is not my [child]. ... Or where I say, It is not your child. Or the child may know that he is not his and at some stage says, You are not my father. Those are things that you think about, that you fear.

Anni mentioned an additional aspect regarding the welfare of the family when she “discussed the issue of secrecy [with a counsellor and her husband]” and wondered whether “having a Mr. X in your family [may] break the family up”.

As Herbert and other male respondents had assumed, several women felt nervous about the semen provider’s anonymity. Geraldine commented that she had “problems because I often think about whether I am doing the right thing” knowing that she would never learn anything about the semen provider. Berta described it as “strange ... having the semen of an unknown man” inside of her when undergoing treatment. This feeling was shared by others who “were afraid ... because it is the semen of an unknown man, and I didn’t know how to manage that, whether it would be a burden to have the child of a stranger inside me”.

Other questions revolved around the needs of the child and sharing about the conception. Geraldine wondered “whether the child should be told. Initially we don’t want to tell anybody, but this is a burden ... for me”. Karola feared that a child might desire more information than she would be able to provide:
Karola: My greatest fear is that the child at some stage reproaches me or that the child does not understand that we did this treatment. That the child at some stage says, well, (...) to put it bluntly, I want to see my genetic father. That is my greatest fear. My greatest fear is the child.

PT: And what would it be like for you if the child said he or she would like to know who the donor is?

Karola: I would somehow be afraid that I could not explain it plausibly so that the child could understand. Why we did it like this ... Or that somehow he will have psychological problems because he doesn’t know his origin, that he doesn’t know who the second part of me is (quiet).

Those women who felt relieved or even “euphoric”, like Helga or Vera, explained that DI presented an additional opportunity if other AHR treatment failed. Even Karola and Ida reported that they were “calmed ... that [DI] was somewhere in the back of my mind, there is something else”, and for Pat, DI had “immediately been there as an opportunity, I didn’t question it”. Some women, such as Zinnia and Zarah, considered DI a chance for them to have a child biologically related to them. This was also the case for Jessica:

Jessica: I still didn’t know whether DI would really be for us. And then I thought I would ... prefer it if they found [some semen] with Jan. ... But then, what always went through my mind was that [DI] would be a possibility of getting pregnant and that the child could be from me, I kept thinking about that, whether that might be a solution.

In addition to being asked about their individual reactions to DI, respondents were also asked how they perceived their partner’s reaction. No differences were found between the reactions of the respondents themselves and how their partners perceived their reactions.

The couples’ process towards DI

For most couples, the decision-making process for building a family by DI was challenging. They discussed their feelings and thoughts, as well as some of the implications arising from using DI, intensively until they had both agreed to start treatment. The time spent discussing these issues ranged from several months to several years and discussion topics included the following areas: unfamiliarity with DI, resolving marital tensions resulting from infertility or sharing emotional processes in adapting to DI, the role of the non-biological parent, the question of whether to inform the child of his conception, and the meaning of the semen provider’s anonymity.
Describing their unfamiliarity with DI, Jessica and Jan used the metaphor of “walking through a door” when they described their decision-making process. Both recalled becoming aware of DI at the same time, but Jan would not have opened the door as fast as Jessica:

Jan: I would have stood in front of it ... and that’s it. Then I said [to Jessica], If you want to, go ahead and open it and I will walk along. But ... if we don’t have a child, that’s fine, too. ...

Jessica: Well, yes, we looked at what it was like behind the door, what it would be like for the child. That was very important for me. ... And another important question was, How could we tell the child? ... and I talked to my girl-friend ... and then I also talked to Jan about it [and told him] that I was thinking about it a lot.

Jan: Yes, I just said that I am almost doing more than others in order to have a child ... to accompany you, to reflect about it, those were our first steps where I was able to follow you.

Helga and Herbert were among the couples that had required many months before they decided to undergo DI. They revealed how ambivalent they had felt and how both of them assumed the sceptical and the optimistic role about DI. When Herbert was first diagnosed with infertility, Helga felt positive about DI, but Herbert said that “it was completely unacceptable” to him. Then he “thought about it a lot” and came to the conclusion “that it is not so bad after all ... the child does have a genetic father, but I am the proper father when the child is there, I raise him and everything”. He also said, “DI is something completely medical ... and nothing bad or forbidden”. However, once he had accepted DI, it was his wife who did not want to pursue it anymore:

Herbert: She was not sure whether this was the right step ... and then I left her in peace ... and she came to me some time later. We had talked about it a lot and she had thought about it.

Helga: [W]e discussed it a lot and [at the beginning] I wanted to know why he was against it. ... But then I had all the time to think what could happen if we had a child like that, ... all the problems ... and I thought I did not want a child anymore. We also discussed whether such a child could endanger our relationship ... and we came to the conclusion that our relationship would not be more or less in danger than without a child. ... And then the more I heard and saw about it the firmer my decision got. It was not that somebody influenced me, because we did not speak about DI ... only about infertility. ... I had to get that clear in my own head.

The couple started treatment after approximately one year.
Several couples found that as individuals they reacted very differently towards the diagnosis of infertility. Markus had known about his infertility for many years and was not surprised when he received his final diagnosis of being sterile. Maren, however, was devastated, and there was some tension resulting from Markus’s rational reaction. Maren recalled, “At the beginning we argued about it, ... this was the only issue we argued about” before contacting the clinic:

Maren: Until we got in touch with [the clinic that carried out DI], we had arguments, afterwards we didn’t.

Markus: The first time we heard about DI, we said, No way, we are not going to do that.

Maren: But now looking back, we did not argue anymore [after we had been in touch with the clinic].

Markus: But back then, you didn’t want to do DI.

Maren: Yes, but we did not argue anymore. ... Maybe I was calmer. ...

Markus: And then we put the ad in the paper [seeking contact with other infertile couples], we got active. Before it was only talking. ... but we only got really active after we had met [two other couples affected by infertility]. ... In this group, we had a perspective.

Maren: But then ... my father-in-law was the motivator behind it all. Our wish for a child would not have not been so great if my father-in-law had not again and again put his finger into this wound. He said, You have to [do this].

Markus: He didn’t say you have to, ... he said, If you don’t do it, you will regret it later. ... He did not say you have to do DI.

At that stage, understanding the meaning of fatherhood was discussed by some couples, such as Zarah and Xaver, as well the question of sharing about the conception with the child:

Xaver: [We discussed] my role. ... Because I needed a little longer until I was able to accept it ... [I needed to] manage it. We also talked about the legal side of it. ... Especially because of making [DI] public. Does the child have a chance at all to access [any information]?

Zarah: Yes, the most important thing was whether we tell the child or whether we don’t. We definitely wanted this clarified before. ... For me it was always difficult to put myself into his situation. We also wanted a solution ( ) how it should end: Do we do it or don’t we do it? Because I am not in his situation. Because, of course, I know that half of the child is from me ... and I think children also absorb a lot from their surroundings, not only the genetic background, just the characteristics. And I think [Xaver] would see a reflection of himself in his child, but it is still different. And that was more difficult for me to understand, what goes on inside of him. And of course we talked about that.

Xaver: Yes, step by step. ... Yes, now I know. It was the beginning .... Do I really want it? Would this be a possibility for me? ... And then, as a result of many discussions, I was able to say, Yes, ... it is OK for me, or for us. Then we took the next step, discussions about ( ):
Do we tell the child? And so on. ... My wife knows that I am somebody who takes a bit longer. I know that she is faster, but she gave me time. We always talked about it a lot. She said it would be OK if I needed this time ... but that we [should] talk about it [so that] she knows what goes on inside of me, what I am thinking about, where I am. ...

Zarah: Exactly, these things. And then I said, Well, if you take the time, then of course I give it to you. Because it is an important topic, that he shares it a little with me. ... I wanted to know what were his thoughts or feelings, so that I don’t sit around for weeks on end and do nothing. And then he decided.

Clarifying the role of the non-genetic parent was also an issue for Cathy and Christine:

Christine: It became clear that it was not only a wish to have a child but also a wish to get pregnant. ... And then there was the question, Do you realise it with a man? ... And it became clear, No, no man. ...

Cathy: That was also a process between the two of us. ... Shall we ... get married? No matter whether with the new law or the way we did it. ... And it was important for you to get married when I was pregnant, that was very classical (laughing), with ... everything, a wedding picture, a big tummy, my goodness, that was pretty strange. ...

Christine: But for me it was important. And it was important for me to be seen in relation to the child, or the child in relation to me. And not that neighbours think, Oh, she went to bed with a man. That was important for me, also in terms of recognition and being together. ...

Cathy: And the topic of fairness ... that Christine did not have any legal possibilities, that was a topic. ... We were also asked by friends ... whether I would treat [Christine] fairly if we separated. ... I am the biological mother and this still has a higher meaning, I find it absurd. ... But that was a topic, how fair you are. ...

Christine: How much power does the biological mother have?

Cathy: How much power. ... And trust; you also trust me totally.

For other couples, sharing about the conception with the child was an important issue. Like Herbert and Helga, Karola and Klaus discussed whether they should “tell the child or [not]” and the semen provider’s anonymity had some impact on these discussions. They felt very unsure in this respect:

Karola: The most important topic is sharing it with the child.

Klaus: Yes, at the moment ... this is an issue. An issue where again and again we wondered, ... what sort of person the donor is, we would like to find out a little more about that. And then we would like to have the possibility, somehow, or somehow enable the child if he wants to, to be able to find out about the donor. And then there is always the question: Can we do it? Are we allowed to do it? ...

Karola: Are we allowed to do it? That is the question I often ask myself (quiet).

Klaus: But it is a question nobody can answer for us. ... We have found this out now, and still we keep asking us this question. ... We can’t consider every detail. We can say, We had the best intentions when doing it. And we can say, We hope it works well. But we
cannot plan in detail all the consequences that may happen. That somehow makes you insecure (quiet).

PT: The question seems to be: Do you have the moral right to conceive a child knowing that one area of the life of that child might become difficult? ... Would you as parents be so selfish and accept this potential difficulty?

Karola: Exactly.

Klaus: That’s right. ... But we won’t find an answer to this question. We cannot think it through until the very end. We have often discussed, and I said to my wife, We could not make an entire life plan for that child until it got its old-age pension or until university, or whatever. That does not work. And the counter question is, Isn’t everybody who has a child somehow a little selfish?

Karola also admitted that she had felt nervous about the interview and worried that, as a result of exposing herself to the questions, she may have become more depressed and would worry even more. She commented in the couple interview that “this was not the case”, and Klaus explained that it was the “neutral and value-free questions” which contributed to this.

Ruth and Rob, who had not yet started treatment, described their decision-making process as difficult; they also commented that they “were never 100 percent sure whether we will have really taken the right decision”. One important issue for them was Rob’s feeling of guilt and how this impacted on his attitude. As he was the infertile partner, Rob had a “bad conscience” which resulted in him “wanting to do something good for my wife”. On the other hand, Ruth’s conscience was also a problem:

Ruth: [I was not sure] whether he could manage in the long run, knowing that the child was not from [him], although he contests this. But I was simply afraid that he only suggested this thought [of DI] because he felt he had a duty to do so, but that he doesn’t really want to do it.

Asked how they, as a couple, might resolve this, Rob replied that it would be his wife who would make the decision and that he would accept any decision she might make. He favoured DI but felt some element of helplessness when he quietly admitted that he “cannot be the one who pressures her. ... And if [my wife] says she won’t do it, then I have to accept this.” Ruth, who described herself as somebody who liked to procrastinate over decision-making, felt very ambivalent about bearing this responsibility and realised how disappointed her husband would be if she decided against DI. Asked what might help her to take this decision, Ruth replied that establishing contact with another couple that participated in this study
and sharing some of her thoughts and concerns would possibly contribute to clarifying her attitude towards DI.

In the couple interviews, several women repeated their anxieties regarding their husband’s management of a child, wondering, as Ida did, “whether he could live with it”, or like Helga, fearing “that [my husband] might not be able to manage it”. Other women, like Tina, worried that their husbands had only consented to DI in order to “compensate his feelings of guilt … [and] he doesn’t make his own wishes a priority”. On the other hand, one woman also voiced feelings of guilt. Pat did not want to undergo ICSI treatment because she considered it too invasive and worried that she “made [her husband] do [DI]”, and therefore wanted to ensure that he “also agreed with the decision”. These issues, and the other differences between the male and female respondents described above, seemed to be openly acknowledged by the couples.

For a few couples, the decision-making process did not take long. Eli and Eric commented that they “did not need much time and [decision-making] went very fast [as] we didn’t need to discuss it”. Wally and Walter commented that they only “discussed it [briefly when we were] on holiday. … We did not want to go back and say we did not try all the options”, and Zinnia and Zach “could not remember” discussing anything in particular. Ian and Ida embarked on DI treatment four weeks after their last treatment attempt with ICSI, and Ian explained, “Social fatherhood is as valuable as being the genitor”. For Fiona and Fred, the decision was also quick. Fred felt very positive as for him “DI was close to natural conception”, and the only condition raised by Fiona was that she wanted “to meet others” prior to starting treatment. The couples started treatment after they had attended a meeting of IDI. Nadia and Norbert decided to go ahead with DI after one failed ICSI attempt, which they did as Nadia insisted on “at least giving it a try”, although Norbert worried about “the invasive treatment” for his wife.

*Public perceptions of DI*

There was little difference between male and female respondents regarding their understanding of the public perception of DI. Many respondents described DI as “a taboo topic here in Germany”, that “it
simply doesn’t exist in public, that “it is not talked about”, or simply, like Pat, commented, “There is no public”. Rob explained that the taboo led to dubious practices:

Rob: Yes, you would like to have … information. In society it is an absolute taboo subject. … When you look in the Internet (..), unfortunately you not only get the information you would like to have, but also [information] that has nothing to do with this issue. Because there are also men offering their (..) services.

Others, such as Peter, commented that the taboo was linked with “a certain inhibition, with men probably more so than with women”, and Herbert explained the interconnection he saw between the taboo and his own reservation in sharing about DI:

Herbert: Well, it is still a taboo subject, that’s clear. I don’t know what people think about it, I also don’t know what the church thinks about it. And (..) for many, it is such a topic. … Personally, I have not noticed it, but I can somehow imagine it. Also, we have not talked about it with our friends. None of our friends know [we are doing DI]. I have no idea how they would react. They would probably say (..), I don’t know why it is such a taboo subject. … Because friends don’t know how to manage it, and therefore you don’t talk about it. … People just aren’t interested in it.

Several respondents compared DI to adoption. Like Rob, they commented that in comparison to the taboo surrounding adoption, which had lifted, this was not the case with DI:

Rob: Adoption has finally succeeded in coming out of this area of taboo. But DI is still fully in it. I would even go one step further and say that people pretend it simply doesn’t exist.

In contrast to their partners, some women used stronger words to describe the negative association of DI. They thought that the public considered DI “suspicious”, found it “disgusting” and “demonised it”, or considered it “dishonourable”. Nadia explained what keeping the secret meant for her:

Nadia: In general, I … have the feeling that even couples who have done this treatment, have children through it (..) often sweep it under the carpet … and most are ashamed, well, not directly, but they are afraid of the consequences, of people talking, so that they don’t even want to tell their children that they are conceived like that. … Because the people we talked to … it turned out that the brother [of some friend] who [worked in the same company as my husband also suffered from infertility and said], Please don’t say anything, when people know, I am finished. And so on. So we did not say anything, why should we, even if we treat it openly. … But because we manage it openly, we have also found out that most couples who have children [after DI] probably don’t want to tell their children, well, it does not seem to have a good reputation.
Geraldine, who with her husband lives in a small town, even feared public denunciation of both her and her husband and the child:

Geraldine: If [people] saw me [and they knew about DI], they would stare at me. And then everybody knows about it. ... But they shouldn’t know, it is none of their business. ... [Keeping DI a secret is to] protect my husband ... and myself, and above all the child. Maybe the child would be ridiculed because of [his DI conception].

Lack of familiarity with infertility in general and with DI in particular, and a lack of information were explained as factors contributing to public apprehension or negative associations. Many respondents, such as Daniel, commented that the public “may not know that [DI] actually exists”, or that “DI is not known in the general public”. Peter explained his views:

Peter: In public there are few discussions ... when you deal with it, you find, for example in this book, the most important information. ... Of course in comparison to other things, let’s say adoption ... there is much less [about DI]. And I think also, in the awareness of the general public, [DI] is much more in the background ... than adoption. ... [where in contrast to DI] I could probably easily put together a bibliography of 50 titles.

Uli felt certain “that DI is looked upon very negatively. I simply think that many, many people simply don’t think about it. ... You read about IVF and ICSI and all these methods, this topic is simply more present in the public arena”, Theo commented that “the public has little contact with it ... and little information”, and Xaver assumed that “infertility is not often mentioned and therefore I think that [DI] is simply not known ... or not transparent”. Others said that the public “does not have an opinion about DI ... as too few people are in touch with it or know people who are affected”, and that “they block any conversation because nobody wants to deal with it”, or “they view it sceptically” and that “there are too many negative associations”. Anni worried that the public may think that DI is not permitted in Germany and that couples who want to pursue it have to go abroad, and Berta, who lived in the former GDR, was unaware that DI was carried out prior to Reunification. She said, “During the GDR times, nobody dealt with [DI]. ... At least you never heard anything about it”. When I commented that it was carried out in the GDR, she felt certain that it was not an option available “for the man in the street, I am sure about that. ... I didn’t know [that it was carried out] I thought it was a medical development that came over from the West”.

Some respondents assumed that the public was ambivalent about DI. Valentin said, “I think there are many different opinions. Some are like this and others like that ... but in between there are a few people”. Christina commented, “There is little awareness. ... You don’t talk about it, but it is silently accepted”.

Klaus agreed and added his views:

Klaus: It is different from case to case, I would say that some see it, well, not necessarily negatively, but probably somehow looking away. ... A large group would say, I would never do that. Until they might be in the situation and then they would think differently about it.

Maren and Olga also thought that among people "there are two opinions", and Karola explained:

Karola: I think there are people who (.) when you talk to them, say (.) That is OK. Then you have a solution. ... The majority would say, You have some crazy idea, I would never do that, it is disgusting (quiet). I can also imagine that there are people who (.) don’t care. Who also wouldn’t care if they knew. ... Because they are not affected, they have no problem with it and would simply say it (.) doesn’t matter.

Helga assumed that “the private opinion is much more liberal”, but that in public “you could not talk about it”, and that it was easier to discuss DI with people individually than in groups. Other respondents assumed that there was a difference in attitude between the younger and older generation. Like Xaver, they commented that the “older generation [may have more] conservative views, maybe saying that it is immoral”.

The German attitude towards scientific progress and more general moral concerns were also given as reasons that contributed towards a negative view of DI. Zach explained this:

Zach: Germans have a negative attitude, everything is negative, everything that has to do with the future, with technology. And this is new in Germany. And an American might think (.) when drinking his beer, you think, Oh my goodness, they (.) are still in the Middle Ages. ... Those are two different worlds, I think, this is new and people simply don’t want to accept that there are other people [who do things differently].

Rob agreed when he explained, “Actresses in the United States publicly acknowledge that they do it ... and nobody crucifies them or burns them at the stake, but this is done in Germany”. Berta said, “Others simply don’t understand that you can do something like that, why you would want a child by any means”.

Eric feared that DI was considered as a possibility “to fulfil your wish to have a child with certain
attributes [as if choosing] from a catalogue", and Cathy explained that the ideal of a two-parent family with both male and female genitors available for the children is very strong:

Cathy: I think [it is viewed] quite critically. In the general population, with my colleagues ... what I found out was that there is a group that does family therapy and they view it critically, the missing fathers and so on. ... And that it is bad for the child and the child will be stigmatised. And of course, there is some truth in it, that this exactly is the disadvantage, ... the child needs a father. ... Or fear of discrimination, so to speak, the welfare of the child ... the child needs a father, and they don’t differentiate and see how many children actually [don’t] have a father these days. ... I still think in the community there is this idea that ... actually, children need father and mother ... although there are other experiences. ... And [I also believe] that there is a change in the community, that people look more ... and that this ideal, this ... dream family exists less and less.

A number of issues were raised only by female respondents. Some women feared that the public may associate DI with having a child from “an extra-marital affair”. Vera agreed with this and explained, “[The child] is from a different man ... it is a child from a stranger, or something like that”. Wally was afraid that DI was not considered a family-building option for heterosexual couples:

Wally: [DI is] a big mystery. And I think most people think there are very few cases of it. Perhaps [they think] it must be very hard for the father and it is selfish for the mother. That maybe it is a lesbian decision, for women who don’t want to have sex with men. Am, that (.) that anyone who wants to earn some money as well, that there is that perception. And, I don’t think that many people in the public see DI as part of a heterosexual, married solution for someone. I think they think it happens in rather special cases.

The negative public perception of semen providers was also seen to impact negatively on DI. Like Dora, Ute feared that others were not aware “of the careful medical screening ... they are [seen as] men who need the money”, and Anni suggested that semen providers were considered “hobos from the street”. Wally, who had lived in England some time previously, remembered an English soap opera, which “showed two criminals, really bad guys, who were earning money by donating their sperm”. This made her angry as it gave “a very negative impression of DI and misrepresented it”.

These negative public perceptions led almost all respondents to express a need for more public awareness and acceptance of DI. They commented that it would help them “if [DI] wasn’t so tabooed [and] ... if it were a little more transparent”, “if there was more information and a more positive environment”, or “if you didn’t run up against walls”, “if it was simply more in the public awareness”, “if it was not presented in a negative way”, “if it was discussed more” or “if the environment was more positive”. Nadia hoped
"for more understanding of both infertility and DI ... and for more reports in the media", as well as "much, much more openness and acceptance". Fred very frankly wrote in the feedback form: "An open management with no secrecy is the only way to manage this topic. The public must learn about it!"

Similarly to Zach, Berta and Brian compared the situation in Germany to that of other countries:

Brian: Let's say it is sad ... that it is still such a taboo subject, that it is not as easy as in England or America.

Berta: Well, his uncle lives in England, and his cousin is a nurse there, for them it was something very natural ...

Brian: Yes.

Berta: It is just like in America. There are semen banks where they can go. Why isn't there something like that here? That would be much, much simpler for many couples. In Holland, for example, they also have them. We found out that you can order semen from Holland.

Brian: That's the problem. There are many things that are not available in Germany.

Berta: Why is it so easy in other countries? ... And here in Germany it is so bureaucratic and difficult. I think the one who donates knows exactly what he does, and we as a couple, we also know exactly what we do. Then why is it so difficult to find a compromise? And to find doctors who have the courage to say, OK, we do it and we (...) might even bear all the legal consequences? ... I am not going to sue the donor or ... the doctor. I think if everything was a bit easier (...) then it would probably not be such a taboo subject anymore.

Some respondents were aware that they could contribute to lifting the taboo but felt caught in a dilemma.

Eric, who is a free-lance tax consultant, explained his views on this:

Eric: The problem could only be solved (...) if the whole topic was raised more in public ... and if it simply became more normal. ... And I think you have to start with the doctors. ... Doctors do not accept male infertility as a disease ... [and] I find this a pity and bad. ... And then the proper preparation of the public is missing ... there is nobody who makes it public. ... That would be an important step (quiet). That’s the problem, as I said, you [go public] and then explain it. ... Well, and when you do free-lance work and you are dependent on people coming to you (quiet) and the cake is already distributed (quiet). Well, I bought this practice, I could not afford to lose a third of my clients because everybody thinks, What did he do? He is mad, we don’t want to go to him and have our things done there. I just cannot afford from an economical point of view [to go public about DI].

Others, like Wally and Walter, made more concrete suggestions:

Wally: I think TV programmes or articles in the press, not something special like the medical press, but just ordinary media [would be helpful]. Explaining the real situation as it is, not when you saw that programme [on German TV], [as this] was just bizarre, you know, these distortions in the media. I think they have a very big effect, because it is the only piece of information [people have]. I think a programme ... on the statistics, how
many people, how many married couples or stable relationships live this way, and that would be really, really useful information.

Walter: Maybe like that, we are not sure where they pick the donor from, maybe it is well done, how they select them. It would be worthwhile, maybe, for the general public to feel that it is not like in that film. Anybody, not just a flimsy, ... well, they just go in there and they just do it for whatever money they get, or whatever, but a little bit more than that. So that it is not what I think it is, there is more to it than just anybody doing it.

Wally: Because in some ways, in essence, it is a very good option. There are a lot of things going for it, but the negative is that if something could happen to take that away, to make it so much more socially acceptable, I think that would be a really positive thing.

Perceptions of professionals

Respondents were asked how they perceived medical and psychosocial professionals regarding their views about DI. As described previously, most respondents felt that medical professionals viewed DI negatively, and only a few were deemed to have positive or neutral attitudes. Respondents of both sexes had the impression that “[doctors] could not manage DI”, or explained, “You could feel their discomfort when discussing” it. Nadia recalled that “this clinic was a secret tip ... [because] it was not publicly known to carry out DI ... [it] was carried out by a biologist ... and this biologist took couples to the side”, indicating that DI seemed an activity that should not be made public, not even within the clinic. According to several respondents’ experiences, doctors could not understand “that a woman would not make use of all possibilities” in order to conceive with her husband’s semen and seemed to “prefer [ICSI] and adoption over DI”. Nadia expressed her disappointment when she found out that doctors had misinformed her and her husband:

Nadia: Well, I found it bad that back then, the doctor lied to us (quiet). Things like that should not happen (quiet). He told us that in Germany [DI] did not exist, probably only for financial reasons, I assume. ... Of course it is clear that DI is less profitable than ICSI. ... It is really seldom done. In my experience, they have never offered [DI] themselves.

Pat had been to several doctors providing DI services and found one doctor who “really enjoyed doing DI”. Pat was the only respondent who had had this experience. In general, respondents did not express any expectations about medical professionals regarding information on family building by DI.

The attitude of psychosocial professionals was perceived to be less negative than that of medical professionals. None of the couples that underwent pre-treatment counselling reported any negative views
from counsellors. The couples that had consulted counsellors or therapists independently of DI treatment, in all but one case, perceived the counsellors to be neutral to positive towards family building with DI.

Both Ruth and Olga commented that they were very grateful for the information the counsellors provided:

Olga: We were so lucky having met these women from Pro Familia who just gave us lots and lots information, issues to discuss and your (.) book, and so on. But of course, not everybody has that, I don’t think. There must be this chain reaction of a lot of luck, so that quite by accident you happen to meet the right people. And the more [DI] is made public and is not such a taboo subject anymore, the simpler it will get for people.

Karola and Klaus, who, as described earlier, had had contact with several counsellors who advised against DI. One counsellor had indicated that DI was a selfish act on the part of the couple and that DI “would lead to the break-up of your relationship”.

Counselling was seen by a few couples as possibly being helpful in their decision-making regarding DI, while others felt ambivalent about this. Anni and Adam agreed that counselling “would have been helpful”, but Anni stressed the difficulty of finding an experienced counsellor:

Anni: What I wish at the moment, or what I need is, well (.) ... a counsellor ... because I notice that I feel a bit ... not really knowing where I am heading to. Last night we talked about it for a long time, and my current impression is that ... we are completely overwhelmed. We cannot decide how to go on. This is where I would like to have a counsellor. ... Also, because I notice that I am crying again, ... it is a burden, this situation, and I have the feeling that I would like to take advantage of counselling, but not with just anybody. On the one hand, for us as a couple (.) to sort out how we should go on and how we can develop factual or emotional criteria, so that we can decide. But that is a difficult question. ... I almost have the feeling that I need to think about the past a bit. Well, that would help very much, if I knew there was somebody in or near [our city] where I could go. ... The infertility counsellor who works with the clinic, well, Dr. [R] says that she mainly deals with IVF and ICSI. Well, I am a little reluctant to call her and ask whether she has already counselled DI couples ... and also, maybe because I went to university in (A-city) and I think she did as well, and somehow she has the same profession as me ... and I have met so many who tend to go in a certain direction where I notice I could not manage it. And I am afraid that she may have these viewpoints ... and therefore I have some reservations.

Although most couples did not comment directly that more information about the psychosocial aspects of DI would have been appreciated, they expressed this need indirectly. Similarly to some respondents during the interview, when they said that they wanted to use me as a resource for legal information, they asked many questions about these aspects or wondered whether they could establish contact with other couples interested in DI through this research project. Ute asked me whether “it is really impossible to
meet a [donor] here in Germany", and her husband wondered whether “other parents tell their children and at what age”. Wally was interested in several issues:

Wally: Do you know how much the donors get paid? ... And is my assumption correct that it is mainly medical students who become semen providers? ... And are there some statistics about how many people are open with their child and how many are not?

Asked for their motivation to participate in this study, several respondents hoped that they would profit from it. Rob explained that he and his wife “had asked ourselves, could you somehow help us in any way to make participation worthwhile for us [by providing us information about DI]”, and Helga, who had not seen a counsellor, remarked that the reason why she and her husband “were very happy to be interviewed ... [was because] this is like some sort of support for us”.

Perceptions of significant others

In comparison to male infertility, fewer respondents shared with family members and friends the fact that they were planning or undergoing DI. Explaining why there was this contrast, men and women alike commented that they “had no idea how they may react”, assumed that others were “too conservative” to understand DI, as “DI is a modern thing”, or said that “only those affected by infertility ... understand, others cannot judge on this”. Many agreed with Ruth’s reservations:

Ruth: I cannot imagine ever talking with my parents about it, ... because there is always this attitude, What do other people think about it? That is always very important [to them]. ... My parents-in-law (...) I think, would react more openly about it, simply because of the fact that they see that maybe their son would have the chance [of having a child] after having tried for many years. ... Strangely, I did not mention it [to my girl-friend] because for me it is still a taboo subject. I don’t know. We have known each other for a long time and very, very well. She would probably not be judgemental, but I think she would not fully understand. And I also (quiet) think, she might be the only one at the moment whom I think I could tell anyway.

Geraldine, who expected mixed reactions, also worried that her decision to undergo DI would be questioned:

Geraldine: [O]f course I would be quite glad to have someone so that I can talk about certain things. ... On the other hand, it is OK because we have made our decision. If we talked about it now with someone (...), parents or friends, and they would say, Oh my
Ida raised similar reasons for not sharing about DI before the child is born:

Ida: I don't want to have the feeling that I have to be the one who [talks about it] before I have had my own experience [with DI]. I think I could manage it more positively if I was very certain about my own attitude. Yes, and if it had worked and the child was there. ... And you love your husband, and he should not be confronted with how much is genetics and how much is upbringing. And once I have my own attitude, I can imagine that I will talk about it more openly, also to people who have a (...) different opinion. ... But at the moment, I only need the warm cozy nest of good opinions in order to [carry out DI]. Nobody needs to know in advance that it is not Ian's child and that (...) it is such a difficult story. I don’t need to burden the child with that. It should be born quite normally and quite normally be Ian’s child, and then at some stage, I don’t know, I am not quite clear how this will work (quiet) but then [I may talk about it].

Several respondents were uncertain whether family members and friends would accept DI. Valentin said that his mother “might accept [DI and] would not say, for Christ’s sake”, Olga assumed that “I could well imagine that [they] could accept it”, and Peter supposed that his parents “would not reject it”. However, they did not share this information as they worried that their assumptions about their families’ reactions might be wrong.

Maren explained that her sister’s negative reaction regarding adoption had stopped her from sharing about DI with her:

Maren: I talked to my sister about [infertility] at some stage ... and my experience was not very positive. I talked to her about adoption, and my sister was not very positive about it. ... When we decided to do DI, emotionally I decided not to tell her (quiet), simply because I had this negative experience, how she reacted towards adoption. And then I thought, I don’t want to tell her (...) if at some stage [the child] is there, I can still tell her then.

Maren and Markus were also afraid of gossip when they voiced concern that their siblings “may talk to others about [the fact that we have used DI]”. Klaus voiced similar concerns and added that he preferred not discussing DI with others in order to avoid the risk of the child learning from others about his conception:
As will be indicated below, several respondents did not discuss DI with others because they wanted to avoid the risk of the child learning about its conception from others. Respondents described two further factors that contributed to their concern about sharing DI information. Otto, who had only shared his plans for DI with one close friend, voiced a vague fear of losing the child:

Otto: I think it is important for me that it remains absolutely (.) anonymous. You (..) well, (..) it is in the moment where our child (..), so that nobody can raise any legal demands or something like that (quiet). And I did not talk to anybody else about it (quiet).

Rob commented that there was “not yet the need to inform other people about [DI] as we have not yet decided to [go ahead with it]”.

Nadia and Norbert were the only couple to have “shared DI with everybody who also knew about infertility”. Norbert explained that he was able to accept his infertility more easily “because I had such an open attitude” and was able to talk to others about it. Explaining their reasons for their openness, Norbert said that he “had always wanted to tell the child” and both he and Nadia added that it would be “a catch-22-situation if others knew but the child did not … and we knew that if we tell others, we have to tell the child”.

*Family members*

Those respondents who had shared about DI with their families commented that “of course, I talked to my parents”, indicating that for them, discussing family-building options with parents seemed natural or common. Comments such as, “it is their grandchild”, a child “would be the child of their daughter”, and that the female respondent’s mother “had the easier part, as it is her grandchild … it is more her genes”,

Klaus: [DI] was mentioned by several people who (.) apparently were a little informed. Well, my (..) brother knows the situation, but he would never ask. And my mother-in-law at some stage mentioned the possibility [of DI], but I did not react. My brother said that [DI] would not necessarily be a solution for him. … And then I can imagine what would happen [if they knew we did DI]: Promising to keep it a secret, they will tell others. And I think the worst thing that can happen is if we had a child after DI treatment and (..) three, four people or five people around us knew and the child didn’t know. And it would somehow become known because this definitely happens (..) then I don’t want to have to explain.
indicated that the genetic connection between genitor’s parents and the potential grandchild led to the feeling that it was easier for the parents of the female partner to accept DI.

Many reactions of parents and siblings, independently of whether it was the family of a male or the female respondent, showed that they accepted or even supported their children’s decision to build a family with the assistance of DI. Norbert recalled his parents commenting that DI was acceptable “if this leads you to your aim”, both Tina and Theo described their parents as “very supportive”, and Markus’s father showed some interest and asked, “When are you going to start?” Other family members “considered DI positive”, said that “DI is no problem” and “gave me a lot of affirmation”. Both Dora and Fiona explained their initial hesitancy and their family’s positive reaction:

Dora: I talked a lot about it with my mother. I have a good relationship with my mother. … I don’t know whether it has to do with the other generation, but initially she was against it (quiet). But when I talked to her and she noticed that I felt quite confident about it, because at the beginning she noticed my insecurity, she always said, If you are not sure, then leave it (quiet). And the more I dealt with the topic and (...) talked to somebody about it, then (...) she, well she somehow confirmed it for us.

Fiona: I talked to my sisters about it, and I somehow feared that I would somehow do something awful if I did such a treatment. And they said immediately, Oh well, if you are for it, it is OK.

Although there was little difference between the reactions of the male or the female respondents’ families, there was a difference in the length and intensity of the discussions. Several men commented that their discussions were brief and to the point. Similarly to Peter, who said that he “talked to his mother-in-law [and] my brother knows … but there are no discussions … they only philosophised about it”, other men had only informed their family. Herbert recalled that his father “doesn’t talk about [DI] at all, because this is what it is like amongst men”, and Daniel explained the approach he had taken:

Daniel: We talked about it before [we started treatment], either there is this possibility or there isn’t. But that we said, we might have said that we will go to the clinic in (N-city) but what, how and where exactly, all the details … and whether we should do it, that was our decision and then we did it. Well, … we did tell them afterwards that we were doing something or that we weren’t. But that we sought their advice, (...) no. Maybe [I would have] from my step-father [who is dead] … but not necessarily my mother, and not my parents-in-law, either.
It seemed that this difference was due to two factors. One resulted from the male respondents’ communication styles as, in the main, they seemed to be more concise and less expansive on emotional issues than the female respondents. The other factor was that male family members’ communication styles were described as similar to their own, and, in addition, DI seemed to be a difficult issue to discuss. Some female respondents said that their own fathers reacted as if they were “a little embarrassed”, or “did not say anything” when the family discussed DI. Maren’s comment also indicates her father’s brief reaction:

Maren: I primarily talked to my mother. And then at first, she did not say anything, and then a few days later, she came with a brochure from a colleague. She had been to see a colleague in (L-city) who does the same. I think, subconsciously, she wanted to find out more than I was willing to tell her. ... My father said, You will do the right thing. ... Well, my mother does accept [DI], they both accept it.

Several respondents, however, were not able to fully gauge their parents’ attitudes. Daniel said that while his mother had accepted DI, he “could not tell you whether she ... rejects it [as] ... she neither advised us for nor against it”. Brian’s experience was similar:

Brian: Yes, well, I did talk about it with my parents, but not as intensely as with my parents-in-law. ... They said from the beginning that it is OK, but what will happen afterwards (..) I cannot say, I cannot see into the future, you know, because ... my parents are not so open.

Cathy also reported that both her sisters thought that “it was great” that she did DI, and her own brother and her brother-in-law offered to donate semen. Although she appreciated this, she did not fully trust it:

Cathy: Even the very conservative [family members], I come from a very Catholic family ... and the aunts and uncles, well the men don’t really say anything anymore. And the aunts, they said ... Well, if it is God’s will and every child is a gift of God. And I thought I did not hear them properly. But, of course, I don’t know what they really think (quiet).

PT: Do you assume that they actually think something different, but that they would not admit it to you because you manage it in such a confident ... way?

Cathy: A part of my relatives ... I think they really think it is OK. And they think that Christine and I are really good mothers and that a child in our family is well taken care of. And then there are certainly other aunts who think ... Well, I don’t really think that is right, or what sort of liberties they take. But more like saying, Oh well, that’s the way the world is these days.
In two other cases, family members offered to donate semen. Adam’s mother suggested using her husband’s semen, which Adam and Anni declined. Zach had a similar experience:

Zach: At the beginning, before I was married, my brother explained that he (..) would give semen for me (.), for my wife. But we never took advantage of that because it was somehow strange.

Similarly to Brian, several respondents described their own family as “reserved” towards DI. Eric explained his mother’s hesitance:

Eric: She knows about it and she, well, she accepts it. I don’t know how difficult this was for her. My mother is, well, I don’t want to say very Catholic, but she was brought up with Catholic beliefs, and that might make it a bit more difficult for her. But (..) towards us she, or towards me, she never commented anything like that she would not agree with it.

Christine reported that her mother had some reservations, but these also seemed to concern Christine’s lesbian relationship:

Christine: My mother celebrated her 60th birthday, a big celebration. ... And then we came in with the pram ... and one of the aunts kept asking me, Who is that woman over there, is that also one of your cousins? And then I said, Don’t you know? That is my wife and (..) also my child. ... And then we did a slide show and [our daughter] was in this slide show. And then we explained the situation to them. And dozens of people asked [questions], but it was clear that my mother hadn’t told anybody (quiet). ... And then we talked to [her] and she said ... she never had a reason [to tell] ... but actually she was glad that I outing myself. ... She had nothing against it, but could not say herself that I was in a lesbian relationship. ... But [my parents] fully accept their grandparent status.

However, she also explained that using DI to build a family was already the second challenging issue they had discussed with others, after disclosing their lesbian relationship:

Christine: For us, being lesbians, that’s where we had to out ourselves the first time. ... Having a sperm donor child, the other comes before, and that is something hetero-couples don’t have. On the one hand, I think that makes it clearer and ... makes it easier, and there is also something that makes it more difficult. We cannot simply go undercover [with our lesbian status the way heterosexual couples can].

The only other concern mentioned by family members was the semen provider’s anonymity. Pat reported her sister’s reaction:
Pat: Yesterday I remembered that my sister ... who has the same problem (.) had said that she did not like it. Well, she would refuse it. And then I did not talk to her anymore about it. ... I rang her again yesterday, and then she said that she would not want this for herself. I don’t know whether she still remembers that I, that we do it. I made a point of ringing her yesterday, and then she said she did not want it for herself. Not (.) for ethical reasons or so on, but (.) when others do it she thinks it is OK, but for herself, she did not want it, she would rather have an affair, then she would at least (.) well, know who the father is. ... She has a problem with the anonymity.

Some family members showed concern for the health of the female respondents. Similarly to Wally’s mother, who “was relieved” to learn that semen providers were selected according to health criteria, Anni recalled her parents’ responses:

Anni: Well, for my mother it was OK. Because she had this case of adoption in her family, she was familiar with it. She knew that her sister's child grew up in a very normal way. ... And my father, I would say he supported it at the beginning (.) and also tried to support it emotionally. And it changed quite a lot in him (quiet) because he experienced what it was like for us with these [treatment] cycles. And at the moment ... he says, Well, if it is the way things are, OK (quiet). And accept it, don’t make such a big thing of it. But that was fatherly care because he is aware of how I am or how we were feeling during that time (quiet). ... [He suggested stopping treatment but] I don’t think ... because he is not open towards the whole issue, but only because he is worried what happens to his little daughter. ... And my mother even financed two treatments.

Other family members showed similar concerns about the family dynamics as the respondents. Fred’s parents were anxious that his wife “has to carry the child of an unknown man”, and Uli’s parents were concerned for him as he “might stand outside a bit as [he] is not the biological father”. Zarah’s father indicated similar feelings:

Zarah: My mother was let into [the secret] from the beginning. ... And therefore she was the only one where I was ... able to say something and so on. And she also knew from the beginning that it worked with a donor. And we told my father three, four weeks later (quiet). ... And well, he took it quite well, I must say. He always stressed (.) well, that Xaver has to be able to manage it (quiet), and thought about Xaver, how he feels. And the topic that this was the way the child was created, he accepted quite easily, yes. Now they are happy ... that they will soon have a grandchild.

Both after the individual interviews and the couple interviews, several female respondents commented in their feedback forms that they had further “discussions with relatives about their attitudes towards DI”, “about sharing, yes or no”, or had asked their “mother-in-law whether ... she would accept a child [conceived by DI] as her grandchild”. None of the male respondents indicated that they had had any further discussions with relatives.
Friends

Although the female respondents reported a greater need to share their inability to conceive with their partner, only a few women and even fewer men shared DI with their friends. Both male and female respondents explained that they feared negative reactions, such as friends commenting that “you make a mess of your life”, a general fear that “this topic would not be accepted ... or [friends] could not understand it”, not wanting “to justify myself”, or friends “making us feel insecure” about their decision to undertake DI.

Several respondents, like Ida, explained that they carefully selected whom they would share DI with:

Ida: I would not have talked to anybody from whom I would have expected a rejection. This is why ... it would have surprised me if there had been [a negative reaction].

Those respondents who did share mainly reported positive and supportive reactions. Ian commented on his discussions:

Ian: Yes, it was like an idea ... and an encouragement ... to think about it. They are two very close girl-friends. ... And I also talked to a very good friend [of mine] ... who has a child himself. And I asked him, well, (.) what was important for him about the fact that it is his genetic son. And (.) he said that it was actually secondary because it is his son. And it is just like Ida getting pregnant and it would be my son ... it is the social aspects that leave a mark, that he leaves his mark, but not that he is the genitor. That was very positive to know. ... And then [we discussed] that this blood (.) relationship ... is actually not valued anymore. ... That in the 21st century it is more about ... certain abilities that you find positive about yourself, ... that you pass them on, your ideas, and so on. ... [And my wife’s girl-friends’ attitudes were] positive. ... They saw it as an alternative. If [anything else] failed, there would still be this possibility. ... There is no reason to give up.

Zarah reported that “a friend was relatively helpful ... she had read a lot and gave good tips [about] ... DI and [others] made a lot of good suggestions”. Pat reported helpful discussions in which she, her husband and a friend explored “how Peter would feel as a father ... and if he could really accept it as his child”.

Sonja recalled one of her friend’s positive reaction, but also her apprehension:

Sonja: She was also positive. She only always said, What do you do if the child is ill and needs something from the father, from the genetic father? ... Those were her concerns, if there is something wrong with the child.
Like Nadia, several respondents were asked why they would not pursue adoption:

Nadia: I cannot remember that there was anybody who somehow said, No [about DI]. Well, sometimes there was someone who asked, Have you thought about adoption? And I told them ... the reasons why we did not want to do that.

Christine recalled that she felt “little resistance” when discussing DI with friends, but Norbert was the only respondent who was confronted with a negative reaction from friends. His friends compared DI to bringing up a child of his wife’s from a previous relationship and said that “you would be crazy ... to bring up a bastard”. After the interviews, several female but only a few male respondents wrote in their feedback forms that they “had talked to friends about the ... questions in the interviews”, or had “informed my friend about [DI] treatment”. They did not indicate any negative reactions.

Others affected by infertility

Several couples had established contact with others experiencing infertility or pursuing DI, attended meetings of regional self-help groups or professionally support groups, or had joined a meeting of IDI. Maren and Markus were very pro-active and placed an advertisement in a local paper seeking contact with other infertile couples. They described their reason for this:

Markus: That was good, that was the first time that we were confronted ... that there are other people with this problem, that we are not alone. Because in our circle of friends, we are the only ones.

Maren: Where we really found peace.

Markus: Yes, where we noticed that there are others.

Other respondents, such as Berta, had considered starting a self-help group in their area but had not yet done this:

Berta: You just can’t start talking; you don’t dare to talk to people [at the clinic] and to ask them, Are you here to do an insemination as well? ... And other couples don’t talk, either. ... There is no [self-help group] and therefore I thought I might establish one myself, because it doesn’t exist. I have already been in contact with Wunschkind e.V. in Berlin, and they will send me some information.
All of those who had established contact with others affected by infertility had shared about DI and, like Sonja, reported that others were interested and supportive of it:

Sonja: They all thought it was good [and did not comment more], apart from one who asked again because there was something with her husband’s semen ... I don’t remember, she had just had a miscarriage. And then she asked for more details, what it was like and the costs, and what happens, what sort of ... or whether you needed [legal] approval.

Vera was surprised how positively the others in a self-help group reacted:

Vera: There was nobody who said, How could you possibly...? Who refused it. I think it is simply [like that] because the others are also in treatment with ICSI. ... They are more open in their thinking. The only thing that was said was (...) that they were surprised that we managed it in such an easy-going way.

Several couples had attended a meeting of IDI and Fiona and Fred explained their motivations:

Fiona: I think I did the first steps because ... I wanted to see how other parents manage [DI], how other parents are ... and what sort of experience they have, and how they deal with the children. And some motivation was also, I did not want to decide before (...), before being well informed or (...) having had some experience ... because the literature is really very thin in this area. ...

Fred: I was also interested ... but I could not imagine ... if these had not been normal parents’ children, I could not imagine if they had looked any different. And this exactly was the case, certainly not from what they looked like, everyone looked a little different. ... If anybody had asked me before, Do you think this child is adopted or is it his child? Well, I would not have known. ... That really, well, confirmed my thoughts and made me feel calm, very calm.

All of those who had attended such a meeting commented very positively:

Jessica: I was really looking forward to meeting couples and children, and (...) I am very excited about how it will go on, that you meet twice a year. I think that is a very good rhythm. ... The group is really good because you can still discuss, there are not so many...

Jan: Yes, and when you get older ... this group can be a big advantage ... [because] the children know each other.

Adam: Initially, it was not quite clear to me how I could profit from talking to these people. ... But then I must admit I was extremely happy ... that I took part, because it was incredibly liberating to talk (...) to the people about [DI], something normal, where in public you are a little shy to mention it. You can talk about it with friends, but you don’t feel so understood. ... And there it was very different, you talked with people for a full day, as if it was the most normal thing on earth and that you feel so well taken care of with this topic.
Adam continued to explain that these meetings "would certainly be helpful for couples at the beginning. To talk to others, this openness ... and a very good atmosphere is valuable for anyone considering DI".

Both Anni, Adam's wife, and Fred added that this normalised their feelings:

Anni: What was so helpful was experiencing that I was really not alone; the theoretical knowledge suddenly became reality. ... [The meeting in April] was great, we were both very (..) moved by it, by the openness. ... Professionally, I have always recommended this to other people, but I had never tested it myself. ... It was great. I was surprised that this group has existed for several years, that they so openly welcomed us, that somehow moved us both. ... Until the last day, we sat with different people and had lunch. ... You got talking and they were really interested. ... And a great wave of support and sympathy ... that was (..) really moving.

Fred: I thought it was very interesting that this group existed. I was not aware of this before. ... I thought it was very good that there are people you can talk to. That makes you feel less like an exotic person or an incomplete person.

Fiona commented that they "had never seen happier families [because] they probably have such a long journey behind them", and Maren said, "My first impression [was] everybody was happy ... and my second impression [was], my goodness, the children are so happy".

For Cathy, "the peer group [was also] something very important", and she and Christine commented on the relationship with another lesbian family:

Cathy: We went to a seminar [called] "Lesbians and their wish for a child". There we met these women because we were looking for couples in our vicinity. And this is how we established contact.

Christine: Well, we initiated it. But they were also very (...) thankful that they had met another couple. ... And we have become good friends. And in September we will go on holiday together, we were simply lucky.

Cathy: And that we got pregnant together.

Christine: Yes, that was super. ... A lot of things worked out. When at the beginning they supported us ... because we had fallen into a hole ... when we learnt that the man [we had chosen as a donor] was HIV positive, where we thought we would not continue [with DI].

All respondents agreed that sharing with others and learning from their experiences was very important or at least helpful in their own decision-making. Those who had not established contact with others pursuing DI viewed this as very important, commenting that in a self-help group "you could talk about anything ... they may know more ... and ask differently", that "it would have been helpful to have met people in the
same situation or who are a little further" along the way, that “it would be interesting to talk to other couples who have conceived a child this way ... to hear their experiences”, that “couples who suffer from the same problem can counsel better than psychologists ... can give better support because they are on an equal level”, or that “it would be great to meet somebody who does DI” and that they would like to have “a group where you can go once a month and share information”.

Others stated that they would like to meet “people ... who are a little further [on]” in order to "hear from their experiences". Herbert said that “it would be interesting to meet couples who have a child [conceived by DI]”, and Ida was curious to “talk to children conceived like that, ... [to find out] how children feel [and] what goes on inside of them”.

The need to “talk about [family building by DI] ... and to [hear] ... about the experiences of other couples” was also given as a reason for participating in this study by several respondents, including Anni:

Anni: I think there were two things [why I wanted to participate]. One was that I also had done some research as a social worker ... and I found it exciting. ... And the other thing is that there have to be publications in this area. ... That’s what I missed. Whether it would have helped me I don’t know. But I missed not being able to read anything, either factual information about couples, or (...) emotional information. That’s what I missed. ... I had even considered running around myself and ... asking women and simply, ... I don’t know about a book, but putting it into the Internet or something like that. Yes, because I think this is simply important and lacking.

Four couples who lived in close proximity asked if it would be possible to establish contact with others taking part in this study and I facilitated this. Several other respondents hoped that they “would hear a little bit about how other couples [manage]”, or that they might “have the possibility of having contact with more couples”.

Understanding the family built with the assistance of DI
Respondents had many different perceptions of and reactions to the concept of families built with the assistance of DI. Many, both male and female, described a family built with the help of DI as “very normal” and commented that “it is [no] different from building a family after IVF [using your own gametes]”. Several male respondents, such as Herbert, said that they would “accept the child as mine ...
[and] would not give it any thought ... as I would be very happy". Other men explained that although “the roots are missing ... this would not lead to neglecting the child or to treating the child differently”, and, similarly to Zach, remarked that they saw “no difference” between social and genetic parenthood.

Some respondents viewed the difference positively and said their future family composition would be something “special”, as building it with DI was considered “a very different path”. Markus stated that “it is as if it had been created the normal way ... but even a bit special”, and Maren added that she thought “it would be more intensive” as she was aware of “how it happened, as you thought about why you had chosen this path ... and simply managed it more consciously”.

Although some respondents indicated that a family built by DI “is more difficult ... [and] you cannot really imagine it”, others explained that it was the transition from infertility to a life with children that was the significant difference. Several respondents shared Tina’s view:

Tina: If it worked, then [all the problems] around us would simply be gone. ... I have the feeling that if it worked, then we would probably be so happy ... that nothing would seem bad for us ... that we would have so much strength, nothing would matter, you would manage anything. ... At least this is what I think. And I also think that because it is not easy, we already have a different attitude. ... If it finally worked ... you would manage the result differently.

A number of respondents hoped that the family’s beginnings “could in a way be repressed” or become “an issue in the background”. Dora and Daniel explained that they may think about “the means of production once a child is coming”, but the fact that the semen of another man was used “would [then] not be an ... issue. This would only become an issue once you let the child into this secret”. Walter said, “Maybe at the beginning [the DI conception would play a small part, but] the daily involvement with the child would take over anyway”. Herbert commented that he “would not think about it much, that the child is conceived with DI, I would not worry about that”, and Helga fully agreed with him. The two couples that had children confirmed this. Ute agreed with her husband that “it is never present in everyday life”, and this was also Jessica and Jan’s experience:
Jan: Well, we have a child; it is as it is. It simply is not a big issue. It is not that I think about it all the time. I think of the child and that is very nice. And I think what makes it easier for me is the fact that [our daughter] Jenny is very much like Jessica. ...

Jessica: And we keep finding things with her that are similar to Jan.

They were asked whether they thought it would be different for them to have a child genetically related to both of them:

Jessica: Well, I think cognitively it would make a difference. But in terms of the love for the child, I cannot imagine it [making a difference]. ... There is not another child that fits us better. But in terms of my head, I think it would be different if I could see some physical features of Jan. But those are unimportant issues. But I would be happy to be able to say, Look, this reminds me of your ears or your eyes. That would be nice if this was also the case, but that is the only thing missing.

Jan: I see it very similarly. There are, let's say, 99 times when I don't think about it and one time [when I do think about it] ... but I can see it positively.

Several others agreed, and Uli highlighted his greater investment in his son's conception as a positive distinction:

Uli: I don't see a difference [between social and biological parenthood]. For me, [my son] is my son. I invested more than others ... to have him, more than other fathers, where it only takes 10 minutes. ... I don't see a difference at all for my child. Because it doesn't have such a great significance, socially or genetically, or biologically, or all three together.

Other respondents realised that there would be additional issues to manage. Adam and Anni, though, explained that “during the first year this would not be an issue”:

Adam: I think there are hardly any differences, only that there is one more issue. But otherwise I don't think that there is anything different between our family and the family next door. ...

Anni: I also don't think ... that in ordinary life, there is anything different from the normal life with a child. But certainly the questions like, What does [the child] really look like? ... And I would look for similarities between the child and Adam. ... But otherwise ... you have to manage the things with a small baby in daily life and they are probably in the foreground.

Explaining this additional issue, Adam said that “the father is not (.) the genetic father”, and Anni added that it was “the influence of Mr. X”. Vera and Valentin commented similarly:
Vera: When the child grows up, ... this may become relevant, you do think, Is he left-handed? ... Does he have this from his father... well, his biological father? And I do think that it will become relevant? ...

Valentin: I think like this as well. I cannot imagine that there could somehow (..) be a crisis or (..) something negative. ... No, we would be happy because we have been through so much.

The fact that the child may have different features or a different character from the parents led several respondents to assume that this may be a reminder of the semen provider's contribution to their family.

Ida and Ian, who believed that initially “everything would be normal”, continued to explain that certain features of the child may remind them of the DI origin:

Ida: Well, maybe if the child starts being different from the way the two of us are.

Ian: Physical features that we both don’t have.

Ida: Or if it became clever in math, or something like that (laughing). ... Then you may think (..) What was the biological father like? [But] we are looking forward to the moment when I get pregnant and we both simply get prepared for this child together.

Xaver, whose wife was pregnant, also assumed that “in every-day situations you don’t think about it ... It is ... very normal, as if it was my own child”, but, similarly to Zinnia, realised that he “will think about [the contribution of the semen provider] once in a while and maybe I will also look (..) at the child a little differently, as if it were my own child ... wondering whether the hair is different ... or maybe the ears”.

Both Xaver and his wife, Zarah, discussed these issues and said that they were unsure “whether this will become a problem or not”. This was also an issue for Geraldine and Georg. They were asked whether they felt that the contribution of the semen provider made a difference to them:

Georg: ... well, no (quiet), at least, I hope not initially (quiet)

Geraldine: Maybe one is a little envious of the others.

Georg: I don’t think so. That might be worse now than when the child is here, because now I don’t know whether it will work. But what I could imagine is that the child will display certain behaviours where you think and say, Well (.), when I hear, he does not have this from my wife and he cannot have it from me, then he must have it from the donor somehow. ...

PT: Does that mean that the donor somehow surfaces again?

Geraldine: Yes.

Georg: That could be.
Geraldine: But that could also happen with your own child, that somehow there are traits that you don’t know at all.

In attempting to create an understanding of the semen provider’s impact, some couples, such as Jan, compared DI to organ or blood donation:

Jan: It was like blood donation. I also received blood after my accident, which was a help at that time. And that’s it. ... Semen certainly also has another quality, but blood is also a life elixir and life-creating, and if it helps, you do it.

Uli agreed with this understanding:

Uli: He gave something away (.) of which he does not know who received it. And I paid for it. I would say, it is like a blood donation. He did not do it for me, ... it is not an invasive surgical operation ... for which he risked his life. He (.) worked for 15 or 20 minutes, depending on whether it was a strenuous or not such a strenuous job (laughing).

Other couples assumed that they would not attribute any special meaning to a family built by DI, but mentioned that “telling the child” may heighten their awareness of the semen provider’s contribution again at a later stage. Eli and Eric also felt this may happen. Eli explained that initially, they would simply be “really happy that I am pregnant”, and Eric added his views:

Eric: [And then] we will worry about all the things that will happen to us [regarding the needs of a baby].

Eli: And of course, this thought (.) about sharing, of course this also plays a role. ... That is an additional factor. ... But we still have some time to think about it. ...

Eric: And in the back of our minds is the question whether we will share DI with the child or not. And apart from that, DI treatment is not an issue any more.

Wally indicated that her open attitude about DI, in general, may create problems as she would wonder, “Who the hell have I told, who haven't I?”

Other apparently less significant areas of concern individual respondents disclosed were their “uncertainty how to react” if others commented on similarities between the husband and the child, the different parental status between the father and the mother, where one male respondent commented that he was “only the social father [whereas my wife] is the social and biological mother”, the fear expressed
by a female respondent that her husband may reject the child and “say at some stage, This is not my child”, or that the child may unwittingly marry “a half-sister or half-brother”.

A number of couples commented on how their perception of this family type had changed. Not having any clarity about the decision to use DI for family building in the past had led “to arguments [amongst the couple about the fact that] ... this is not your child”, whereas now, a family resulting from DI was seen positively. Rob explained his response to DI:

Rob: Four years ago, I would have judged [DI] very differently. [Now] I think that only on the social level can parents show whether they are competent in raising children at all. Because only biological conception is missing doesn’t mean that you are a bad father, quite the opposite. Maybe you make an even greater effort because you always have the feeling that something was missing before.

Most couples, like Maren and Markus, did not differ in their views regarding a family built by DI:

Markus: It is a possibility for me to have a child. Therefore I must say it is a nice way ... and then I don’t say, (...) I don’t feel as if I am the father. It is the opposite, [the child] grows under the heart of my wife, my wife is a part of me, and therefore the child is a part of me.

Maren: I think (...) that couples opting for this path have a great advantage compared to couples who have children normally, because the husband is much more involved ... whether you want to press the injection needle, inseminate ... I have the feeling that we are much more involved in these roles ... and have a great advantage over other couples.

Only two couples indicated there were differences in their perceptions of family building with DI. Similarly to Zinnia and Zach, Theo hoped that the fact that Tina carried the baby inside of her body would contribute to him being able “to forget” the fact that a semen provider was involved, whereas Tina was certain “this will always be an issue as we know that this is the case”. Both couples, however, did not indicate that these differences would result in any difficulty for them.
Meanings of biological and social parenthood

Although many respondents commented about how important it was for them to have a child genetically related to both parents, and several had considered asking a male family member to donate semen in order for the family genes to be continued, once they had made the decision to pursue DI, almost all male and female respondents defined the social connection as more important and as having a greater impact on the child’s development than his genetic origin. There was no indication that respondents were aware of this shift. After having decided to pursue DI, male and female respondents commented that “the genetic [aspects] play a less important role … that many things are a result of education”, that the genes contribute “[only] 15 percent”, “that genes do play a role but education is more important”, that “the biological sperm is a little in the background”, or that nurture would contribute “95 percent” to their child’s development.

Only a few respondents indicated that the genetic origin was important for them. Helga, who only later in life met the man who fathered her, indicated how her own experience impacted on her attitude:

Helga: First I wanted [to do DI] and then I didn’t. And those were my concerns, my thoughts. Because I don’t know my genetic father myself. … And I thought for myself, it is important to know my genes … just simply to know that my father is there and also my grandparents, to know their names and where they come from. I think that is a little bit important for me. On the other hand, I did not have a father, my [mother’s husband would] have been my father had he not died.

Wally and Walter were one of the few couples who also placed importance on the genetic background:

Walter: [M]aybe [the relationship between nature and nurture] is 50/50.

Wally: [I]n the case of DI, I have heard already that they have 60 percent of the nature input and the nurturing is at least half of who you are, the social background, etc. Nurture depends on the social context of the child. … Even if the child has begun in genetics, according to its genes, and it has got everything going for it, and gets into a really bad social situation, I think it could destroy it. Whereas I think the nurturing can do a lot with whatever, the genetic identity, I think nurturing can give a lot of positive, a lot of benefits.
Perceptions of the child

Many respondents, especially males, indicated some hesitation or concern about their ability to form a relationship with their (future) child. Jan, who had a daughter conceived by DI, explained that forming a relationship “was not a process completed”, as he often “had the feeling that ... the child is further away from me than in the case where it would have been my biological one”. Similar perceptions were reflected in other men’s attempts when creating a narrative in order to understand the bond with a child conceived by DI. Again, several respondents used adoption as a metaphor. This was so for Maren and Marcus who agreed that with DI “the risk of a surprise” would be smaller as the child would carry Maren’s genes. Brian commented that he would “accept the child, it is then my own child ... it is a little like adoption”.

Other respondents assumed that they would have to overcome feelings of strangeness and unfamiliarity with the child. Rob and Otto reported that “the child would first of all ... be a little bit foreign, in terms of my feelings”, and Stefan explained his views:

Stefan: [A child resulting from DI is] not quite my own child. But then ... [you] see the child growing up, and I love children ... and then it becomes your own child. You bring it up, you see it growing up, you are there when it is born and then this overrides [your concerns].

Others, such as Ida, indicated some anxiety that the child may express “character traits of a man who, should I have known the man, I would have never chosen [as the father of my child]”. Olga explained how respondents internally processed these emotions:

Olga: Of course it is the child of an unknown [man] that grows in my stomach. But somehow, ... the fact that I am still together with my husband and ... that we have sex ... takes away a part of it, and the greatest part is actually from Otto. Of course it is not Otto’s child, I know that, but being together, loving each other and the partnership [has more weight].

Several male partners agreed and felt similarly to Fred, who explained that “the fact that Fiona is pregnant with the child ... automatically makes it my child”, and Theo, who commented that “being there during the entire [time of pregnancy] and when it is conceived” helped him to feel as if he was the father of the child. Geraldine, however, mentioned an additional anxiety. She raised the possibility of a child
conceived by DI “being handicapped” and felt unsure “whether we could manage this in addition to a strange child”.

Perceptions of motherhood and fatherhood following DI

There was a significant difference between the perception of motherhood and fatherhood following DI. Motherhood, as a result of the genetic connection to the child, was described by almost all respondents as more secure and certain than fatherhood. This was reflected in respondents’ comments such as, “for women it is easier as they carry and bear the child”, and that “there is a distortion, the triangle [of mother, father and child] is not an even-sided triangle”. Having observed men during one of the IDI meetings, Jan felt this attitude was confirmed. He reported that the male attendants seemed “quite cool about not being the genetic father. But I am not sure if they really are so cool about it. ... I always think that there is such a feeling, and then I ponder about it”.

Female respondents confirmed that they had “the easier part” in this type of family and were concerned about this. Jessica explained that her husband “had the most difficult role in the entire thing as he was not fertile ... and this is a lack ... as he could not father a child”. Anni reported that she “had the fantasy for a long time that [Adam] surpasses simply everything, he pushes [the semen provider’s contribution] away and ... at some stage when we have a child, there is the big argument” indicating that ignoring the difference may not only be an issue at the present time, but may result in problems in the future. Given that Adam was such a pragmatic person, these fears diminished, and Anni felt increasingly confident that Adam “would have no difficulty with his role as a non-biological father”. Wally and Walter reported similar anxieties:

Wally: I think ... if we were having a crisis in our relationship ... if there was a child through DI or not, ... when I am looking at the baby all the time, and so in love with the baby, and not in love with you, that maybe you would think, Hah, does she think about the donor ...

Walter: Yes, I think like we were talking at the beginning, going for DI or not, but Wally was far more concerned about how I would react to it.

Wally: I think that is because... I was going for homeopathic treatment ... and, am, the doctor said, Oh look, [DI] is much too hard on the husband, you shouldn't do that. ... But one thing which was a great comfort to me, and whether it is true or not, I just think it is
true, is that often the baby actually looks like the father, when the father has a lot of contact with him because of the mimicry, how he moves his hand or flicks his hair, or whatever. So I actually think the mimicry, they start to look very much like people in their environment. And that was really great news for me, a really exciting piece of news for me. And she said that, for example, children who lived with a nanny, if they have lived with a nanny for many years, it is sort of their mother and it's because of this close physical contact, those mimics. And I thought that was great (all laugh).

Men often described themselves as “the secondary father”, “not the father”, or as “only the social father”.

Some, such as Peter, indicated that this difference in parental status had contributed to their preference for adoption.

Peter: [W]ith adoption you are certain that both have the same distance from the child, and with an insemination I might feel ... that I am further away from the child than the biological mother. That’s clear (quiet).

Peter went on to describe his perceived incomplete and marginal parental role in some detail:

Peter: If you compare adoption to DI, I spontaneously prefer adoption. ... My wife prefers DI because there is at least one in it; ... the woman is the genetic mother, this deficit is smaller. ... Maybe I am envious ... I may feel a little marginalised if my wife has a child from another man ... [and] that would not be the case with adoption. ... Of course, I want my wife to be able to have children ... but I must admit that I cannot contribute anything if my wife wants to become a mother. Well, I cannot take this away from my wife by saying, If I cannot, you are also not allowed to. ... I must grant that to her. But this is very difficult, I must say.

Apparently, several female respondents felt similarly. As previously indicated, preference for adoption in order to share an identical parental status towards the child was mentioned by several female respondents when discussing parenthood following DI. Tina felt that she did not want to enjoy the “advantages [of the genetic connection]”, and Olga wondered whether “it may be better to adopt or to have a foster child, then both are at the same point”. As Christine’s comments indicate, this was not limited to the male partners, but seemed to be a general feeling voiced by those partners who did not share genetic links to the child:

Christine: Yes, that is a big difference. ... If I had a genetic child, then I would feel at home ... the role would be different. ... That’s a point where I am vulnerable, the [lack of] biological connection or where I can be marginalised more easily.

Almost all respondents assumed that these would be transient challenges, which, as described, would subside once a child was born. Only one female respondent voiced her fear of on-going difficulties.
Whereas Theo thought that family building with DI would be forgotten with the advent of pregnancy, Tina was of the opinion that this issue “would always be there”. She was also worried that her husband might reproach the child in a problematic situation and tell the child that “it is not his”, or that the child might confront his father with a similar remark. Theo was not worried about this, though, primarily because the couple had not yet conceived and “this situation is still far away”, but also because the couple intended to share information about the conception with the child and this would take away the pressure. All other respondents felt confident that they would manage these issues and, as Olga put it, that they “would grow into this role and that it would not be discussed much [after some time]”.

The meanings attributed to the semen provider

There were distinct differences in the meanings male and female respondents attributed to the semen provider. Many men, when asked how they felt about the semen provider, commented that they did not have any feelings towards him. Eric explained that only the interview reminded him “that there was a third, unknown person involved”, and other men, similarly to Valentin, explained their need to consciously suppress any thoughts about him:

Valentin: I don’t know [the semen provider]. Well, maybe I am trying consciously to suppress this topic in order not to think about it. And I don’t want to find a solution. I will never get to know him. And I leave it at that ... and my thought is sometimes, well, how should I put it? (..) It could be my child. Simply like this, if she gets pregnant, then [the child] is from me, in terms of my thoughts, in order not to deal with it too deeply. ... Maybe subconsciously this would be the direction.

For other men, the semen provider was an instrument they used. Daniel described him as a tool he needed:

Daniel: Well, I see him like a tool or a help or (..) well, how should I put it? I am a technical person. And I have a problem (.) and a solution. In order to solve the problem, I need a tool. And I know what the problem is, and then the tool ... will simply be used. And that was it. ... At the moment I don’t think about it much, what it will be like later ... when a child is here ... I couldn’t say at the moment. If we have a child ... and I met [the semen provider] ... then I might try and find out a little more about his background, what he does, his hobbies, professional training, whatever. But at the moment I don’t have a real need.

Other men commented that they had no desire for any information about the semen provider. Their comments were similar to Markus’s: “The more you know, the more you want to know ... and there is no
end to it”, and Rob commented that not having any information about the semen provider “makes the whole thing much easier for me ... as I cannot compare myself to someone I don’t know”.

However, several men also showed ambivalence towards having some knowledge about the semen provider. Adam explained that he did not want “close contact ... because this could lead to conflicts”, but he would like to know “what he looks like, how he lives and what sort of person he is ... because you try and understand ... why a child may react in a specific way in certain situations”. Daniel also wanted some “anonymous information ... such as his age, ... his training or what he does”. He explained that he “did not desperately need this information, but if the clinic made it available, I would take advantage of it”.

Others were interested in information such as, how much “they are paid for donating semen”, or their general motivation in donating semen. Markus suggested inviting a semen provider to one of the IDI meeting but worried that “the others would probably say, You are crazy”.

Two factors seemed to contribute to many male respondents’ difficulties in developing any emotional feelings towards the semen provider. One, as Markus explained, was their difficulty in managing the thoughts or feelings they had towards him:

Markus: You have a crisis when you cannot have any children. Then you think, What sort of donor do I have now? And you arrive at the next crisis. At some stage, this goes into the psychological (..) where the margin becomes very narrow and where it can tilt. I think that the more thoughts you have, the crazier it makes you. ... If I had to think about the donor, what sort of man he is, and what he does, and why ... then I would at some stage go mad.

Rob shared this attitude and added that thinking about the semen provider may also be detrimental to his relationship to his future child:

Rob: And the less I think about him, the better for the child as well as for me. It doesn’t mean (.) that I consciously suppress this thing ... but the more I deal (..) with this problem, the more I get enmeshed with other things. [There are] too many thoughts that could keep me from making a decision. ... If I had a three-year-old child, the worst thing for the child would be if it felt that whatever I do with the child, I always only reflect. The child would sense this, that with the parents, there is a certain distance, a blockage, which stops the parents. I don’t want to do this either to my child or to myself.
The second factor was the lack of a concrete manifestation of the semen provider’s contribution as, similarly to Daniel’s situation above, the wives had not yet conceived. Adam, as did Otto, expected to think about the semen provider once his wife had started treatment:

Adam: I don’t think about [the donor] because it has not yet worked. And as long as it has not yet worked or we are (...) uncertain as to whether we will continue [with DI treatment] this of course can be put aside. ... During the treatment cycles, you do think about it a little ... and I feel as helpless as the donor (quiet).

Some men confirmed that they had become more interested in the semen provider once their wives had started treatment and, like Stefan, at that stage, wondered about the semen provider’s physical features. Others, however, who had developed similar curiosities at the beginning of treatment, recalled that these thoughts had subsided after a while. Theo explained that they might surface again “once we have been successful [in conceiving a child]”, and Valentin, whose wife was pregnant, commented, “Routine has set in and [thinking about the donor] has stopped”. Two men, Daniel and Stefan, who prior to the interviews indicated no interest in the semen provider, commented in their feedback forms that they thought “about the donor and what motivated him to do this”.

Several male respondents indicated that they had a slight sense of gratitude towards the semen provider. This feeling, however, again was difficult, as the partners of these men had not yet conceived and, thus, the person of the semen provider was perceived only as a vague possibility. Georg expressed “admiration for such people” who provided semen, and Norbert said that he was “glad that other men did something like this”. Jan was the only man who, albeit jokingly, actively acknowledged the genitor of his daughter by “politely thanking him in my prayers, or something like that”.

Although many women agreed with their partners about the lack of emotion towards the semen provider and felt grateful for his deed, many more female than male respondents commented on the semen provider. They also expressed a greater variety of affective responses. Like Vera, some wondered “about his reasons to do something like that ... how he will feel later on knowing that there are children ... belonging to him”. Others voiced a need to “somehow create a relationship to” the semen provider. Anni did so by “smelling his semen” after the inseminations and she, similarly to others, made him more tangible by giving him a fictitious name, such as “D 13 [or] ... Mr. X” or “Gustav”. 
Some women, similarly to their partners, expected to reflect more about the semen provider once they became pregnant or had a child. On the other hand, Zarah and Eli, who were pregnant, did not think about him much. Others did at the onset of treatment, but less so as they continued. Helga, however, “had sleepless nights” because she, similarly to Pat, Ida and Karola, thought a lot about the semen provider during treatment. Jessica and Ute, who both had children, “occasionally” thought “about physical features” wondering from whom their children had inherited these.

Many more women than men indicated curiosity about the semen provider. Maren wondered “whether he really looks the way I imagine” and was certain that she “wants to meet him” if she conceived, Geraldine and Pat speculated on “what type of man he is, ... whether he looks similar to my husband, ... the family he comes from, ... what [his motivation is] to give semen”, Dora, Eli and Tina wanted to know about “his character, his job, his way of living”, and Ute was curious about his level of “confidence”. Cathy recalled how she managed this:

Cathy: At the beginning it was terrible not knowing anything about him. ... I had the need to fill this picture, this empty shell and then something changed. At some stage I thought, It is OK that [the information] is not there. And I started to put together all the information, piece by piece, and then ... started to compose my own picture.

Helga recalled how she had composed a list of questions about the semen provider, which she had intended to ask the doctor. She also wondered whether “he was married, ... had other children”, but the list apparently included many more questions than she could remember. Ruth explained that having some information about the semen provider, such as “social context and professional training”, would facilitate the decision-making process towards DI. She voiced her fears of the semen provider having “criminal tendencies” and was afraid that there would be “something in the child that I cannot control. ... It is something absolutely unknown that is put into my body”. However, she also felt some ambivalence and commented that sometimes she “felt OK [and] I would not be interested in [knowing] anything ... [but] the next moment ... these questions would devastate me totally”. Dora had wondered what it would be like to meet the semen provider and also expressed significant ambivalence about this:
Dora: Then I thought, How should I react? The donor is registered ... but would I want to know who the donor is in later years? Although I think he knows what he has done, I know what I did. Why should I not be able to meet him? ... I don't think I would have a problem in a case like that, because there is nothing. I don't want anything, and he won't do anything to me, but he knows what happened with his semen.

Similarly to the male respondents, women also indicated tendencies to ignore the semen provider's contribution. Fiona explained that ignoring him "would lower the burden [of DI] ... and [contribute towards] dealing with it normally". Ida functionalised him when she explained that "there is no person, for me ... it is a Petri dish. This is peculiar, there is really no person behind it". However, these were not only the anxieties the women had for themselves, but also emerged from their need to protect their partners. Tina described her fear that knowing the semen provider would force her to recognise him as a person and acknowledge that he might want to meet the child. She explained, "It would be bad for me and my husband if there was a sort of confrontation with him". Wally associated thinking about the semen provider with betraying her husband and was relieved that she did not have any information about the semen provider. She explained what thinking about the semen provider meant for her:

Wally: [T]here would be an element of betrayal there, because it is not something that I would want to say to Walter. It is not something that I think Walter needs to hear, that I am thinking about the donor. I think it would be hurtful to him and I don't want to have any secrets from him, so I don't want to think that there is something I am thinking about which I can't share with him.

PT: And do you think if Walter knew that you thought about the donor, he would feel hurt?

Wally: Yeah, and that's why I wouldn't want to tell him, and the fact that I would not tell him would be like betrayal. So there is (.) not the fact that, I don't mean that because I am thinking of the donor it is betrayal, it is just the fact of keeping it a secret is a betrayal. And I am only keeping it a secret to avoid hurting him.

PT: How would that hurt him? Do you have any idea?

Wally: Yes, that maybe it could be dangerous that when you have a child, a lot of couples seem to ... become fixated on the child and [there is not sufficient] attention [for] the husband, [he] feels a little bit alienated. I talked to [the counsellor] before, and I think in such a situation, if I have explained to Walter before that I think a lot about the donor, that he feels doubly alienated because it could be that I am not just fixated on the child, I am mostly fixated on where that child comes from.

The semen provider's roles

For almost all male respondents, the most challenging of the semen provider's roles was when he was considered a "competitor". They explained that they were afraid "that there is something between myself
and the child", and like Brian, they described themselves “as the only loser” in this family scenario as they feared that their child would not accept them as the father, and as Brian said: “I would be tempted to compare myself with this [person and wonder whether] I can stand up to him”. Rob, similarly to Otto and Valentin, explained his anxiety in some detail:

Rob: There is this old German proverb: ‘What you don’t know, doesn’t make you curious’. I cannot make any comparisons to somebody I don’t know. I don’t need to look for similarities to the father if I don’t know him. And the more (.) anonymously this takes place, the easier for me. We have read of couples who looked for a donor within their families, ... a brother or distant relative. ... The thought that this child could be my brother’s child would be unbearable for me ... I would probably, with every smile of the child, simply look, and think, Does he have his eyes, his gestures, his mimicry? ... And if you leave it anonymous, certain things are easier.

Many men agreed with this and commented that they did not want any information about the semen provider, as this would “take away ... a piece of my personality”. Eric explained that such thoughts stopped his curiosity about the semen provider:

Eric: [Not knowing anything about the semen provider] is pleasant for me, (.) maybe I don’t want to know anything about him ... because I am afraid that something would be between myself and the child. The way it is at the moment, I borrowed something, and once the child is born I am the father. There is nothing between us, no knowledge about someone, there is absolutely nothing between us, this is the most pleasant thought. This is why I don’t think about it at all.

Several female respondents agreed with their husbands. Pat also commented that the semen provider would be “a competitor” for her husband, Tina and Wally associated it, as in the passage quoted above, with elements of betrayal, and Zinnia assumed that for her husband “it would be difficult”, as the child would remind him of the semen provider.

While women also attributed a role to the semen provider, in contrast to their male partners they did not perceive this as threatening. Although Ute expressed some concern regarding her family life, she favoured contact with the semen provider:

Ute: And I would like to have more information about him or ... simply a connection to him. ... This is also dangerous ... [as] it would be like an incision into our family life ... but we would have to see how we manage this. I would like to have this contact, would like to know who he is, but I would not like him to interfere into our family life. I simply want him ... as an acquaintance ... not as a significant person in our family.
Many couples discussed these differences openly in the couple interviews, with the female partners feeling more comfortable and indicating a greater curiosity about the semen provider than their husbands. Otto commented that the semen provider would not have any significance for him, whereas Olga said the child would remind her of him “every so often”. Jessica and Jan, although they both planned to share about DI with their daughter, displayed similar differences. Jessica described the semen provider as “having done a lot”, but Jan said, “He didn’t do very much”. In Helga and Herbert’s case, Helga wondered whether she would be able to trace certain features of the child back to the semen provider, while Herbert commented that “he donated his semen and I don’t have anything else [to do] with him, ... there is no place for him”. Wally described the semen provider as “a guardian angel”, whereas her husband said he “would not have a physical role ... and no physical presence”.

Other anxieties concerning the semen provider concerned the potential behavioural and emotional reaction of their future children. Several respondents, both male and female, feared that the child would be drawn to the semen provider and would tell the father, “You are not my daddy”, or that the child might be torn between two father figures. Uli explained some of the risks:

Uli: With being curious you are risky. ... If I knew [who the donor was], I would also give my son a chance of knowing him ... and then I would risk that he might want to know more at some stage, that there are problems at some stage, that he cannot orientate himself, ... that he would be torn ... between two father figures.

Eric spoke for many men when he remarked, as above, how much the child’s rejection of him as the social father would hurt him. Ida and Ian raised more concrete anxieties, fearing that the semen provider might make alimony demands, want the right to visit the child or “could even state that, This is my child ... I want to raise it”.

In order to avoid having to manage these anxieties, many male and female respondents attempted to ignore the semen provider’s contribution. They said that he “does not have a role or a meaning at all ... and should not get one”, that “he would be standing far away”, would “not have a function [or] ... a role”, that “he has no place”, or that “this topic is not present for me”. As Otto put it, “It is good that you don’t know him. It gives you some certainty; you don’t start comparing yourself to him. ... You can simply
say, you don’t know”. Ida, who prior to the interview had not reflected on the semen provider, also confirmed in the feedback form that “I have not thought about the donor much at all, and I won’t do it in the future, either”.

There were only a few indications that respondents had developed an understanding of the issue of fatherhood after DI and the meaning to them of the semen provider. As described above, Wally called him “a guardian angel”, adding that he was “some sort of bearer of gifts that helped in the process”, while Christine explained that for her, the semen provider needed to be given a place:

> Christine: I thought about it again ... what it would mean for [Claire, our daughter] not having ... a biological father. And then I said that he needs to have a clear place within us. I was more conscious of this after [the individual interview]. ... He needs a place, well, allocated. Not so big, but we said, He needs a place and .... I thought, well, there is a person who may think about her and who may ... have the connection in his mind and he needs a place. ... He became less anonymous as a result. ... And so this image of him sitting, well I see him with his back to the kitchen table, as a family father. ... And I find this pleasant, yes.

Cathy explained how she and Christine had agreed to call the semen provider “donor daddy”:

> Cathy: ‘Father’ implies a certain social role, which he does not have and will never have ... and ‘donor’ sounds strange. So we put the two words together and made one because both are accurate. He donated and somehow he ... is her father.

Tina and Theo had come to the conclusion that “father” was reserved for the semen provider as the genitor, and the less formal and more emotional notion of “daddy” was used for Theo. Theo explained that clarifying this “increased our confidence”.

Although Jessica disagreed with the concept of referring to the semen provider as a father, she also had a clear understanding of fatherhood:
Jessica: There are different types of fathers for me. In former times, the father was the one who fathered the child and lived with the child. But today there are many fathers who do not live with their children. On the other hand, there are fathers who are not the genitors. This shows that the word ‘father’ has been given a bigger meaning. And some children really live with two fathers. And for me it is very clear that Jan is the father. I would never see the donor as the father. The child is there because of Jan. If the donor had not given his semen, certainly this child would not have been born, but somebody else would have been the donor and a different child would have been created, but a child from us.

The complexity of family building with DI was also revealed in the words and notions respondents used in order to describe “fatherhood”. In many cases, male respondents especially associated the word “father” with the genitor and made comments such as, “the child has the right to find out who the actual father is”, “you have to tell your child that you are not the father”, “I cannot become a natural father”, “I am only the social father” or “I may be disappointed if I got to know the real father”. The semen provider was described as “the father”, “the unknown father”, “the genetic father”, “the biological father”, “the actual father”, “the original father”, and, as noted above, “the competitor”.

**Discussing the semen provider**

Most male and female respondents had not discussed the semen provider with significant others. Those who had, commented that others were curious about him. Zarah explained this:

Zarah: [We talked] with friends or our family. Of course they are very curious: What do you know about him? And such questions. And you can only say, well, I don’t know myself. ... Or you discuss it. I discussed it a lot with my mother. ... But you cannot recommend anything to each other or give tips. It is more sharing but not knowing anything.

In contrast to the male respondents, several women commented that they had discussed the semen provider with the doctor. These discussions, however, were limited to the understanding “that all donors are anonymous”, and that “it is difficult to recruit donors”. There was no indication that the roles and meanings of the semen provider were explored during counselling.

Some respondents commented that they had had discussions about the semen provider with their partners. In almost all of these discussions, respondents expressed their curiosity about the person of the semen provider. Olga and Otto wondered what he looked like, Anni and Adam, as well as several other couples,
were curious about his professional background. Berta and Brian wondered about the semen provider’s reactions, “his feelings and thoughts and motivation”. For other couples, such as Maren and Markus, and Pat and Peter, couple discussions about the semen provider were prompted by the individual interviews. During the couple interview, Markus raised the notion of the semen provider “feeling like a hero who wants to pass on his genes this way”. Though this suggests that Markus had feelings of inferiority, as already described, he was interested in inviting a semen provider to one of the future meetings of IDI. As Pat said in the couple interview, she would be interested in “having a photo of him for the child ... and a sort of letter about his life”.

Sharing information about DI

As Figure 7.2 shows, the majority of respondents (16 females and 14 males) had decided to share information about DI with their children and only one (a male) had decided against information sharing.

![Attitudes towards sharing DI](image)

Figure 7.2. Attitudes towards sharing DI
In almost all cases, couples were in agreement regarding this issue. Maren and Markus's and Helga and Herbert's comments were typical examples:

PT: Do you have the same attitude regarding information sharing?

Markus: Yes, with this topic we have always agreed.

Maren: Yes, we have.

Markus: And we have always said that [the child] has to grow up with this [knowledge] from the beginning.

Herbert: Well, I think you should be honest with the child. Once it has reached an age where it can understand, then you should slowly explain it to him.

Helga: Not make it a secret.

Herbert: Yes, but you should also not all of a sudden tell him, You are a DI [child]. One should slowly get the child used to it.

For one couple, one partner was in favour of information sharing while the other was opposed to it. For two couples, one partner was undecided while the other was in favour of sharing. This was the case with Ruth and Rob:

Ruth: My question is simply, If you protect the child from the truth, wouldn't you lie your entire life? ... And with adoption, they recommend telling the child as early as possible, and not to live with this lie. ... But the question is, Wouldn't the child have a happier childhood or a more satisfying childhood if there was not the burden of this issue? Because then the child only knows one daddy and accepts him as his daddy. ... [And my husband] prefers dealing with it quite openly, to tell the child that it was [conceived] as a result of a donor ... because he is much more factual, he has accepted it much more and doesn't make this separation [between] biological and social father.

These different attitudes did not seem to lead to any difficulties for these couples; in fact Dora and Daniel welcomed this difference:

Daniel: This is not a problem. In fact it is positive that in one area we don’t have the same opinion. ... A colleague of mine always says, You should have a proper argument with your wife once a month. But we haven’t managed [to have an argument] in seven years. ...

Dora: We have always found a solution ... and therefore I am not worried, there will be a solution [for this as well].
Most respondents who had shared information about DI, and most of those who felt certain they would share it with the child in the future, felt confident that their view would not change. They commented that they “could not imagine” that anything would change their views, firmly stated that “no, nothing could change in this respect”, and were “convinced that [being open] is the right way”. Only Helga and Tina explained that they might reconsider their attitudes if they had the feeling that the child “was very sensitive ... or instable”, or “if it was very bad for the child to learn [about his conception]”. Those respondents who had not yet formed a firm opinion, such as Brian, who had decided against sharing, felt less certain about their decision. Brian commented, “Maybe once the child is born and bigger, the question will surface again, maybe once the child asks [I will reconsider this]”. His comments were similar to Daniel’s: “First of all we have to have a child ... and later we decide”, and he added that “there could be a situation where you tell the child”. Geraldine commented that “attending a seminar” and discussing this issue with others might impact on her views.

Most of the respondents who felt confident about sharing about the conception with their future child had considered to some degree how they would approach this. As Zarah commented, “We will tell the child in a child-appropriate way ... and will also wait until we see how many questions the child has”. She and her husband described their plan:

Xaver: I imagine that you feel very free and easy about it, and that the child may even have an impact on [how you share]. You begin with, Where does the child come from? ... Well, there is a daddy and a mommy.... And about the birds and the bees and ... then you mention the donor, or maybe that there is another man who gave us something, because ... I couldn’t do it. And then we had you, this is how you grew up with us. Yes, in a bit of a playful way.

Zarah: Yes, and we also both agree that it is the child who comes up to us [and initiates the discussion] and it is not us who will say, Well, now sit down [because we have something to tell you].

Jan and Jessica, who had compared DI to organ donation, again referred to this concept when they discussed sharing DI with their daughter:

Jan: For me, sharing would have been a greater problem [than for my wife] as I would not have had the right words to explain this to the child, but I knew ... I could rely on my wife ... and we created [metaphors] so that we could deal with it more easily. For example, we compared it to donating blood and organ donation. I have a donor’s passport for that.
Jessica: And other people do [donate blood] as well. . .

Jan: That is very normal for us.

Some respondents differentiated between being open about the conception using DI with the child, close family members and friends, and others. They considered conception resulting from DI a private family matter “which is shared with our parents” and “is a personal thing . . . I don’t need to talk to everybody about”. Fred explained his approach:

Fred: We want to talk openly about it, but we don’t want to talk openly with anybody and everybody. Well, I don’t want to put a sticker on my shirt [saying] I am not the father or something like that. I think that is rubbish because it not anybody else’s business.

Jan explained his need not having to justify himself:

Jan: [There are many friends] who do not know about it in detail, at least not explicitly. And I don’t know whether it is important for them to know, otherwise they might have asked more. . . And on the other hand, [once I had reached a point where] I didn’t have to justify myself, and then everything became much easier. . . My parents know and two, three close friends, and this makes me feel that I am not keeping it a secret.

Christine had also considered this:

Christine: We always have the problem or the additional issue that we have to out ourselves as lesbians. And then the next question is, Where does the child come from? . . . [But I think] people don’t assume that it is a DI-child. And I would carefully consider to whom I talk about that. . . Friends and family know, but for example in kindergarten, I don’t know what exactly to say. . . I would always decide [in every single new situation] whom I would tell.

Factors prompting discussions about information sharing

Most respondents recalled that the discussion concerning information sharing started “relatively at the beginning” when commencing treatment, when consulting a public notary or undergoing pre-treatment counselling. As Daniel explained, this issue was relevant “from the first moment on, . . . you have to be aware that there is a second person which is, so to speak, the father, the genetic father. . . And you are forced to deal with this, what you think about this”. Zarah explained that it was important for her to clarify this with her husband prior to treatment:
Zarah: [My husband] said, You don’t have to be [open]. ... and we had some arguments. I had the feeling that I had to convince him to deal with it openly, because I could not imagine really doing it, and then it may even work. And then he says, Oh, no, I don’t want the child to find out about it.

PT: So it was important for you to sort this out before treatment?

Zarah: Yes, ... but it was also important for my husband; he said he would definitely not start treatment unless we had discussed how we would manage this. ... And then he took longer to sort out all his feelings ... but it was important that it was also his decision to be open with the child.

A second group of respondents had considered adoption prior to pursuing DI. These respondents commented that exploring issues such as sharing with adopted children about their origin contributed to their awareness of similar needs for children conceived by DI. Pat and Peter recalled thinking about this:

Pat: Actually [we thought about sharing] relatively soon after we had registered to adopt a child.

Peter: That’s when we reflected on it very intensely. Of course we knew about the condition for DI and that the child had the right to find out, but ... this did not have anything to do with sharing. This actually came with adoption. ... After we had heard that it is of advantage for the child (.) that this advantage is not very dangerous ... to let the child know from a pretty early point on that it is adopted. ... This gave us the idea that this may be [similar] for [a child conceived by DI] inseminations.

Other factors that initiated consideration of information sharing included respondents having read my booklet, a professional background in a psychosocial area which “included the knowledge that you cannot manage family secrets”, and personal attributes, as with Nadia who described herself as a person who “does not only think from now until noon ... when I do something, I also reflect ... on what sort of consequences this could have in several years time”. In addition, several respondents commented that participating in this study had contributed to “thinking more about sharing”.

For many couples, sharing was an important issue discussed in detail between the partners. Helga and Herbert remembered that they “discussed a lot [amongst themselves]... day after day, and day after day”. Jan and Jessica discussed “how we should share it with the child ... and what it is like if the child talks to other people about it”. Karola and Klaus explained that “sharing was the biggest issue” for them, and Eric recalled that this was discussed at the beginning:
Eric: This was the first thing [we discussed], to think whether you share it with the child, which arguments are in favour of it, which arguments are against it. Therefore my wife and I had lengthy discussions ... and we will certainly need help telling the child.

In many cases, it was the female partner who initiated the discussion around information sharing; again some respondents indicated that their professional background led to this. In other cases, women had shared DI with friends or relatives and this led to discussing information sharing with their husbands. Some men commented that they did not “really have a need to discuss” this. Norbert also felt this way when he said that he probably would only need to talk about sharing “once a child has been born”, but his wife Nadia insisted on “at least thinking a little bit ahead”.

Only a few couples had not raised the issue of information sharing prior to the individual interviews. This was so for Berta and Brian, who were pursuing treatment at the time of the interviews:

Berta: We were a little curious [after the individual interviews and wondered], What did you say? And what did [I] say? And we noticed disagreements ... but as long as the child is small ... it is not important. ...

Brian: I think when the child is 10 or 15 years old ... then I might want to tell them [but I am very unsure].

Other couples, such as Dora and Daniel, had not discussed information sharing at all, even amongst themselves. Although Daniel explained that he thought about the meaning of the semen provider as soon as the couple had considered using DI, and that they had “dealt intensively with this part [of DI] ... we never raised this question. And from the outside, I don’t think that [without the interviews] there would have ever been the initiative to [discuss sharing]”. Valentin assumed that this would only be necessary “once a child is there”, and Rob explained that there was not yet the necessity to make a decision, as the couple “had not yet clarified whether we will actually do [DI]”.

Discussions with and attitudes of others regarding sharing information about DI

Eleven women and three men had discussed the issue of information sharing with family and friends, while many others indicated that they had had brief discussions. They recalled that those they had talked
to did not take up the discussion of information sharing. This was especially the case with medical and psychosocial professionals.

*Family members and friends*

In almost all cases, it was the female partner who initiated a discussion about information sharing with family members or friends. They received mixed reactions. In some cases, the advice was ambivalent and respondents said that “some say, You have to [share]. And others wonder why” you would need to. In others cases, family members recommended against information sharing. Berta’s mother suggested “waiting and deciding later how you will handle it”. Dora talked to both her mother and her mother-in-law and, like Georg, was confronted with contradictory advice. Her own mother recommended “telling the child”, whereas her mother-in-law recommended “not telling [and]... not thinking about it”. Georg tried to explain this difference:

Georg: I talked to my brother about it ... and he said he would not talk about it ... but my brother is from this area here. And my sister-in-law said she would talk about it, but she comes from a big city. ... Maybe this is why their opinions are not the same.

Herbert described his mother-in-law’s reaction as reserved and explained that this was due to the fact that she “knew nothing about this area. And she’d rather not say anything than say something wrong”. Both Sonja and Nadia had discussed sharing with their parents and other relatives and were supported in their attitudes towards openness and “honesty”. Nadia’s mother compared DI “with adopted children, and if they have a right, then [DI children also have a right]”.

Some couples wanted to ensure that family members could understand their motivation for openness and were aware that they might require time to process this. Wally explained her strategy:

Wally: I think we did talk to someone, because when we told people that we were doing DI, I think we gave a lot of details of what [the counsellor who carried out pre-treatment counselling] had said. And we talked about the example of drawing a donor in the family tree. And we did talk to other couples about that and everything, really, [they were concerned] that we would be so open and wasn't it too complicated for a child to understand. ... But to me, when I talked, I did talk about what it would be like for the child.

PT: And their reaction was that it might be very complicated for the family?
Wally: Yes, and they were very surprised.

PT: Do you remember who initiated these discussions? Was it you or was it your family?

Wally: It was me, because it was very much telling them what [the counsellor had] said, and telling them what our process was, and it took some time for them to digest it. Like I said last night, we didn't really get many reactions or opinions, it would be more like questions. And maybe because people were a bit dumbfounded about the whole thing, and it takes some time to think about it. Or if they were negative, they didn't want to hurt us, come back with a negative reaction.

Anni and Adam also had long discussions with Anni’s parents and explained how they convinced her parents to understand their need for openness:

Anni: My mother was not quite sure whether openness would be good for the child. My father did not really comment on it. And then we tried to give some examples so that they could understand why I would find a secret problematic. And my mother understood. It didn't change her attitude but ... she could understand what I said. But she ... is a woman who has no problems with keeping secrets ... and she could have kept it a secret.

Other couples who have used DI

Four couples had attended a meeting organised by IDI. All of these couples reported that discussing the psychosocial issues of DI with other parents had strengthened their intention to share information about DI. As described earlier, Maren was amazed about the happiness this group conveyed. She also remembered that “sharing [about the conception] ... was a normality for them”. Adam said, “All but one couple in this group had the attitude that they were open [about DI] ... and there were older children, which indicated that they had managed to be open”. Similarly to Fred and Fiona, Jessica and Jan described meeting others as a normalising experience for them and for their daughter:

Jan: This family meeting was great. ... And I think it is very important for the parents that you get together, but especially for the children, ... so that the children grow up in some normality. ... I think we have to continue so that our child has the feeling she is just as normal. [And we also went to the meeting] so that our daughter could meet other children [conceived by DI] ... And they use certain terminology ... and this makes it normal. It is not anything special, it has its justification.

Anni commented that “the openness in this group ... was a revelation, it was great. ... There was a lot of support and empathy and it was very moving”. For Fiona, the group “has become very important, it was a real confirmation ... of our decision ... and by the time we left, I felt much stronger about our decision [to
Cathy recalled that "we talked about this issue ... and this is where I have all my knowledge from. And apart from a few exceptions, they said that the child should basically grow up with this knowledge [of being conceived by DI]." Cathy and Christine also attributed a lot of significance to their lesbian peer group:

Cathy: We were very lucky because we had our own peer group, other lesbian families who already had children. And [we were able to see] how they dealt with the children ... what they call the mothers. To see how this works or what may become difficult, well, the peer group, that is very important.

Others, such as Geraldine and Georg, who planned to attend a seminar preparing couples for DI, hoped that "in this seminar, we can learn about new attitudes or ... opinions or meet other couples in the same situation. We have now decided not to share ... but we are still interested in new attitudes and to find out more". Eli reported that in an Internet chat forum, she had contact to others and "the question whether you share DI or not is raised again and again". She and her husband, however, like most respondents, had not met other couples personally.

Similarly to respondents who needed to have contact with others carrying out DI, most respondents also considered information from "people who are one step further" as helpful, and they wanted to talk to "people who have conceived children this way". Like Tina, they wanted to find out how others manage sharing about the conception or wished to attend a "self-help group". Berta was considering establishing "a support group for infertile couples considering DI", and Ida was even interested in "talking to children who were conceived that way". Karola wanted to maintain contact with other families "so that the child has the possibility of meeting others who were also conceived by DI". Other respondents had participated in this study so that they "could find out about the experiences of other couples, so that you hear via this study from them and maybe establish contact with them".

Medical professionals

Several respondents raised the issue of information sharing with doctors and received very varied reactions. Some doctors strongly advised against information sharing. Georg recalled that "the doctor [he]
consulted said she would definitely not [share]". Klaus and his wife, however, both agreed that disclosure would be important for the child:

Klaus: We asked the doctor specifically about [sharing] information, that we would consider managing it openly if we did DI. Then we found out that the doctor had absolutely no experience with couples managing it openly. He said again and again, You will find that you will forget that the child resulted from DI treatment. ... Then I asked him, ... What if we talked to the child and ... [what if] the child would like to have the possibility of getting to know his biological father? ... And then we were told pretty straightforwardly, that ... anonymity is the fundamental precondition for the clinic. ... And we were told very carefully that they could not guarantee still having the documents once the child is 18 years old. [This was] like [them] telling us, If you look [for information] in 18 years, you will definitely not find anything anymore. And that was not necessarily a satisfying answer for us.

Jessica and Ute recalled their attempts to discuss information sharing with their doctors:

Jessica: We had the first interview with Dr. (K) and had a discussion with [another doctor before that]. And she very strongly recommended not telling the child. Then I quietly attempted to say that I didn’t feel comfortable with that, but she rolled over it like a stream roller, and then I didn’t say anything anymore. I noticed that you couldn’t talk to her about it at all. There was no sense in saying anything about it. And then I thought, Well, I will do treatment here, but I won’t talk about how to manage it with the child, I will have to look for other support for that. ... I went to see her again [after I had been to the IDI meeting] ... and she asked me whether this meeting was really so important for me. And I told her that it was, ... that I also found it important for my child. And I wanted to tell her a little about it, but she interrupted me and said, For others it is very different. ... I had the impression that there was no space for discussing this.

Ute: Dr. (M) absolutely recommended against being open because they had had very negative experiences. ... There was one family that had to move away, only because they also kept it a secret [and didn’t want anybody to be able to find it out]. And I talked [to many girl-friends about DI] because I am a very open person and direct. I think anything else would be lying, and I couldn’t live with that. ... And I did not have any problems with the fact that we manage it so openly. ... And we listened to what the doctor said but found our own way.

Several other respondents were advised that “there was no need to tell the child”, and that “it should stay within the family, as for the public, it is your child [and] anything else is unimportant”. Others, such as Daniel and Brian, were told, “You have to decide yourself”, or that it “was dependent upon the child ... but [the doctor] recommended more against [sharing]”. Vera and Valentin also raised this with their doctor:
Vera: [Sharing information about DI] was talked about with the doctor, but it was not an issue that was properly discussed. She asked whether we had made a decision ... and told us to think about it and also said, I cannot give you any tips. ... She could not make any recommendation about sharing, she only wanted us to think about it. ... And we have thought about it ... and now we have come to a point where we have said: We will put it aside [and not make a decision]. As otherwise you only think about that. ... When I get pregnant, we will have nine months to think about it.

Only in a few cases did doctors recommend “telling the child sooner or later”, but respondents felt that “this was only mentioned by-the-by”. Both Peter and Valentin recalled comments made by their doctors:

Peter: [The doctor said] that the child has a right to find out his genetic father when it is 18. ... But there was no encouragement or motivation ... to tell the child. I think it was more oriented towards, well, people are content when they have a child and in general do not even want to know.

Valentin: It was mentioned briefly but not in depth. It was more about the physical issues. One recommendation [from the doctor] was that we should simply not think about it anymore but pretend it is something ... very normal. We go to treatment and we go home, that’s it, ... as if we have a child the natural way, with each other. [Sharing or not sharing information] was not an issue.

Berta and Brian’s doctor explained that they “had a moral duty to tell the child the truth. ... He was of the opinion that the child has a right to learn this”. Berta reacted strongly to this advice:

Berta: I listened to all of that ... and then we left the clinic and got into the car, and I thought, He [won’t decide] what I am going to do and what I am not going to do. ... If this had been his precondition [for treatment] then ... I would have looked for a different [doctor]. ... That would have been an intrusión into my private sphere, that is something that will concern us as a family later on, he doesn’t have to live with the consequences. ... Those are our consequences, not his, and I think he cannot tell us what to do and say. He can say, In my experience [telling] is better or is not better. But we won’t let him tell us what to do.

Fred also recalled being advised that “the child has to be told” but could not remember whether it was the doctor or the lawyer who gave this advice. Cathy and Christine recalled that the doctor they consulted did not comment on sharing information but “had a very clear attitude, he said, You have no rights ... only the child has the right to learn anything about the donor”.

Others commented that the issue of sharing information about DI was not discussed at all with the medical professionals, and this lack of discussion, as already described, led respondents to lower their expectations in this respect. Maren felt humiliated by the reaction of one doctor. When she insisted on
discussing this issue, he commented that she “probably needs this [discussion] for your mental well-being”. As indicated earlier, Zinnia said that she and her husband were required to sign a document indicating they would not be allowed to talk about treatment. Although this statement did not explicitly comment on sharing information about DI with the child, she felt that the doctor did not favour this. Disappointment about the lack of information about peer support was also mentioned by Jessica who “had the feeling that doctors are not aware that there are groups … and there seems little interest [in passing any information on to patients]”.

Some of those couples who had taken up pre-treatment counselling were given contrary advice by the medical and the psychosocial professionals. Eli described how this happened in her case:

Eli: The psychologist recommended telling, and the doctor recommended against it. ... Then we told [the doctor] that the psychologist sees it differently, but we did not discuss it anymore with him. ... It was strange [getting such contrary advice], but you can understand the doctor, as for him it is only annoying if someone tries to find out who the father is, because this is not easy for the doctor because he granted anonymity to the donor.

Psychosocial professionals

With the exception of those respondents who underwent pre-treatment counselling, only a few respondents commented on discussions with psychosocial professionals regarding sharing information about DI. The couples who underwent pre-treatment counselling, such as Wally and Tina, had already decided to disclose DI to the child and this decision was supported by the counsellors:

Wally: When [the counsellor] asked us, Will you tell the child? [And we said, Yes]. She said, That is very positive. And she gave us a little bit of encouragement. ...[The counsellor said that] you could explain to the child that this is a real matter-of-fact thing ... this is how you explain it, what you say to a three-year-old, a 12-year-old, and she gave us very practical stories.

Tina: [The psychologist explained that you can use] a sort of story, that you ... first tell the child you really wanted to have it, that you say that we have waited a long time for you ... and then the procedure ... in a way so that the child understands ... and then later that the doctor had to help ... and then that we got help from another man.

Eric also recalled that information sharing was the “main topic ... and there was a very clear recommendation to definitely tell the child” when they saw the counsellor. Anni and Adam, on the other
hand, who had consulted a different counsellor, said that they “had to raise this issue ourselves, we asked her, she did not make it an issue”.

Several of those respondents who had sought counselling during treatment or independently of their wish for a child, commented that the issue of sharing information about DI was not discussed. Two respondents, Jan and Norbert, found that the counsellors had little experience with infertility or DI. Jan described his experience:

Jan: The family therapy [we did] was very healing for me. ... In the last session we discussed how things would go on and we said we were now on our way [to do DI]. And I had the feeling, this woman was a little reserved, I had the feeling that she had not yet had many couples where this was a topic.

Norbert was also very disappointed in the counsellors he and his wife contacted. He recalled that one counsellor “didn’t have the faintest idea [about infertility], you could have replaced her with a hobo”.

In Rob’s case, sharing information about DI was not an issue raised with the counsellors at that stage:

Rob: I cannot remember [discussing] sharing information about DI. Our question was more, Should we do this treatment or not? ... We only briefly mentioned what should happen with a child later on. Should you tell the child or not? But this was not the central issue of the discussion.

Geraldine and Georg were among the few couples who were advised by a psychologist that they should not disclose DI to their child. The advice Olga and her husband were given by the counsellor they consulted was more indirect:

Olga: We talked to Dr. [M, the counsellor] about this topic, and she said that after 20 years, the documents are gone, that there are couples who tell the child, but that you also have to decide whether the child has this right to find out, or whether you want to keep it a secret, that there are many couples who take this secret with them to their graves. ... She did not recommend anything but encouraged us to think about it ourselves and to maybe return to her [in the future and discuss it again].

Cathy was the only respondent who had consulted an independent counsellor “who supported us ... to manage [DI] openly, as in her opinion, she thought, the more secret, the greater the burden”.

Psychological support was considered important by one male and several female respondents, such as Pat, in order “to find out about all the possibilities there are” in terms of managing sharing, as well as some advice on how and when to share information. Others, such as Klaus, stated that they would have preferred professionals who “know about this area … and not psychologists who are inexperienced”. A third group of respondents spoke out for “something similar to adoption seminars” and suggested that such information seminars should be strongly advised or even mandatory. However, several male respondents also indicated some ambivalence about professional advice. They commented that they had not raised the issue of sharing information because they “did not have this need”, as Daniel said, while Walter recalled that he had no desire to “talk about [information sharing] much”. This did not correlate with any intention of keeping DI a secret, as Daniel was still uncertain about and Walter clearly intended to share about DI.

**Factors impacting positively on attitudes towards sharing DI**

Various factors encouraged respondents to disclose DI with their (future) children. Many considered keeping the means of conception a secret was a major burden they may not be able to shoulder. Given that many had discussed DI with family and friends, some wanted to avoid the child learning about his or her origin from others. Those respondents who had considered adoption reported a heightened awareness about the meaning of biological roots, and some considered knowing about one’s origin both a right and a need everybody should be able to enjoy.

**Avoiding the burden of secrecy**

The reason given by most respondents for openness was their feeling that a family secret would be a burden for everybody involved. Several men and women described themselves or their partner as “an honest person … who could not live with such a secret”, commented that living with this secret would involve “some pressure”, explained that they “didn’t want to spend [their] lives telling lies”, or were afraid that they would “blab and that [the truth] would come out”. Wally simply stated that she was “hopeless at keeping a secret”, and Helga showed concern about her need to be open and wondered whether “this was a very selfish attitude. But we both think that we … could simply not live with a
secret”. Walter and Zarah said that they did not “always want to carry this secret around with” them, and Klaus explained that for him “secrecy and hiding this issue was admitting … that I am not sure whether this is the right thing”. He also explained how he was managing the pressure:

Klaus: In the last weeks I summarised everything, although we don’t know yet whether we will do [DI]. … I wrote a long letter, wrote down how everything happened … all these ups and downs and our decision, why it is as it is, in order to have some clear memories for the future, because I think it will fade away; also, in order to be able to explain [to the child] why [we did it]. … It was strange, but it was a little liberating (.), [as if] I got it off my chest [and thus it was not such a great pressure any more for myself].

Olga, who had not yet decided whether to share any information about DI, talked about her fear regarding her own and her husband’s ability to keep this a secret:

Olga: And sometimes I wonder whether one can really manage this. It is not easy [never to talk about it], for me but also for my husband. It is certainly very difficult to bear this … [and] never to talk about it. In a way it is like a pressure, somehow.

She also commented on her brother-in-law’s knowledge of DI:

Olga: I don’t know whether [my husband] will really manage … not to talk about it. Some time ago, his brother came … and he always talks a lot to him, they get on very well, [and he mentioned] something about the Internet and sperm donation … and I thought, well, this topic is not as unknown [as I thought] and others know more than I assumed, therefore I don’t know [whether it can be kept a secret].

Anni, as a social worker, explained how her professional background contributed to her attitude:

Anni: My first thought was that I did not want to create a family secret. That has to do with my profession. I worked at a child guidance institution for some time, and I know what sort of catastrophic damages family secrets can cause. … I would not want to do that to my child. … I think this is very destructive.

Ensuring the child learns about his conception from his parents

As described at the beginning of this chapter, most respondents had shared their experience of male infertility with family members and friends, some also planned to do the same with DI. All of these respondents were aware of the risk of the child learning from others about his or her conception. Pat had talked about DI with many of her friends and relatives:
Pat: There are many people with whom I was able to talk and I made use of this. ... Many people know ... and a friend passed it on to others, then my mother knew and then our relatives as well. And this was a problem for me when we started DI. [The doctor who carried out DI] said that ... you should tell children when they get married ... but I knew how many people knew ... and considered this a problem. I felt pretty nervous, realising that everybody knows but my child [would not know].

Many others made similar comments. For Adam and Anni: “The option [of not sharing any information about DI with the child] is over ... as ... others know already, we have no other possibility, even if we wanted ... [because] I am certain that the child would find out at some stage”. Klaus said that he “could imagine that relatives do tell others. ... Tell them not to tell anybody else, and then they do tell others”. The worst consequence for him was if “four or five people ... knew about it but not the child, and then [the child] would somehow find out”; as noted earlier, this was a reason for him not to share information about DI with others. Tina commented about her husband and said that “he was certain that at some stage the truth would surface ... and this would cause a lot of damage because the trust [of the child] is gone”. Berta and Brian were anxious that during a family conflict “one word leads to another” and “it would come out, and this would be much worse than if we had been honest and told [the child]”. Fred felt the secret could be revealed by accident:

Fred: There are silly accidents and you find out and it is a shock for the child. ... The others make some sort of silly comment which may even be true to some degree. Why make it an artificial secret if it is not even worth being a secret?

In two cases, respondents feared that relatives might share information about the conception with the child. Stefan worried that his “child may somehow learn from my brother ... and then I would prefer telling him myself”, and Zach reported that his “older sister ... once told me, if we had children, she would tell them ... that I am not the father”. Therefore he favoured “telling the child ... [as] nobody else needs to interfere with our marriage in this respect”.

Many respondents felt that it would be detrimental for the child to learn about the form of conception from other people rather than the parents. Berta and Herbert commented that “it would be unfair” to learn from relatives, Vera considered it “the worst thing possible” if the child found out from others, and Anni stated that “these consequences would be much worse” than the parents sharing about the conception with
the child. In addition, Uli explained that by sharing this with the child themselves, parents could also “decide themselves … when the right time was [and] have some control” over this issue.

Those couples who did not intend to disclose the conception with their child or felt unsure about it, yet had talked to family, felt that they could fully “trust” them and considered the risk was minimal of their parents wittingly or unwittingly sharing this with the child.

Several respondents also explained that sharing about DI with the child at an early age was important, not only in order to avoid the risk of others telling the child, but also because they assumed that teenagers may find it difficult to learn about their conception during puberty. This was the case for Eric:

Eric: Well, if a teenager in puberty finds out that I am not the genetic father, without preparation, I think this is extremely difficult. Also, for an adult person, should I [die and] somewhere in my documents you (..) find something about the sperm bank, this must be a shock even for an adult. And he could not get any more explanations then. If I took this decision, then everything … would have to be destroyed. But then I would have to live with a lie … and this is an unpleasant thought at the moment. … At the moment, it is a process of decision, [and it is] a decision for life.

Ian worried that “sharing information about DI at a later stage … can be [traumatic] for the child as their intact world would break to pieces”, and Fiona wanted to avoid such “a shocking experience” for the child. Klaus intended to share DI early as “the worst scenario I could imagine was sharing after puberty … or feeling forced to share [because the child learnt through some accident] as this would be a massive loss of trust for the child”. Georg added that keeping DI a secret could also become problematic for one partner as he or she “would have nobody else [to talk to] should anything happen” to the other.

*Learning about the needs of adopted children*

Several respondents commented that learning about adoption, either from friends and family members or undergoing the interviews required prior to adopting in Germany, had made them aware of the possibility and importance of openness. Jan recalled an aunt who had adopted two children, “who has always had great ways of talking to the boys about their origins”. Jan’s wife Jessica, who was also influenced by these family members, in addition, recalled some professional experience:
Jessica: I met a girl when I did some youth work. She came to a course when she was 14 and her parents told us, as the facilitators, that she was adopted, but that the child would not yet know. And they [as parents] still did not know when they should tell her. And that was very painful for me, it went against my grain and I thought that couldn’t be true. They really tell anybody and everybody, but they don’t tell the person closest to them, that can’t be.

Similarly to Pat, Walter and Wally were encouraged by the adoption seminar to “talk about [the way the family was built] from an early age onward”. Maren and Markus recalled the interviews with the adoption agency:

Markus: This issue [of information sharing] was discussed, and for them it was very important. ... They said something very useful, which I still remember today: ... If you tell a child at 18 that you are not the right father, then a world collapses. But if you tell a child already when you change his diapers ... it is certainly much easier. ... It is like learning a language. When you teach a child three languages from the beginning on, then when he is 18, he will speak three languages fluently. Teach me three languages and probably in ten years I cannot speak them fluently.

Wally also explained how her involvement with adoption impacted on her attitude:

Wally: Before we knew anything about DI, my feeling was that the donor would remain anonymous, and that was a good thing for me. During our process of learning about adoption, it was made very clear to us the importance of identity for the child, and the fact that you could get the name and address, actually may be a very healthy thing because of the child, and I had a positive attitude about it afterwards.

Adoption literature was also spoken about as influencing respondents’ attitudes. Peter, who had read a lot of literature on adoption, said, “There are many long-term research projects indicating that an open adoption is better than the traditional ... and not being open”. Xaver admitted that he had never considered “what it would be like not knowing your roots ... because it was not an issue for me”. But he and his wife had also read several books on adoption, “and this is where we learnt what it means not knowing your origin”. Berta compared children conceived by DI to adopted children and commented, “You know that most adopted children want to get to know their parents. ... And I think this is similar for children [conceived by DI]”.
The right and need of knowing one’s biological origin

Several respondents, amongst them some who were undecided whether they would share about DI, considered knowledge of biological origin a right everybody should be able to enjoy. Similarly to Markus, they explained in general moral terms that “children have a right to grow up openly”, “a right to ask who the father is”, or “a right to know where you come from”. Valentin commented, “You have the right because it is the truth”, and Nadia was certain that “currently, there are even discussions about a law [saying] the children have this right”. Eric wanted “to bring up the child with certain values ... and honesty is one of them”, and his wife Eli commented on honesty and its impact on bringing up children:

Eli: There are many silly accidents [by which the child could find out about his conception]. But for me, it is simply honesty towards my child, as otherwise all the education will be in vain. ... And the decision is simply how important honesty is in relation to the needs of my child. ... We want to bring up our child in honesty, and therefore we need to be honest ourselves. But the fears [of sharing being difficult] are there, of course.

The assumption that openness will increase the child’s confidence and self-esteem was mentioned by several respondents. Fred believed that “the child will be stronger if it can manage it easily ... it does have this, in inverted commas, handicap, but [by being open] you contribute most to [the child] being as strong as possible”. Ute said that she and her husband “want to bring up our child as a confident child ... we hope that she will consider [her conception] as something normal”, and Maren explained that she wanted to give her “child some self-protection factor. Knowing about his conception means that he can manage it more easily if he is attacked.” Rob commented on the normality of “every person wondering about his roots. I also questioned my roots ... [and] this was only an expression of puberty, nothing more or less”.

Several respondents commented that being able to access information about one’s biological origin was also important “for medical and legal reasons”. A potential medical reason for openness was given by Ian who stated that his “child may worry about inheriting testicular cancer” that he suffered from. His wife, Ida, agreed with this:
Ida: Should ever anything happen, the child has to know that, for example, it could not have a bone marrow transplantation from his father, or why ... the child does not have to be afraid of any inheritable diseases of his father, ... or that it doesn’t have to be afraid of getting cancer because his father had cancer.

Jessica also raised this issue and criticised the current practice:

Jessica: Many parents don’t think about the burden of the child becoming ill. ... The child is seriously ill and then learns that the father is not the actual father, that there is someone else, a donor ... and that is a problematic situation. Then parents are confronted with this burden ... and need to find a way to tell the child in an OK manner [about DI]. ... That doesn’t work. The more I think about that, the sillier I think it is. And for the children, it would also be much better if it was open. ... I hope that [IDI] and their work and such seminars, that this will continue and that it opens it up a little.

Further factors

Several other factors contributed positively on respondents’ attitudes towards openness. One was their feeling that “children may sense [the truth], like adopted children who were told too late ... as sometimes, they can feel in the atmosphere [that something is different]”. Ida and Ian agreed with this and commented that “children sometimes wonder about things but cannot put it into words, ... maybe like, Why am I not interested in books but daddy is interested in books? ... or football or whatever. ... And then of course the child wonders”. Ruth and Rob as a couple, however, were not in agreement about this. Ruth was certain “that children sense” such issues, but Rob commented that this was “rubbish” as all children have a phase during which they question their own parentage.

Those respondents who had read my publication on family building with the assistance of DI felt encouraged to consider sharing. They commented that “all important aspects including sharing were mentioned”, and recalled that this had resulted in a “deeper reflection, ... realising that [the issue of sharing] was very important”. For several respondents, such as Eric and Zarah, reading the publication “was the first time ... I dealt with [the question] ... shall I tell the child, which reasons are for telling, which are against, and ... this is when my wife and I had a longer discussion”. For others, it was important to read “how other men manage [DI and sharing]” and to find out “about the views of other couples”. Although for some, the publication “encouraged sharing”, others appreciated that it “showed possibilities, but in the end the parents make the decision ... and it was like a guideline but not a law”.
A more indirect factor seemed to be the personal attitudes regarding sharing. When respondents were asked to imagine they were themselves conceived by DI, and if they had a desire to know about their conception, almost all female respondents answered positively; and while some male respondents also answered positively, some seemed less certain about this. Anni said that she “would not like to live with this secret”, Dora commented that everybody “has the right to know where you come from”, and Pat simply said, “Of course, yes”. Stefan stated that he “would like to know” but was not sure whether he “would also like to meet [the donor]”. Xaver explained that “it would be important [for me] to know what [my genetic parents] look like”, and Fred said that he “may not have the need to know it when I am 18, but by 21 at the latest, that’s when everyone should know … that your father is not your genetic father”.

For a number of respondents, participating in this study had resulted in “being able to put things into words … and to structure thoughts”, in “clarifying my position and feelings even further and to realising that our path is the right one”, and “understanding that sharing with the child early on was very important”. Georg, who was advised “by the doctors not to share the conception with the child”, commented that after the interviews he “challenged this [advice]”. As with previous issues, some respondents accessed my experience and knowledge. Wally, as indicated earlier, asked whether “there were some statistics about how many people are open with their child and how many are not” and wondered whether they were “open because they were advised” to be. Others wished to know “what age was appropriate for information sharing”, and “how children reacted if they found out that the father is not the genitor”, or wondered whether I “knew parents where the children wanted to know” more about the semen provider. Several commented more generally on the fact that they “had never had such in-depth discussions about the topic [of information sharing]”.

In two cases, that of Jan and Helga, challenging issues of the family-of-origin had contributed to their intention to share information about DI:
Jan: I have the feeling that our circle of friends consists of family secrets or difficult family circumstances. ... The best friend of my mother committed suicide, another girl-friend who lived in our house for a long time, her mother died very early and she was told that she was to blame for her mother’s death. ... I know that my grandmother was born out of wedlock. ... So I think it also has to do with life experiences. ... You are simply more mature when you [have a child] later in life.

Helga, who was born out of wedlock and informed about this when she was a small child, explained why she planned to share DI with her child:

Helga: Maybe it was the fact that I had no father that contributed to me being open. [My mother] had been open from the beginning ... and she had a partner ... who for me was my father, I called him ‘daddy’, and he was my father. ... And then when I was 14 or 15 it became clear to me that there was someone else, someone who conceived me, and I often [call him] ‘father’, but often also ‘genitor’. ... And my mother had never kept it a secret.

The lesbian couple, Cathy and Christine, had a very different reason for sharing information about DI:

Christine: For me there are only disadvantages if we don’t talk. It is important for me to make it open because then I can be seen in relation to the child. As long as it is covered ... people can still think that she went to bed with a bloke. ...

Cathy: [It is] important that we are seen as a family.

Factors impacting negatively on attitudes towards sharing DI

All respondents, including those who had opted to share information about DI, described many factors that made it difficult for them to share about the conception. These factors included the wish to protect the child, the uncertainty regarding the child’s ability to manage the knowledge of conception by DI, the husband’s fear of being rejected by the child and the lack of information about the semen provider.

Protecting the child

As already described, couples expected the public to hold negative views about DI. They also assumed that these negative views could impact harmfully on the way children were treated. Therefore, one of the key issues most respondents described as hindering openness was the need to “protect the child from negative public reactions”. Similarly to Klaus, many commented that they were unsure how “the environment manages [DI]”. They feared that the child would be “ridiculed”, that “other children at
school would not become friends … and the child couldn’t cope with this”, or that children conceived by DI “would be ostracised by others at school or would have disadvantages”. Fred feared that “the general public, especially the mass media, [would] somehow comment negatively on such children”, and Geraldine, as illustrated earlier, feared that others would ostracise the child.

Although applying for an adoption raised the awareness of many respondents about the meaning of biological origins, many commented that explaining the origins to adopted children was easier than explaining this to children conceived with the assistance of DI. This was not only because of greater social acceptance of adoption, but also because they were able to draw on existing narratives to share the origin with adopted children. Respondents commented that sharing adoption was “easier … as it is managed much more openly [in general] and you can always read something about it”. By contrast, they were worried that they “may not be able to explain [the conception by DI] plausibly to the child”, and that as a result, the child might develop “psychological problems”. Eli commented, “With adoption you don’t have to fear negative judgements, an adopted child is accepted more easily”, and Georg felt with adoption “you help a child and this is something you can feel confident about towards others … whereas [DI] is not so accepted”. Klaus simply commented that “adoption is more socially accepted”, and Berta believed that “you can explain to the child why her parents could not keep her and that we helped out”. In addition, Ida explained that the fact that “nobody knows about DI treatment” and that it is much less apparent than adoption, “as you … walk around with a big belly”, also makes it easy to keep the conception by DI a secret.

Just like respondents expected others to have negative reactions towards the child, a small number also feared disapproving reactions towards themselves as the parents. As discussed earlier, for Eli, who had a practice as a naturopath, and whose husband, Eric, was a free-lance tax consultant, there was a risk that sharing about DI with the child and with others may impact on her and her husband’s professional career:

Eli: [My husband] had such fears [that people wouldn’t come to him anymore]. But I think that would be going too far. … I do think people would talk about us behind our back, but at some stage, this would stop. I don’t think that any of my patients would not come anymore.
Other factors regarding the need to protect the child were related to the possibility of some psychological or physical instability in the child. Dora and Daniel said that “depending on the character of the child [we may not share any information] ... as it is a burden for the child”, but they also felt unsure about “how to determine” such an instability. Helga explained her views:

Helga: If a child was very sensitive, or if I caused some damage to the child, physical or mental damage, then I would not do it. If the child was handicapped, ... if it was somehow unstable ... [sharing] may at that point in time [increase this instability].

Ruth and Rob also explained their difficulty in foreseeing the impact of openness:

Rob: You have to see how the child develops. ... You cannot just tell the child, like an adopted child when it starts school, You are a donor-insemination-child.

Ruth: Yes, you have to [be aware of] the psyche of the child. ... Every child is structured differently ... and you have the fear that this [information] totally throws the child over. .... These are all the points ... where you cannot say how you will decide, you just can’t foresee.

Rob: And I would even go one step further [and say], if the truth leads to something bad, I prefer the lie, if this lie contributes to people living together in love.

Ruth: You just don’t know in advance.

Rob: I [agree,] you don’t know.

Lack of general information and literature on sharing information about DI

Many respondents felt uncertain about when to share and lacked narratives for sharing information. Some commented that DI conception was “too complex” to be understood by young children. Otto considered not sharing “simply better for the child ... in order to ensure a reasonable upbringing, especially during puberty”, and he continued, “When you are 23 or 24 ... you may be strong enough to manage something like that”. Ian also expressed his concerns:

Ian: I cannot imagine that a child under 14 ... understands anything at all. ... And then you must realise that for this child, when you tell him so late, the world breaks to pieces, which until then hopefully was intact. ... That means if you share with the child, you may bring problems into an intact family, which I think you can do without.

Others, such as Norbert, however, assumed that a child “may [understand] at the age of four or five”.
Ida and Ian explained the need for appropriate timing and said they “would not share DI with the child ... in extreme family situations of stress ... so that the child will never have the feeling that he was told because he was a bad child”.

Like other respondents, Jan described that his inability to find the “proper words to tell the child” would have been his greatest problem. Fortunately, he was able “to rely on [his wife Jessica] who, as a teacher, was able to make our [two-year-old] child familiar” with her conception, but he admitted that “I would have certainly not have to courage to do so” at an early age. Berta also thought this would be difficult:

Berta: I think it is very difficult. ... How do you tell your child? You cannot simply go there and confront the child with it, [like], Listen, we could not have any children ourselves ... and therefore we decided [to do DI] and you were born like this. [Because] what would the child think about it, if it learns how it was conceived? Those are all these questions where I say, Oh no, we had better not tell the child. ... But of course, this would not be fair to the child, either.

Respondents also criticised the lack of information regarding “sociological or psychological developments” in the area of DI, as well as the lack of “information about children in puberty or children above 18”. As described earlier, several respondents explained that their motivation to participate in this study stemmed from the desire to support such research. They felt thankful “that someone was doing research at all”, and “wanted to contribute with our own experiences” as they hoped this “would help [other] couples in five years time, when the data has been analysed”.

As already mentioned, almost all respondents had read German books, brochures and leaflets on infertility and were disappointed that family building by DI and information sharing were only marginal issues in the books. Daniel was again critical of the fact that he was not able to “find anything specific [on sharing]”. According to many respondents, most books described “the modern treatments for infertility, but did not [inform] ... about DI ... or [the question] of sharing DI”. Even Pat, who “had read all books ... on infertility, ... everything available in the library”, commented that in some books, DI was described “as an old [type of treatment] not required anymore as there is ICSI”. Only Tina and Wally had read English literature on DI, which also provided examples on information sharing; Cathy and Christine had read a German book for lesbians using DI for family building.
Many respondents voiced a need for more literature that provided narratives “which you can [use to] explain to your child the [conception by DI]”, general information on the “development of children who were told or not told” about their conception, and on “how the children view [openness] ... in 10 or 15 years”. Almost all respondents agreed that the decision regarding sharing would have been easier if there “had been more general information” from the beginning. They participated in this study in order to “encourage others to be open”, and to help “shed more light into this darkness”. Jessica and Jan also commented on this aspect:

Jessica: I simply find it important that the issues are called by their names, that a broader group of people becomes aware of them. And then more people will realise that being open is a better way. We know that this is not the norm [but] I think that it is better for the children and for the families. And I think such a research project can contribute to showing this and to showing adequate support, which might be needed.

Jan: I couldn’t agree more.

The husband’s fear of rejection

As already pointed out, many male respondents considered themselves to be a less important father figure than the genitor. This also resulted in their anxiety of being rejected by their child should they share the biological origin with him or her. Eric’s passage from the couple interview indicates his concern regarding sharing:

Eric: The father is [the person] who brought up the child. I will remain this person (quiet).

PT: Do you feel confident about that?

Eric: It is not 100 percent; there are doubts, of course.

Eli: You never know how the child develops. ...

Eric: Of course, ... I also have anxieties. ... If we start sharing with the child early, (.) what will happen in puberty? I am afraid of that. On the other hand, lots of other parents have many difficulties with their children during puberty ... or if they have something their parents don’t like at all. ...

Eli: This will be similar for us. And of course, there is the difference that ... you are not the genetic father. ...
Eric: Yes, and this is what I am afraid of. ... It would probably hurt me very much if my child tells me, You are not my genetic father. ... that would probably hurt me very much. ... This would hurt me much more than if [the child was untidy] and dropped paper everywhere, because it goes deeper.

Rob explained in general terms that "the burden [of DI] is great, both for the child and the parents", and therefore he favoured "not talking about problems that you cannot solve [as] there is no solution to this problem". Similarly to Brian, Rob and Adam were also concerned that the child "may react in a rejecting way ... towards me" and worried about statements such as, "I don't care about you as my father", should the child be informed of his conception. Norbert, although he felt "that the child may not reject [me as his father]", said that "you can never know", indicating his uncertainty about this issue. Herbert and Helga also expressed their anxieties in this respect:

Helga: You had concerns.

Herbert: Yes, I did have concerns. If the child ever says, You are not my father, it could be that he says that, that he distances himself from me and doesn't accept me anymore. Although I love the child just as much (...) as if he had been created the normal way. But if he distances himself from me ... 

Helga: This is what I am also afraid of ...

Herbert: That he doesn't accept me as his father; ... that he doesn't love me anymore or something like that [is what I fear most].

Eric described these fears as potentially becoming greater once the child is older:

Eric: One of my concerns is also, how will my child react later in puberty? Once the entire truth is out, what will this be like? I am a little afraid because it could well be that I will be rejected, which I don't really want to experience. This makes me lack confidence.

Several male respondents, such as Theo, voiced their fear of the child feeling drawn to their genitor:

Theo: Then there are the thoughts [of the child]: Who are my real parents? How do they live? And so on. Where do I come from? What did I miss? Or what would they have done better? Or whatever. ... Then if [there are problems between us and the child], it may suit the child to look for a reason: Now I know [why I don't get on with my father].

This fear was also voiced when male respondents described how they might have reacted if they had been conceived by DI themselves. They were hesitant and described their anxiety regarding the position of the social father. Herbert said that he was afraid that the child "may turn away" from the father, and Peter
explained that he would rather “live with an illusion” than run the risk of the child turning to the genitor.

Klaus explained his reaction:

Klaus: I also wondered about [my own reaction had I been conceived by DI]. I don’t know, I really don’t know. ... I don’t know whether it would be very important for me to know about my genetic origin. ... The social environment is much more important for me ... and [in a way] I tell myself that the social issue is much more important in terms of a father than the biological origin. ... I would be afraid that I may only see the positive sides ... and I would wish that the weight of the social father would be much greater ... but I don’t really know.

Lack of information about the semen provider

Many respondents commented that the difficulty in accessing any information about the semen provider resulted “in the worst case [for the child] not knowing anything about his genitor”. This led several respondents to question whether sharing information was appropriate:

Rob: If the child finds out that he is not from me as the father, what does the child do? It may be that he wants to get to know the father, the so-called biological [father which is] very difficult to put into practice.

Berta: You tell the child that it is from a different father ... and then I think, the child will ask, Who is he? What does he do? Where does he live? All of these things I cannot answer. ... And therefore I think it is much too difficult ... and we had better not tell [the child]. If we knew more, we might be inclined to share more readily.

Zarah: You cannot say anything about him [to the child]. ... If you could at least tell the child, Well, he is a train driver. ... Or something like that, ... that would make it a bit more tangible. ... But I know, if I were this child, I would be very curious and would want to know what he looks like or what he does.

Eli feared that her child may not only “have lots of questions ... [such as], Who is the father and shall I try to find him?” but would also be worried about unknown half-siblings. According to her, children may wonder when “[they cross] the street and ... think, this could be my half-sibling”. She and her husband also indicated concerns about the semen provider:

Eric: The most important reason against sharing is: How do we expect the child to handle it? ... I might make my own life easier by sharing, but I impose the difficulty on the child. The child has the problem that it is a DI-child, but it cannot talk about it to anybody because the public has such a negative attitude. ... [The question is also], Who is the genetic father? ...
Eli: This will also be a central question.

Eric: When can I meet him? Can I meet him? … Maybe he has a family with three children and thought, well, I took the money for DI, I needed it for my university [education] or during my professional training, and that was it. And the child will get a negative reaction from his genetic father. I am not sure whether I might [only] make my own situation easier by telling [but make the child’s situation worse].

Again comparing DI to adoption, Anni commented, “You can give the [adopted] child answers, at least partly, and we cannot do this [because] the documents are destroyed”.

Respondents did not explicitly suggest that there should be more information on semen providers so that this could be given to children. However, Ute wondered whether I myself “knew children that wanted to know more” about the semen provider, and Peter, like Pat, suggested that there should be “a photo” for the child that could be put this into the photo album so that the child would have some more tangible information about his genitor.

Lack of peer support

Many respondents commented that they “did not know any couples pursuing DI”, or that they were not aware of any self-help group for this population. However, almost all respondents considered contact with other couples pursuing DI was very important. They wanted to establish contact “with couples with the same problems or who are one step further on”, so that they could learn from them, “talk to parents who have a child [and] to find out about their experiences”, and they wanted to meet “people who know what they are talking about [because they are affected themselves]”. Others wished to attend “a group once a month”, wanted to find out “how other people manage” information sharing, “talk to children conceived by DI”, and to “find out about the experiences from those who have been open about DI”.

Many of those respondents who had not consulted counsellors or established contact with other couples pursuing DI, like Brian, commented about the general lack of information regarding sharing DI:

Brian: I don’t know [any other couples] … and that’s why we tried to somehow get some information or talk to someone about it, or as my wife put it, we should establish a self-help group.
Summary

Most respondents in this study used DI as a response to male infertility. With very few exceptions, the experience of male infertility for both male and female respondents had a profound impact on their emotional well-being. They felt overwhelmed, desperate, powerless, and were devastated about the fact that they could not conceive - something they had considered so natural and desirable. Almost all described male infertility as a taboo topic, and men and their partners felt stigmatised and feared being ridiculed. Despite these anxieties, all the female respondents but one, and many of the male respondents talked about it to others. Women explained that they felt a great need to share the emotional burden infertility meant for them, and both men and women wanted to avoid having to lie to others, or they felt put under pressure to explain why they did not have children. This also included a small number of couples who did not intend to share DI with others or the future child, or who felt unsure about disclosing their experiences of DI. Some women, however, wanted to protect their husbands from painful comments and made others believe that they were affected by infertility. In the main, respondents received understanding and empathetic reactions, both from persons carefully selected for disclosure and from those with whom they had spontaneously shared their experiences of male infertility. At the same time, some respondents found that providing adequate information about male infertility, as well as the time and space for others to process it, resulted in people being able to understand its significance for the couple. As a result, people unaffected by infertility were able to react in helpful ways.

Although most couples were aware that DI was practised and legal in Germany, they considered DI to be a questionable way to build a family. This resulted not only from the lack of general information about DI, but the perceived reservation of medical professionals; respondents reported that they were only informed about DI once other family-building options had been exhausted. Respondents also felt that the lack of reimbursement for DI treatment from the health insurance system was unfair as other AHR treatments were reimbursed. The legal situation was confusing for most couples. Several male respondents considered there was a lack of clarity about paternity after DI. Furthermore, respondents had different and contradictory information regarding the length of record keeping and the offspring’s rights to access information about the semen provider. Several couples sought counselling prior to embarking on DI; for some, this was required by the clinics, for others it was helpful to clarify psychosocial issues relevant to infertility and DI. In most cases, counselling was described as helpful. The lack of information
and counselling motivated some respondents to participate in this study; they hoped that the interviews would provide them with an opportunity to access my expert knowledge, explore psychosocial issues and consider once more their attitudes towards DI. Many respondents voiced their need for more information regarding the legal and psychosocial aspects of DI. They also desired the opportunity to learn from others, either indirectly by reading literature, or directly by sharing in a group setting.

Regarding the initial reaction towards family building with DI, there were differences between male and female respondents. Women tended to associate family building with the assistance of DI with some uncertainty and attributed negative meanings to it. Men, on the other hand, saw this type of family building as a practical solution for their problems. For both, however, it raised many questions, concerns or even anxieties, and therefore most couples had intensive discussions and a lengthy decision-making process before starting treatment. Many respondents, regardless of their gender, considered DI an issue that was tabooed in public. Others assumed the public to have little information about this family-building option, which in their view contributed to people being unfamiliar with, and thus reserved about DI.

As a result of these assumed unfavourable attitudes, only a few respondents shared with others their plan to build their family with DI. Most of those who did so, however, were shown acceptance, understanding and support. Sharing with others experiencing infertility was also described as valuable and helpful. This was especially the case for those who had established contact with other couples pursuing DI or with families built by DI. Sharing with this group was perceived as significant and beneficial because it helped to normalise respondents' feelings and facilitate their decision-making process regarding the use of DI. Some couples participated in this study in the hope that this would enable them to learn about others or to establish contact to other respondents, which in fact, four couples did.

A need for public awareness and acceptance of DI, as well as more information about this option, was expressed by many respondents of this study. This taboo and lack of information, according to respondents, could be counteracted by raising public awareness through means, such as television programmes, newspaper and magazines articles, as well as books about DI. The availability of literature, as well as the possibility of sharing with others in the same situation, respondents assumed, would also contribute to facilitating their own decision-making process.
Many respondents described family building with the assistance of DI as normal; for others it was associated with apprehension, concern and, in comparison to a family in which children are the biological offspring of their parents, with additional issues to be managed. These included the difficulty of creating an understanding of this type of family, comprehending the meaning of fatherhood and accepting that there was no available information about the semen provider. Male respondents indicated a greater tendency to suppress thoughts about these issues, whereas the female respondents voiced these concerns more openly and seemed to feel less threatened by them. Most couples expected these concerns to subside once a child was born. Two couples, who had children, did indeed explain that their love towards their children overrode any concerns they had had beforehand. One father, nevertheless, explained that the bonding process with his daughter did not develop as easily as to a child who may have been conceived with his own semen. The lack of an understanding of family building by DI led some respondents to use the analogy of blood or organ donation or compare families built by DI to adoption.

Respondents indicated uncertainty regarding fatherhood following DI. Being a father with the assistance of DI was associated with having a secondary role and as being at a greater distance from the child than the mother would experience. Many respondents were anxious that the child would be drawn to the semen provider instead of the father, and explained that suppressing any thoughts about these fears helped to manage their anxieties. This lack of confidence was also reflected in the terminology respondents used both for the father and the semen provider. In numerous cases, it was the semen provider who was referred to as the real or the actual father, indicating that social fatherhood was perceived to have a less significant status. In addition, almost all male respondents considered the semen provider a competitor.

Most respondents in this study intend to share information about DI with their (future) child and some had discussed this with family members, friends, peers and professionals. Reactions of family members and friends were varied. Some encouraged openness, others advised against sharing the means of conception with the child. Other couples experiencing infertility and interested in DI unanimously favoured openness and respondents felt encouraged by their views. This support was greatly appreciated. Recommendations by medical professionals were varied. Some doctors advised respondents strongly against sharing, others explained that there was no need for openness and many did not comment on this
issue. A few doctors supported or even advised respondents to share information about the conception with the child. Psychosocial professionals' views towards sharing were just as diverse. Most of those counsellors who carried out pre-treatment counselling favoured information sharing and supported respondents by providing narratives for sharing. Most other counsellors consulted during DI treatment did not explore information sharing and some respondents were critical of the fact that these counsellors were inexperienced in infertility and DI.

Explaining their motivation for sharing information about the conception with their (future) child and with others, respondents gave a range of reasons. One of the most important issues was the anticipation that secrecy might result in a burden and may become difficult to endure. Since many respondents had discussed male infertility with others and some had also shared their use of DI treatment, they also believed that there was a risk that the child might learn about his conception from others. By being open with the child, they avoided this risk and were able to determine an appropriate time for this discussion. Many respondents had contemplated adopting a child. Learning about the needs of adopted children had raised their awareness for the importance of knowing one's biological origin. Independently of this knowledge, others considered information of this both a right and a need everybody should be able to enjoy.

Although most respondents favoured information sharing, they reported a number of factors they found challenging. Many feared that children might experience negative reactions if others learned of their conception. Respondents therefore considered keeping the means of conception a secret as a way to protect children from being ostracised or ridiculed. Comparing DI to adoption, many felt that adoption was much more socially accepted and therefore easier to explain both to the public and the child. Several respondents felt uncertain about the impact of openness on the psychological well-being of the child. The lack of information and literature regarding the timing and narratives respondents might use was another major factor potentially hindering openness. Many male respondents feared that informing the child about his or her genitor might lead the child to feel drawn towards the genitor and consider his or her father secondary, a fear which corroborated feelings of uncertainty for men. Therefore, keeping the conception a secret was considered a protective factor in their role as (future) fathers. The lack of information about the semen provider was another major obstacle towards information sharing. Respondents explained that it
could be easier for children not to know about their conception than to know about it, but never to be able
to find out about the man who provided the semen.

Respondents voiced a need not only for more information and literature giving advice on sharing DI with
children, but also for opportunities to meet other couples carrying out DI and parents of children
conceived by DI. They wanted to exchange ideas with and learn from them. In order to share in an
appropriate and helpful way, they considered research in this area an important tool for developing
knowledge. In fact, some respondents participated in this study in order to contribute to improved
knowledge in this area. They also hoped that doctors would no longer diminish the importance of the
psychosocial issues involved in DI and wanted counsellors to be available who were experienced and
knowledgeable in these issues. In addition, some respondents held the view that preparation seminars for
couples interested in DI, similar to adoption seminars, would be helpful or should even be mandatory.
Chapter 8
Discussion

This chapter will discuss the results of this research alongside existing knowledge, research, policy and practice in the area of DI. The focus of this study is on parental decision-making in sharing information about DI as a means of building a family. The results show that a wide range of factors impacted on respondents' thinking and decision-making regarding information sharing. For the purpose of this discussion, these factors will be grouped together using a micro, meso and macro typology. While this chapter will focus on the discussion of the impact of these micro, meso and macro factors, it will also include a discussion of the methodology. This is because of the study's commitment to a reflective approach. This reflection has led to some observations about the knowledge that has emerged from the methodology adopted and what has been learnt from this.

Factors that impacted on decision-making regarding information sharing
As the results in the previous chapter show, parental decision-making for or against sharing information about DI was not taken lightly. For most respondents in this study, the issue of sharing information with offspring was one of their first considerations when they contemplated the use of DI, suggesting that it is a vital and critical question when considering DI. Nevertheless, several respondents had not considered information sharing and the interviews were the first occasion for them to explore their thinking regarding this. Many couples had extensive discussions amongst themselves, and for some, “sharing was the biggest issue” family building by DI raised for them. One couple reported that they had decided “not to start treatment unless we had discussed how we will manage” sharing information. Some respondents had shared DI with family members and friends. Most also intended to share their use of DI with the children they have or will conceive with the assistance of DI. As described in Chapter 3, this is not the norm in
Germany, which is not surprising in the context of evolving practice in this area. Several writers have pointed out that it has been difficult to carry out research in the area of DI because of the secrecy around it (Golombok et al., 1995; Lycett et al., 2004). It is understandable that those individuals and couples who do not wish to openly acknowledge their use of DI are unlikely to participate in a study that might require them to disclose intimate details of their attitudes and beliefs. It may be that their decision to opt for secrecy and privacy reflects the shame and stigma that has for so long been the chief characteristic of DI practice, both in Germany and internationally. Because of this, studies examining issues of information sharing inevitably attract those who do not feel threatened by disclosing their motivations but feel confident about their decision to utilise DI despite the common worries and anxieties family building with DI can raise. Hence, with respect to the proportion of parents who disclose DI, the results of this research are unlikely to be representative of couple thinking in Germany. However, the underlying factors respondents considered significant and influential regarding their decisions are likely to be representative. Respondents in this study not only explained factors that facilitated sharing, but also described a multitude of aspects that impeded open acknowledgement of the use of DI. Some of these factors confirm previous research, but many others highlight new areas of knowledge and thus contribute to a more comprehensive understanding of parental decision-making with regard to sharing information about DI.

The discussion will explore in detail the factors that influenced respondents’ decisions regarding information sharing at the micro, meso and macro levels. Consistent with social systems theory each level and the factors contained within each level interact with other levels. The nature of this interaction will also be explored.

Micro factors cover the intrapsychic and interpersonal aspects of the individuals and couples taking part in this study. The micro section will discuss respondents' considerations of nuclear family issues and their thoughts, feelings and attitudes towards the semen provider who is so essential to their family building. The semen provider could be viewed as a part of the nuclear family, or the extended family – or both. Because of this, discussion of factors related to the semen provider could have been contained within either the micro or the meso section. I have included the semen provider in the micro section because of his centrality to the respondent couples and the fulfilment of their desires. The meso section discussion will focus on extended family factors, friends and others experiencing infertility, as well as factors
resulting from the respondents’ experiences with professionals. The macro section discussion will focus on the social and cultural context of, and the impact of social policy and legislation on DI. The following illustration (Figure 8.1) seeks to portray the different levels of consideration or analysis and how each level influences and is influenced by the other levels.

Figure 8.1. The matrix of interrelationships between the micro, meso and macro levels

The interaction between the three levels is revealed in the results of this study which show individual concerns were influenced by societal attitudes and that the legislative framework impacted on professional management, which in turn affected parental decision-making. This analogy by level of typology is another reflection of the social work dictum that private troubles and public issues should be considered simultaneously (Mills, 1963).
Factors located at the micro level

This study indicates that diverse and powerful factors influence parental decision-making pertaining to the male and female partners using DI and to the nuclear family. It suggests that men's emotional experiences are similar to that of women's, but men express their experiences differently. As male infertility was perceived to be a shameful and stigmatising condition, many men and their partners were uncomfortable about disclosing this to others. This public management of male infertility impacted on couples' decisions to share information about DI: in those cases where couples feared stigmatisation, they revealed neither male infertility nor their use of DI, although keeping this a secret was considered a psychological burden. Furthermore, this study suggests that families built with the assistance of DI, although they have existed for over 100 years, are a new family type for which awareness of and knowledge about is only beginning to emerge. This was highlighted by respondents in their struggle to make sense of the semen provider's contribution and the difficulty they experienced when attempting to make sense of this family building option.

Men's affective reactions to infertility are similar to those of women

For almost all male and female respondents, male infertility led to strong emotional reactions. Respondents felt overwhelmed and powerless, and were devastated about their inability to have a child. Though most female partners were not physically affected by infertility, they viewed themselves as being directly affected by their partner's inability to produce viable sperm to enable them to become pregnant.

In the review of the literature, data and views were contradictory regarding the emotional repercussions of infertility for women and men. Whereas many researchers found men were less distressed than women (for example: Freeman et al., 1985; Hammer Burns & Covington, 1999; Wright et al., 1991), others contend that these differences result from gender-specific reactions and the social context (Berg & Wilson, 1991; Daniluk, 1997; Nachtigall et al., 1992). As these issues pertain to social interactions with significant others, they will be discussed in the next section analysing factors located at the meso level.

23 With five couples in this study, both partners were diagnosed with infertility or found to be a carrier of a genetic disorder.
Several writers also suggest that methodological considerations can contribute to inaccurate representations of men's emotional experiences (Abbey et al., 1991; Berg & Wilson, 1991; Boivin et al., 1999; Daniluk, 1997; Greil, 1997). In addition, writers point out that methodological considerations can distort results. Daniluk (1997), for example, is critical of the fact that men tend to be underrepresented in research. The latter is not the case in this study, as apart from one couple, all participants were heterosexual couples, and equally as many male as female partners were included. Other writers are critical of the study designs of some research, as well as the standardised measures, arguing that they may be less sensitive towards typical male emotional expressions (Abbey et al., 1991; Berg & Wilson, 1991).

It seems that a qualitative approach, such as applied by Mason (1993) and used in this study, has much to offer in increasing the understanding of the emotional impact of infertility on men. Similarly to respondents in Mason’s (1993) study, men in this study openly acknowledged and gave detailed descriptions of their emotional reactions. The open-ended questions provided both men and their partners with the opportunity to disclose their entire range of affective reactions, and men in this study made ample use of this. The combination of individual and couple interviews, as used in this study, yielded even richer data than interviewing individuals or couples only. With several couples, one partner had more accurate memories of certain situations and reminded the other of these. In this sense, partners complemented each other's experiences and memories and this provided for more in-depth material than would have been possible from individual interviews. This suggests that standardised measures developed up until now are sufficiently sensitive to measure female responses to infertility, but these cannot be expected to measure male reactions with similar accuracy. Gender-sensitive measures must be developed in order to capture reactions that are typical for men. Qualitative research, such as this, offers a basis for developing such instruments in order to capture typical male reactions to infertility and should, as Meryn (2005) suggests, be seen as complementary to quantitative strategies.

The stigmatising effect of male infertility and its impact on information sharing

Infertility, especially male infertility, has been described as a stigmatising condition (Lampman & Dowling-Guyer, 1995; Miall, 1986, Schaffer & Diamond, 1993; Schilling, 1995; Valentine, 1986). Miall (1986) contends that in the United States, two traditional fertility norms are widely accepted. These are that all married couples should reproduce and that they should want to reproduce. Such a pronatalist
attitude is likely to be similar in other Western societies and perhaps worldwide. Hence childlessness can be considered to be a form of deviant behaviour as it violates these prevailing norms (Miall, 1986). This is confirmed by recent theories of social stigmatisation. For example, Kurzban and Leary (2001) and Neuberg et al. (2000) draw attention to both biological and social reasons for social stigmatisation. They point out that individuals unable to cooperate and contribute to the well-being of groups or who threaten successful group functioning run the risk of being stigmatised and excluded. Though neither Kurzban and Leary (2001) nor Neuberg et al. (2000) explicitly refer to infertility as a physical quality obstructing group functioning, such an inability may be perceived to be an impediment for groups. Fertility ensures reproduction and can be considered to be a vital quality of an individual’s and a group’s functioning. Furthermore, Stangor and Grandall (2000), as well as Pflüh and Henry (1993), contend that such threats can be symbolic and often involve deviance from social norms. As Miall (1986) explains, in pronatalist societies infertility represents such a violation. Results of this study support these theories. Having children was perceived to be normal and desirable, and respondents described themselves as feeling out of place on many occasions, as they did not have children. This not only impacted on their individual well-being but, as will be analysed when discussing the factors located at the meso level, also on their interaction with significant others.

Male infertility has also been associated with shame, as it is perceived to be linked with virility and potency (Houghton & Houghton, 1987; Lee, 1995; Mason, 1993). Given that society expects men to be strong, confident and healthy (Brähler et al., 2001b), men suffering from infertility are anxious about being seen to lack masculinity or considered weak and unhealthy. Both men and women in this study fully supported this view. Men suffering from infertility were perceived to be “unmanly”, as the public assumed that as a result of their infertility they were impotent. Although respondents in this study were aware that this link was not in fact true, they seemed unable to ignore or avoid this public perception. Not surprisingly, infertility also impacted negatively on the self-esteem of male respondents both in this and other studies. Mason (1993) found that many men she interviewed felt a sense of personal failure and guilt because of their infertility. In Nachtigall et al.’s (1992) study, men who had been diagnosed with infertility exhibited a greater loss of self-esteem than those who had not received this diagnosis. Kedem, Mikulincer, Nathanson and Bartoov (1990) found that even men who were only suspected to be infertile reported low self-confidence.
In many research projects, parents acknowledge these negative implications of male infertility and explain that their desire to keep male infertility a secret is an important factor in not sharing information about DI (Brewaeys, 1996; Cook, Golombok, Bish & Murray, 1995; Daniels, Gillian & Gillett, 1995; Golombok et al., 2002; Manuel, Chevret & Cyba, 1980; Rowland, 1985; Schilling, 1995; Zoldbrock & Covington, 1999). Yet only two studies do not indicate such a link (Gottlieb et al., 2000; Rumball & Adair, 1999). Many respondents in this study did not make a link between these two issues, either. However, several applied strategies typical of stigma management in that they attempted to conceal male infertility or lessen the effect of it (Goffman, 1998). In some cases, it was the female partner who suggested to others that she experienced infertility in order to protect the public image and the feelings of her partner, implying that male infertility was seen to be more stigmatising than female infertility. In other cases, those female partners who experienced infertility themselves only disclosed this but not their partner’s infertility. A third group of men had revealed their infertility to others, yet had not disclosed the full extent of it. It is possible that they expected moderately impaired fertility to be a less stigmatising condition than severely impaired fertility or sterility. It is also possible that they considered this to be a helpful strategy in that not revealing DI means that others may assume that the child was conceived with their semen despite a low sperm count. As these management strategies pertain to the interaction with significant others, they will be discussed in more detail in the section analysing factors located at the meso level.

At the same time, studies indicate that some individuals disclose both male infertility and their use of DI to significant others, but do not intend to share their use of DI with their child (for example: Brewaeys, 1996; Cook et al., 1995; Daniels et al., 1995; Golombok et al., 2002; Lasker & Borg, 1989; Manuel et al., 1980; Rowland, 1985; Schilling, 1995; Snowdon et al., 1985; Zoldbrock & Covington, 1999). Apparently, these individuals need people to confide in and share their experiences with, but not all seem to be aware of the risk that their children might learn about their origins from these confidants instead of from them as the parents. Respondents of this study did not draw a link between disclosure of male infertility and sharing information about DI with their (future) children. However, many confirmed that they did not discuss their use of DI with others in order to avoid the child learning from others. Therefore, right from the beginning they limited the number of people they discussed DI with or curtailed their need
for sharing, and restricted this number once they had become aware of this possible link. The latter was not easy, and this was highlighted by one woman who only became aware during the interviews of how many people she had talked to and began to regret this. From a systems perspective, this indicates the interrelations between the micro and the meso level: sharing with significant others impacted on respondents' views regarding sharing information about DI with their (future) children.

In some studies (Brewaeys, 1996; Daniels et al., 1995; Schilling, 1995; Snowdon et al., 1985) couples indicated that they considered themselves to be in control over the information of their use of DI and trusted their confidants not to disclose this to their children. In contrast to these studies, most respondents in this study felt that they were unable to control information about their use of DI once it was shared with others. Consequently, they feared that the child might learn from others instead of from themselves as the parents. Realising that this could impact on a trusting relationship within their families, they wanted to avoid this (see Chapter 4, pages 64-65, for a discussion on trust within the family). However, there was a distinct difference between the smaller group of respondents who were uncertain about sharing information about DI with their (future) children, and the majority of those respondents who felt confident about discussing DI.

Apparently, the need to share can be very strong and the results of this study suggest that it is especially strong for women. However, those who were uncertain about disclosing DI to their children both in this study and those reported in other research (Brewaeys, 1996; Daniels et al., 1995; Schilling, 1995; Snowdon et al., 1985) seemed to have greater confidence that they could trust others, although they were aware that they would actually have to be more careful than those who favoured sharing information about DI with their children. It may be that their need to share with others led them to take risks but to assess these risks differently; their need to share seemed to be stronger than their concern about others' disclosure. By contrast, the group of respondents in this study who favoured sharing information about DI with their child, did not trust others to the same degree; they worried that others might talk to the child. As discussed earlier, for this group, having shared information about DI with significant others was in fact an additional reason for sharing about DI with the child. This raises the question of which group's risk assessment was realistic. Clinical experience suggests that this is a common fear of parents, but there is only sparse research (Hewitt, 2002) and anecdotal evidence (Ward Leslie, 1997) indicating that
children may learn about their conception from others rather than from their parents. Other researchers have not investigated the question of who disclosed the manner of conception to the child (Cordray, 1999/2000; Turner & Coyle, 2000). This may indicate that this fear is unjustified but nevertheless common.

Berger (1982) points out that discussing male infertility and sharing information about DI are two separate tasks. The secrecy surrounding DI, according to him, interferes with a successful progression through the task of resolving the emotional implications of male infertility and making a decision for or against the use of DI. In order to resolve these implications, he argues, along with other writers, for leaving sufficient time between the diagnosis of male infertility and the decision to pursue DI to separate the emotional impact of the two decisions (Berger 1982; Blaser & Gigon, 1989); Berger (1982) also recommends pre-treatment counselling, as do a number of writers (Brähler, 1990; Mahlstedt & Greenfeld, 1989; Thorn & Daniels, 2003; Zoldbrock & Covington, 1999). Given that for several couples in this study there was a long period of time between the diagnosis of infertility and their decision to pursue DI, and that they voiced a need for counselling, these recommendations seem appropriate and helpful. Support after male infertility is diagnosed, as well as prior to embarking on treatment using DI, seems necessary to assist couples in exploring their emotional needs before, during and after treatment, and the issue of information sharing, in order to develop strategies to fulfil these needs. This also highlights the need for addressing long-term implications prior to embarking on treatment, in order to raise awareness of the potential consequences for the child of sharing the use of DI with others.

The psychological implication of a secret on the secret-bearer

The results of this study point out that keeping the form of conception a secret created pressure and tension for respondents. Keeping DI a secret was described as a burden both in the short and the long term and many respondents decided to disclose their use of DI in order to avoid this pressure. Furthermore, reactions of several respondents indicate that Smart and Wegner's (2000) concept of deep cognitive activation is helpful in explaining the pressure respondents voiced. In social stigmatisation, this concept describes a psychological state during which stigma-related thoughts, though subconscious, become accessible and influence behaviour and judgement. Individuals who suppress such thoughts are
plagued by mental control problems, and these can result in impaired health, such as depression and anxiety as well as social isolation. Respondents in this study indicated similar anxieties. Though they did not indicate that subconscious stigma-related thoughts dominated their interaction with others, they felt pressured by the secrecy, were afraid they might unwittingly disclose the truth, considered themselves “hopeless at keeping a secret”, and did not want to spend time and energy on telling lies. This suggests that cognitive activation of intrusive thoughts and mental control problems can also operate on a conscious level. As a result of their awareness, respondents in this study implemented strategies to counteract the potential negative consequences. The strategy applied by most was to reveal the stigmatising condition to others and especially to others in a similar situation. In one other case, a different strategy was found to be helpful. One male respondent wrote down his experiences of male infertility and DI treatment, initially for a different reason, as he wanted his future child to be able to learn about his reasons for using DI. However, he recalled that the process of writing down and thus externalising his emotions and experiences was a liberating experience for him. Apparently, while person-to-person disclosure helps to reduce the toll associated with cognitive activation, externalising this in the form of writing down experiences, keeping a diary or similar activities can also be helpful. Again, this can be addressed and explored in pre-treatment counselling. As will be shown when analysing the usefulness of preparation seminars in the next section, the opportunity to discuss and share with others during these seminars can further contribute to counteracting cognitive activation (Thorn & Daniels, 2003).

The emergence of a new family type

Results of this study show that there is a lack of understanding of the specific composition of families built by DI. Almost all respondents found it difficult to make sense of this family type and were unable to develop a coherent concept for the type of family they would be as a result of using DI. Indications of these uncertainties were the values attached to biological and social ties and the confusion of combining both in one family. When respondents were initially confronted with infertility, all favoured treatment possibilities enabling them to procreate with their own gametes. A biological connection with the child was considered very important and a way to avoid these uncertainties. Many respondents pursued IVF and/or ICSI in the hope that this would result in a pregnancy. At that stage, family building options such
as DI or adoption were not considered because of the desire for a child biologically related to both parents. However, once these options had been tried or were considered to be unrealistic, family building by DI and, in many cases, the possibility of adopting a child was explored. After respondents had decided to pursue DI, biological links were considered less significant, and both male and female respondents deemed nurturing relationships to be more important. There was no indication that this shift in meaning was a conscious process. It seemed more a subconscious adaptation to a situation which presented no other choices but the acceptance of a family composition including relationships based on social ties. However, there were many indications that respondents perceived great differences between a family based on biological ties only and one built by DI and that they found the latter challenging. Respondents appeared to lack a coherent cognitive and emotional framework for families resulting from DI, especially the meaning of another man's contribution, appropriate terminology for the two men involved and an understanding of the reactions of children. Their confusion about the significance of blood ties and social ties became apparent not only in the terminology they used for the semen provider and the social father, but also in the meanings they attributed to the two male persons. On many occasions, they used words such "the real father" for the semen provider and described him to be the father in the psychological sense. At the same time, some respondents feared that the social father had only limited significance for the child. In fact, one male respondent described himself to be "the only loser" in a family built by DI. From a systems perspective, the semen provider can be described to be a subsystem in families built with the assistance of DI (Payne, 1997; Simon et al., 1999; Steinert, 1997); respondents apparently had difficulties defining boundaries between their subsystem as a family and this subsystem of the semen provider.

The attempt to make sense of the contribution of a second male and the need to appreciate both social and biological ties within one family, both seemed challenging for respondents. Snowdon and Snowdon (1998) explain that the perceived importance of biological and nurturing ties signify a tension in families with adopted children and in families with children conceived by DI. This study points out that this tension may already be experienced prior to the birth of children. Couples in this study not only subconsciously re-evaluated the meaning they gave to biological and social ties; they also indicated confusion as to what family type was most appropriate as a comparison. Many negated differences between family building by DI and families in which children are the biological offspring of both parents,
others compared families by DI to families following adoption, where neither parent has a biological connection with the child, or to families that are “reconstituted” or “blended” where children are the biological offspring of one partner or the other and some additional children may be the offspring of both. Male respondents explained that a child conceived by DI would be similar to their partner having a child from a previous relationship. This suggests that in the eyes of most respondents the significance of social and biological ties mutually excluded each other: it was either the biological connection which was deemed to be important or the nurturing relationship. This is understandable given that other family types make it easy to view both as having such mutually exclusive qualities. In families following adoption, for example, both are social parents and the relinquishing parents are the genetic parents. In families that are reconstituted or blended following the breakdown of previous relationships, the emotional bond between both parents and the child remains, while one parent enters a new and only nurturing relationship with the child. Families built by DI are similar to those built by oocyte donation, and are the only family compositions in which one genitor does not have a nurturing role with the child, one parent has social ties only and the other parent has both social and biological ties to the child, resulting in an asymmetrical parenthood (Thorn, 1999). Anthropologists such as Finkler (2001), Franklin (1999) and Strathern (1992) have pointed out that Western societies place high value on genetic connection and deem this to be highly relevant when considering family and kinship. From a sociological perspective, Haimes (1988) adds that children in families built by DI can be viewed as crossing socially accepted boundaries by indicating interest in the semen providers, as the divide between biological and social parenting is fundamental in Western society. Respondents in this study apparently struggled with this divide, the meanings attributed to kinship, blood and genetic ties, and a family composition combining both biological and social connection.

Although the first report of a couple using DI goes back to 1884 (Gregoire & Meyer, 1965), open acknowledgement of it is only a recent development. Only in the last 10 to 15 years has family building with the assistance of DI been under scrutiny. In this sense, families built by DI are novel and must be considered as being different from other existing family types. The tradition of assessing biological ties as being unbreakable and stronger than social connections, as well as the continuing supremacy of families based on biological ties (Schneider, 1980), is likely to have contributed to the dichotomy of nature versus nurture. Family building by DI requires a shift in thinking based on polarities and a move to appreciating
the significance of both social and biological connections as a basis for family. Although this shift was not easy for respondents of this study, there were some indications that movement from a dichotomous way of thinking was possible. As will be shown below, in these cases, the semen provider was acknowledged as the genitor and attempts were made to understand and attribute a meaning to his contribution; thus, there were attempts to define and clarify boundaries between the subsystem of the parents, the children and the semen provider. Results show that there is a great need to develop an understanding of the specific compositions of families built with the assistance DI.

**Making sense of the semen provider’s contribution**

Similarly to the findings of Schilling and Blonski (1994) and Snowdon et al. (1985), male and female respondents in this study reported different attitudes towards and thoughts about the semen provider. This study indicates that these different views do not only manifest themselves once a child has been born but, as does the tension regarding the family composition, at earlier stages while couples are considering DI or pursuing treatment. The results further show that in contrast to the study conducted by Schilling and Blonski (1994), both men and women had little difficulty in verbalising their fantasies and anxieties regarding the semen provider. There is no indication that Schilling and Blonski (1994) explicitly asked respondents in their study about the semen provider. It is possible that discussing the semen provider is a delicate issue, which is only raised if, as in this study, respondents are questioned about him.

In this study, many men consciously suppressed thoughts about the semen provider, describing him as an instrument they needed, but denying any interest in him. This group of males found having information about the genitor of their (future) child to be challenging; one man commented that information about the semen provider would result in diminishing his own significance as a father figure, another blatantly admitted that he “would go mad” if he knew anything about him. Furthermore, some men raised the fear that knowledge about him could result in a preoccupation or even obsession with the semen provider and the fear of such a fixation could impact negatively on the relationship with their (future) children. Clearly for them, the semen provider signified a threat as he was felt to compete with the role of the father. They felt replaced by the semen providers in their role as the genitor of their child and this resulted in anxieties regarding their own fathering role. It is likely that they also felt substituted in their function as a virile and
potent male partner, as well as an active progenitor. Other men acknowledged their ambivalence and voiced some curiosity about the semen provider. They were interested in non-identifying information, such as his looks, age and professional background, and wondered about health aspects. Even this group, however, felt that personal contact could “lead to conflicts”, as one respondent admitted. Furthermore, several respondents were certain that features the child inherited from the semen provider would remind them of his contribution. Thus, even if men attempted to suppress the semen provider’s contribution, his influence would be evident because of the physical features the child may have inherited. Only a few male respondents expressed gratitude, amongst them one who jokingly acknowledged this feeling, giving the impression that he resorted to a joke in order to minimise his embarrassment. The strong anxieties voiced by male respondents in this study were not reported to the same degree in two other German research projects. Schaible (1992, p. 89), in his survey of 46 German parents who had used DI, for example, found that all fathers “considered themselves to be the proper father of their child”, but he concluded that “of course they would not feel good about getting to know the donor”. This indicates that there were some reservations, but the nature of these reservations was not explored by the author. Goebel and Lübke (1987) in their German study, also reported a strong bond between fathers and their children conceived by DI; interestingly, they referred to those fathers who had separated from their wives as “‘fathers’” (p. 639) in inverted commas, suggesting that to the authors they were not regarded as proper or complete fathers. Snowdon et al. (1985), summarising the findings of a survey carried out in England, reported very similar anxieties to those expressed by male respondents in the present study. The authors reported that “although fathers had accepted their children, the concept of fatherhood remained difficult for them”, as they had an incoherent feeling of uncertainty and unease resulting from confusion about their role (Snowdon et al., 1985, p. 42). As in this study, many fathers kept referring to the semen provider as the father in the true sense, and felt confused as well as vulnerable as a result of this. More recent research suggests that this confusion has not subsided (Kirkman, 2003; Lycett et al., 2005; Rumball & Adair, 1999).

Although many female respondents in this study agreed with their partners that the semen provider presented a threat for the husband, they themselves indicated much more interest and curiosity about him. They did not repress this interest during the interviews. They openly acknowledged curiosity about the semen provider’s looks, character and motivation. Several women voiced a great need to counteract the
semen provider's anonymity and applied various strategies to do so. They gave him fictitious names to make him more tangible as a person, attempted to "compose [their] own picture[s]" of him by putting together the little information they had, or compiled a list of questions about the semen provider the doctors were expected to answer. One female respondent remembered the urge to smell the semen provider's semen after the insemination because of her need "to create a relationship with him". Clearly, for these women the semen provider signified an interesting collaborator who assisted them in their desire to have a child. The distress of complete anonymity of the semen provider resulted in vivid fantasies for them. Some were anxious that he may have criminal tendencies, others were concerned that the background regarding his social status was very different – always lower than their own. Given that the female respondents carried the semen of these unknown men inside their bodies, the lack of information suggests a feeling of loss of control over their own body. At the same time, some women voiced strong ambivalence. They felt gratitude towards the men who provided the semen, yet were both devastated and relieved at the lack of information available to them. Though several women also acknowledged ignoring the semen provider as a helpful strategy to manage their own ambivalence, most in this group did so in order to protect their husbands. One female respondent highlighted this when she associated thinking about the semen provider with betraying her husband. She worried that this would be painful for him, and although she seemed unable to stop thinking about the semen provider, she initially commented that she had not discussed this with her husband. In the couple interview, however, she openly acknowledged her worries towards her husband and he indicated that her fears were exaggerated. The only female respondent who voiced no ambivalence, but rather a need for acknowledging the semen provider, was the co-mother in the lesbian couple. She felt that this would clarify her status as the second mother and signify a clear indication that there was no previous or ongoing relationship to a male genitor.

In other studies, the attitude of the female partners is not widely explored. Snowdon et al. (1985), for example, merely comment that women, as in this study, suppressed thoughts about the semen provider in order to avoid hurting their husbands. In the other German studies and in international studies referred to above, there was no information about the views of the female recipients of DI as a subgroup. Only Kirkman (2004a, p. 328) drew some attention to the fact that not just one partner but both partners were anxious "about the usurping sperm provider". It is likely that the views of the female partners have received little attention because of their biological connection with the child and the resulting perception
that this bond is stronger than the social bond between the child and the father. However, such a perspective fails to acknowledge the systemic dynamics within families according to which all interactions are reciprocal (Payne, 1997; Simon et al., 1999; Steinert, 1997). The fact that women suppressed thoughts about the semen provider in order to protect their partners indicates that such reciprocal dynamics operate within the parental subsystem. The fear of those men who felt that their preoccupation with the semen provider could impact negatively on their relationship with their children suggests that such dynamics also operate between the parental and the child subsystems. There was no indication in this study that the different attitudes impacted negatively on the marital relationship. However, the couple interviews revealed that there was some acknowledgement of the women’s concerns and some couples had tentative discussions about their different views. It is possible that even this limited acknowledgement resulted in a better understanding for each partner. This would suggest that open acknowledgement and discussion of different attitudes and associated worries between partners can result in a better understanding and a more realistic assessment of individual fears and fantasies, and this should be encouraged in counselling.

Both male and female respondents in this study were in agreement that the semen provider had a potentially difficult role for their (future) children. As they viewed the genetic connection of the semen provider resulting in a strong bond between him and the child, they expressed anxieties that their child might view him as the “actual” father and reject the social father, and they worried that the child could be torn between two father figures, indicating that the child, as they did themselves, would find it difficult to understand the role of the semen provider. This fear was also reflected in the words respondents used to describe the semen provider. He was referred to as the “father”, the “unknown father”, the “genetic” or “biological father”, the “actual father” or the “original father”, which left the male partner described as “only the social father” or “not the natural father”. Clearly, they lacked less emotionally laden terminology to describe the semen provider’s contribution. As a result of this higher significance attributed to genetic connection and their uncertainty as to how a child might view this, respondents also feared that the bonding process between the father and the child could be difficult. They assumed that the father would have to overcome feelings of strangeness and unfamiliarity and that there would be more distance and less intuitive and spontaneous attachment than between him and a biological child. Similar fears were also expressed by the lesbian co-mother, suggesting that this was independent of gender. It was
assumed that any bonding difficulty would be transient and would diminish after the birth of the child. One male respondent whose daughter was conceived by DI reported that he did indeed feel the bonding process with the child was "not yet completed" and the bonding between him and the child was qualitatively different from that of his wife and the child.

As a result of the secrecy and the lack of research, there is little empirical knowledge regarding the offspring’s definition of the semen provider; only a small number of research projects have examined how offspring view the semen provider in relation to themselves. In several studies, offspring are found to refer to the semen provider with terminology suggesting a parental role such as "donor father" or "biological father", as well as using language describing him as an insignificant person, such as "the stranger who masturbated into a glass vial" (Turner & Coyle, 2000, p. 2047). Some writers conclude that offspring "expressed a need to know who their donor fathers are and, if possible, to have some sort of relationship with them" (Turner & Coyle, 2000, p. 2050). Scheib et al. (2004) in their study of 12 to 17-year-old teenagers also found that offspring used ambiguous language for the genitor. However, they explained that these teenagers were not looking for a father figure in the semen provider, but rather that they felt extremely curious and wanted to know their genitor’s identity (Scheib et al., 2004). This is confirmed by Kirkman (2004b) who found that the 12 offspring she interviewed considered their parents to be their “real” parents, despite using ambiguous language such as “genetic father” for the semen provider. In another study, it was not the offspring’s direct attitudes which were sought, but parental narratives for information sharing (Rumball & Adair, 1999). Although this study provides only limited evidence as to the children’s definition of their relationship to the semen provider, the authors refer to one respondent’s experience. When sharing information about DI with her son, this mother suggested that he had one mother and two fathers. The mother reported that her son “flatly denied it and said [this] wasn’t true” (Rumball & Adair, 1999, p. 1395), suggesting that the child did not view the semen provider as a father figure and differentiated between the father and the semen provider. The authors reported that the mother intended to use the term “donor” rather than “second father” when sharing information about DI with her son. Analysing anecdotal material from the newsletters of patient organisations (for example: Donor Conception Network in Great Britain; Donor Conception Support Group in Australia) or individual stories published in books and magazines (Anonymous, 2002; Franz & Allen, 2001; Lorbach, 1997) may be problematic because it could result in a distorted picture. Until recently, many of the
experiences of these adults were overshadowed by the secrecy of DI and unfavourable circumstances when their conception by DI was disclosed to them. For many of them, it was the secrecy that had dominated and negatively influenced their feelings towards both parents and the semen provider. Some more recent material, however, suggests that both children and adults conceived by DI are developing a clearer understanding of the semen provider than respondents assumed in this project. The British Donor Conception Network (2003) prepared a video in which several people aged between seven and twenty years who were all aware of their conception were interviewed. Though indicating curiosity about the semen provider, all clearly identified their mother’s partner as their father. In a survey of members of the British Donor Conception Network views, Blyth (2004a) reported that children and young adults who had been conceived with the assistance of DI also demonstrated the ability to differentiate between their father and their genitor. Adults who had been conceived by DI portrayed in German television documentaries confirm this as well (Schieder & Kaiser, 2004; Stevens, 2005).

The following illustration (see Figure 8.2) conceptualises the different views family members have of the semen provider. For the father, the semen provider signifies a competitor as he replaces him in his role as the genitor of his child and the fertile partner of his wife. For the mother, the semen provider represents a collaborator as he helps her to conceive a child. Currently, as noted earlier, there is only limited knowledge about how children define the role of the semen provider. The uncertain or contradictory concepts of the parents may therefore be projected onto the children. In these cases, it is likely that children feel as uncertain as their parents. Recent research and anecdotal material provides some indications that children distinguish between their nurturing father and the semen provider. They view their mother’s partner as their father and regard the semen provider as a significant person about whom they feel curious but do not view as having a parental role.
Results of this study indicate that the biological connection between the semen provider and the child was perceived to be so strong that respondents feared the semen provider may demand rights and place importance on a relationship with the child he helped to create. Respondents worried he could insist on visitation rights or may even have the desire to raise the child himself. Therefore, it is important to outline the views of semen providers. At the beginning of the 1980s, it was suggested that semen providers should remain completely invisible; their contribution was reduced to the provision of semen (Glezerman, 1981). In fact, men who expressed interest in the outcome of their semen provision were considered unsuitable and their samples were unlikely to be used (Johnston, 1981). Even at the end of the 1990s, it was assumed that there was no ongoing relationship between them and the families they had helped to create (Winston, 1999). However, until that time, it was mainly medical doctors who reported semen providers' attitudes. This no doubt represented the doctors' biomedical focus, which clearly neglected psychosocial factors. This also provides an indication of the doctors' own anxieties. Not using the semen of men who were interested in the outcome of their sample suggests that doctors at that time needed to create closed boundaries between semen providers and recipient couples. These boundaries were seen to offer protection from potential difficulties resulting from the exchange of information or the establishment of personal contact. Daniels (2004a, p. 212) describes this as a closed model in which
“information about [the semen provider] is managed by the professionals, many of whom ensure the room is locked and that they hold the key”. The semen provider in this model occupies the position of an outsider, and it is the doctor who acts as a mediator between the semen provider and the recipient couple. There is no direct contact between the couple and the semen provider (see Figure 8.3).

Figure 8.3. A closed model (adapted with permission from Daniels, 2004a, p. 212)

More recently, social scientists have been able to establish access to semen providers and ascertain their attitudes more directly. Summarising the results of 20 research studies carried out between 1980 and 1997, Daniels (1998a) concludes that many semen providers acknowledge the significance of their contribution and are aware of the psychosocial implications this has for themselves, the resultant offspring and their families. In addition, some of the studies indicate that these men wish to be acknowledged and are interested in the children they helped to conceive (Blood, 1996). A growing number are willing to be contacted by offspring (Daniels et al., 1997). Although some semen providers feel a degree of responsibility towards the children conceived with their semen, both in Daniels’ (1998a) meta-study and in a later survey of semen providers (Kirkman, 2004b), they cede parenthood to the social
father. This suggests that semen providers themselves have a clearer understanding of the significance of their contribution for the child than the parents in the families built with the assistance of their semen. Although there is no information available on whether semen providers see themselves as having a relationship to the recipient couple, and, if they do, what the nature of this might be, it suggests that the parental anxiety described above is largely unnecessary. Similar research in Germany has not been carried out, and there is currently no knowledge about the views of German semen providers. It is likely, however, that their attitudes do not differ greatly from those in other countries. Figure 8.4 illustrates the meanings semen providers attribute to the different family members and their relationship to the child.

Figure 8.4. The different meanings of the family members from semen provider's perspective

It is likely that the biomedical focus and the secrecy surrounding DI have hindered the development of an understanding of the role and contribution of the semen provider. For other family types, such as families following adoption and families that are reconstituted following a relationship breakdown, the difficulty of attributing clear roles to family members has been described as a double-bind (Miall, 1989), and the concept of boundary ambiguity has been drawn upon to explain this difficulty (Krähenbühl et al., 1995). This concept is based on systems theory and was developed by family therapist Haley (1977) to point out that family members may have different views of the significance of those who are not part of the nuclear family but nevertheless play important roles for some members. In families that have been reconstituted,
the former partner of the mother who may have had a biological or nurturing relationship to the child, for example, remains the father of the child, and thus, is a significant person with potentially close emotional bonds. From the perspective of the child, he is a significant family member. From the mother’s perspective, however, as she has entered a new relationship, he signifies the former partner; her emotional bonds are with the new partner. Though the ex-partner may not be viewed by her as part of the new family, she is reminded of his position by her children and their continuing contact with him. Similarly to this family type, families built with the assistance of DI seem likely to experience boundary ambiguity resulting in uncertainties. Writers have attempted to contribute some clarity for these families, but are not in agreement in their recommendations. The first attempts towards clarification were made in the 1980s when Snowdon et al. (1985) suggested a detailed nomenclature for families built with the assistance of DI. For the two men, they recommended “genetic father” for the semen provider and “social father” for the nurturing male. However, using “father” for both, as indicated above, is not likely to contribute to a better understanding of the separate roles. Towards the end of the last century, the term “donor” was used in guidance books (Frost Vercollone et al., 1998; Noble, 1987), but there was little discussion about the need for a clearly defined concept. In 2001, Daniels and Thorn (2001, p. 1794) reported that finding appropriate terminology was an ongoing and unresolved issue for parents, and suggested a clear differentiation between the two men:

For the child, the person who is the primary loving and nurturing male in their lives is the person they identify as being ‘father’. To use the term ‘father’ for the semen provider, when he is not present physically, nor involved in loving and nurturing, is to create a situation which has the potential to cause confusion for a child. Our suggestion to parents is that they use the term ‘the man who gave his semen’ when they are referring to the semen provider.

The need for clear and unambiguous language is highlighted again by Daniels (2004a) in his book, Building a Family with the Assistance of Donor Insemination. Such clear language is also supported by Montuschi (2003), one of the founding members of the British Donor Conception Network, who, nevertheless, stresses that children tend to use their own language, which may change as they develop. Lorbach (2003, p. 17), on the other hand, a mother who has used DI, in summarising the experiences of families built with the assistance by DI, suggests the need for more flexibility and is of the opinion that “each family has to find the terminology that is comfortable for them”. This could be perceived as contradictory advice. However, it is likely that the need for clear terminology is vital while the families
using DI are creating their own specific identity, as were respondents in this study. Terminology at this stage serves to develop and transport meanings within and outside of the family. Once meanings have been developed and explicitly or implicitly agreed upon, and there is a better understanding of the position of the semen provider and the role of the father, it is possible that words and phrases will become less relevant. For above all what is of most importance is the meaning that every family member attributes to the semen provider. Although the boundary ambiguity did not result in keeping the use of DI a secret for respondents in this study, they voiced a need to learn from the experiences of those who “are one step further” ahead and have conceived a child; this need for role models will be explored in the section discussing factors located at the meso level. Though in the main, respondents raised this need for their own immediate support, some also wanted to talk to children conceived by DI and to “hear from their experiences”, suggesting that they were interested in children’s views of this family constellation; perhaps they also hoped to learn what terminology others used to define the roles of the two male figures in their families. Finding appropriate terminology for the two men involved is therefore a helpful and vital component in the development of a better understanding of this family type.

In this study, the confusion regarding the roles and meanings of the semen provider did not impact on parental decisions to share the use of DI with their (future) children. They differentiated between their own fears and the needs of the children. Though several feared that disclosing the biological origin to their (future) children may lead to the child rejecting the father, none of the respondents indicated that this would prevent them from sharing information. Nevertheless, the lack of a concept for this family type resulted in few respondents sharing DI with significant others; after all, respondents felt that explaining the role of the semen provider would be challenging and could result in misunderstandings. Furthermore, in some cases, boundary ambiguity resulted in couples avoiding discussing the semen provider, altogether. The female respondents feared that sharing their thoughts about the man who provided the semen would be painful for their partners, and although some men confirmed that this was the case, most felt able to manage this difficulty. Evidently, individuals and couples considering DI can profit from comprehending and defining the contribution of the semen provider as qualitatively different from the meaning of the social father, while at the same time acknowledging that he is of significance for every family member and especially for the children. The use of unambiguous descriptions for both of these
male persons is likely to reduce the threat the semen provider presents for the parents, and especially the social father, and to encourage information sharing and discussions about family building by DI.

**The impact of a different family composition on the identity development of family members**

In this study, two areas highlight the importance of recognising the need for coherent identity development for family members. Knowledge of one’s biological origin was considered an important factor for sharing DI with children. Respondents felt that this would increase the self-esteem of children, would make them “stronger” and more “confident”. Although most favoured information sharing, many felt uncertain about the appropriate age for this. Some considered it best when children were young so that they would grow up with this knowledge. They wanted to avoid a disruption of their child’s identity, which they felt would be possible if DI information was shared at an older age. Others assumed DI was too complex for young children, feeling that sharing information about DI after puberty may be more appropriate because a better cognitive understanding would be likely. Several also worried that children may not be emotionally stable enough to manage information about their conception by DI. A factor increasing uncertainty for many respondents was the lack of resources, especially literature designed to provide advice in this area and facilitate sharing DI with children. This suggests that respondents were aware of the meaning of information sharing for the identity development of children. Furthermore, respondents indicated that they themselves required time to accept family building by DI as a positive alternative. Many couples in this study had lengthy periods of discussion amongst themselves before starting medical treatment. For a small number of couples, in fact, these discussions took place over the course of several years. They explained that they needed to mourn the fact that they could not have a child biologically related to both parents, adapt to this reality and then adjust to the use of DI.

Theories about identity development suggest that individuals must develop a coherent understanding of themselves (Erikson, 1977). In order to achieve this, personal continuity, a sense of belonging, as well as continuity of attitudes and behavioural patterns, are vital (Fröhlich & Drevers, 1981). Though identity does not mean a rigid view of oneself but a view which is continuously renewed and adapts as a result of communication and interaction with others (Gergen, 1991; Krappmann, 1973), subjective and objective
personal coherency must be maintained in order to avoid an identity crisis (Erikson, 1977), or in Giddens' (1992, p. 53) words:

> It is the self as reflexively understood by the person in terms of her or his biography. Identity here still presumes continuity across time and space; to be a 'person' is not just to be a reflexive actor, but to have a concept of a person as applied both to self and others.

Adoption researchers point out that “it is crucially important for children to have detailed and accurate information about their origins if they are to make sense of themselves” (Feast, 2003, p. 82) in order to avoid “genealogical bewilderment”, a phrase coined by Sants (1964) describing uncertainty resulting from the lack of knowing one’s biological origin. Triseliotis (2000, p. 84) contends that “the adopted person’s family of origin and ancestry, race and ethnicity, represents only one aspect of social identity but nevertheless, a vital one that cannot be ignored”. Identity, also in the view of these writers, is composed not of a single component but of several, such as personal experiences, social relationships, physical appearance, heritage and genes (Feast, 2003). A complete understanding of oneself is not possible if there are gaps in the knowledge about one’s biography (Haines & Timms, 1985; McWhinnie, 1967; Triseliotis, 1973), which confirms theories about identity development.

Respondents in this study, along with other parents who have used DI, have questioned whether early disclosure is appropriate (McWhinnie, 2003). For adopted children, early disclosure has been recommended for many years (for example: Feast, 2003; Triseliotis, 1973; Wiemann, 2001). Though children younger than five years are unlikely to be able to cognitively grasp the meaning and some of the implications of adoption (Brodzinsky, 1984), early disclosure has been found important so that they can integrate this knowledge into their development and feel that they have always known about their origins (Triseliotis, 2000). This suggests that early disclosure can prevent a disruption in the identity formation for children whose parents are not the genitors.

For many years, adoption researchers (for example: Barran & Pannor, 1989; Feast, 2003; Haines, 1988; McWhinnie, 2003; Triseliotis, 1993; Wiemann, 2001), as well as social scientists (for example: Blyth, Crawshaw & Speirs, 1998; Daniels & Taylor, 1993; Pettle, 2002), have argued that parallels can be drawn between the identity development of adopted children and of those conceived by DI, and are therefore
supportive of information sharing in families built by DI. Emerging research in the area of DI justifies drawing such parallels. Turner and Coyle (2000, p. 2049) report that the adults conceived by DI that they interviewed “continually reported that they needed to know their genetic origins ... [and had] a perceived loss of agency or self-efficacy” as they could not access information about their genitor. They conclude that this posed a threat to their identity. Similar feelings were echoed in previous studies by teenagers and adults conceived by DI (Baran & Pannor, 1989; Snowdon et al., 1985) and in individual portraits and anecdotal material (Franz & Allen, 2000; Frost Vercollone et al., 1997; Lorbach, 1997). Results from this study also suggest that information sharing with the child is viewed by parents as contributing towards normalising this way of building a family for the child. Respondents described that disclosure provided them with a “self-protection factor”, as it increased their confidence in their ability to manage this different way of building a family, thus developing an identity as a family built by DI. Furthermore, this suggests that respondents intuitively drew links between disclosure, a coherent identity development, and the reduction of stigmatisation. They felt that accepting and acknowledging the conception by DI as normal and non-devaluing improves self-confidence. This is confirmed by writers in the area of social stigmatisation (Hebl et al., 2000).

The need of respondents to adjust to the use of DI suggests that they were also subject to change and to adapting their own identity. In contrast to extensive literature on identity issues for children, only a few writers have explicitly described the psychological process for adults experiencing infertility (Bassin, 1989; Daniels, 1999; Greil, 1991; Thorn, 2000c). Daniels (1999) and Thorn (2000c) suggest that individuals suffering from childlessness are forced to undergo several phases of adaptation of their identity. They not only have to adjust to being infertile, but must also accept the use of medical technology to conceive a child. Once these possibilities are exhausted, they have to adapt to remaining without children or pursuing a family building option which includes social parenting for both parents (in the case of adoption) or one parent (in the case of DI). Identity theory suggests that such a process of identity adaptation can be facilitated by interaction and communication with others (Gergen, 1991; Giddens, 1992; Krappmann, 1973). This is what respondents did, albeit in most cases, with partners only discussing this between themselves. As will be explained in the section discussing factors located at the meso level, it was the fear of stigmatisation which resulted in only a minority having discussions with significant others. It is possible that the discussions with those not experiencing infertility, referred to as
“mixed interaction” by social stigmatisation writers (Hebl et al., 2000), have a positive impact with regard to creating a better understanding of the stigmatising condition (Corrigan & Penn, 1999; Hebl et al., 2000). Identity theory also suggests that mixed interaction, and thus an acknowledgement of a difference that extends beyond the couple, can help the stigmatised to adapt his or her personal construct and incorporate and integrate aspects that are novel or even perceived to be negative. It is only by acknowledging and discussing aspects perceived to be negative that these can be subject to scrutiny, re-appraisal and, potentially, re-integration into individual identity with a less negative connotation. Though respondents could see this link for the development of children, they did not explicitly make this link for themselves. While several social scientists have spoken out for pre-treatment counselling and/or a waiting period prior to treatment (Brähler, 1990; Mahlstedt & Greenfeld, 1989; Thorn & Daniels, 2003), they do not refer to identity adaptation. Nevertheless they argue for acknowledging the psychological difference between medical treatments using the biological gametes of both partners and technologies involving donated gametes, and for providing opportunities for recipients to discuss the specific issues involved and to develop ways of managing them. In addition, they stress the importance of having sufficient time between the suggestion of DI as an option and the beginning of treatment, again indicating some awareness of identity adaptation. Furthermore, legislation in several countries, such as Great Britain, mandates couples be offered pre-treatment counselling, not least in order to explore the implications of treatment and to adjust their expectations (Blyth, 1995b) (see Chapter 4, pages 77-85, for the provision of counselling in several countries).

Despite their awareness of the impact of disclosure on identity development, respondents voiced uncertainty and wished to have access to resources for information sharing; some were motivated to take part in this study in the hope that the author would be able to answer some of their questions. Clearly, they would have considered literature or professional advice, confirming their intuitive assumption helpful in this respect. It is likely that the availability of such resources contributes to more confidence about information sharing.
Information sharing and its meaning for family dynamics

Many respondents in this study suggested that keeping a secret could create tensions within their family, and they wanted to avoid this. As explained earlier, they were not only concerned about their own ability to keep such a secret, but also worried that children may sense differences, such as wondering why fathers have different interests than they have or picking up on hidden clues exchanged between parents. Though young children may not be able to verbalise such perceptions, respondents nevertheless assumed that children could “feel in the atmosphere” that something was different. Furthermore, the significance of honesty and openness as important family values was also raised. Respondents wanted to be role models for their children in this respect and felt this would only be possible if they themselves were honest towards their children. For others, information sharing was interlinked with the trust children feel towards their parents. They feared that the truth might surface and that this would violate the children’s trust in their parents and strain family relationships.

According to psychoanalytic theory, it is the fear of exposing vulnerability that results in not disclosing certain issues to others (Avery, 1982); secrets in this sense serve to protect the secret holder from exposure of a vulnerable or, in this case, a stigmatising condition. However, psychoanalysts point out that parents run the risk of subtly communicating secrets through mixed messages (Avery, 1982), a similar notion to deep cognitive activation of a stigmatising condition described by Smart and Wegner (2000). In family therapy, the impact of secrets in a family has received extensive attention (for example: Bradshaw, 1995; Imber-Black, 1995, 1998; Karpel, 1980; Papp, 1995; Sants, 1964; Wiemann, 2001). Haley (1977) uses the notion of triangulation to describe how alliances are developed amongst those who know about the secret, and as a result, those who are unaware are excluded. He contends that such alliances negatively affect relationships in families. They have potential for abuse of power and, as respondents in this study feared, for destructive disclosure. Such detrimental disclosure has been reported both in research (Barran & Pannor, 1989; Cordray, 1999/2000; Hewitt, 2002; Snowdon et al., 1985; Turner & Coyle, 2000) and by teenagers and adults conceived by DI. In the case of the latter, disclosure took place after the death of a sibling (Cordray, 1997; Spencer, 1997), prior to or as a result of parental divorce (Allen, 1997; Kallstrom, 1997), as a result of identifying the blood group required after a pregnancy termination (Barran & Pannor, 1989), or after the death of the father (Stevens, 2005). Disclosure under these circumstances resulted in additional traumatisation for these teenagers and adults. Imber-Black (1995) describes family secrets as
having a toxic impact on family relations. According to her, in addition to straining relationships, they block communication and can destroy trust and reliability within relationships. In this respect, for many years, adoptive families have also served as an analogy for those built by DI (McWhinnie, 2003; Triseliotis, 1993; Wiemann, 2001). Feast (2003) therefore concludes that being truthful and honest with children about their origins is vital in both family types in order to avoid the generation of mistrust. There is increasing evidence that these analogies are justified. Turner and Coyle (2000, p. 2049), for example, when investigating the experiences of adults who were conceived by DI argue that, “a consistent finding within the study was the negative and ongoing effects of withholding secrets and the knowledge that ‘things were not quite right’”. Similar observations were reported by Baran and Pannor (1993), who found that in secret-bearing families, such as those resulting from DI, unspoken messages were passed between members. The unequal balance between parents regarding their social and genetic connection to the child resulted in slight differences in parental roles and was “subtly and imperceptibly sensed by the children” (Baran & Pannor, 1993, p. 84). Anecdotal reports (Franz & Allen, 2001; Lorbach, 1997) confirm this. In addition, Hewitt (2002) and Cordray (1999/2000), both conceived by DI, verified that the teenagers and adults they surveyed sensed that a secret was being withheld from them during their childhood. Over half of these respondents were aware of this before the age of 10 years, which is not surprising given that over two-thirds felt that their parents’ relationship was negatively affected by this secret. Books on the experiences of parents who have used DI point out that they are as concerned about this negative impact on family relations as family therapists (Daniels, 2004a; Frost Vercollone et al., 1997; Lorbach, 2003).

Summary

Research findings are conflictual regarding the emotional impact of infertility on men. Whereas some writers indicate that men seem less distressed than their female partners, others have pointed out that these differences do not result from the affective reactions themselves, but from methodological procedures which for many years have resulted in inaccurate representations of men’s experiences. This study confirms these criticisms. Male participants indicated they had as severe emotional reactions as the female participants. It was the qualitative design of this study which enabled men to openly
acknowledged and provide detailed accounts of their experiences. This highlights the need for more qualitative research prior to developing standardised measures to ascertain data.

Both male infertility and family building by DI have been associated with social stigmatisation. Stigma theories have shed new light on the causes of this. Writers believe that there are biological and social functions associated with stigmatisation. Individuals who are biologically unable to contribute to the well-being of a group, such as those not able to reproduce, or who violate social norms, such as men suffering from infertility, which is linked to a lack of virility yet are expected to be strong and healthy, run the risk of being ostracised. Respondents in this study applied typical stigma management strategies to conceal these stigmatising conditions or lessen their effect. These included keeping male infertility and DI a secret, suggesting that it was the female partner who was affected by infertility, or acknowledging a decrease in fertility rather than the full extent of infertility or sterility. Despite their need not to reveal a stigmatising condition, several respondents, and especially female respondents, talked to others about their condition. This has also been reported in other studies. However, in contrast to other research, this study indicates that many were aware that disclosure of male infertility and/or DI could result in others accidentally sharing this with the child. For many respondents, this was an important reason for their intention to disclose their use of DI with their (future) child.

As in other studies, respondents in this study confirmed that keeping a secret can represent a psychological burden for the secret-keeper. This study draws on concepts of social stigmatisation theory in order to explain their manifestation. Stigma theory contends that the attempt to keep an undesirable condition a secret can result in an unconscious activation of thoughts related to this condition. These become influential over behaviour and judgement. Suppressing such thoughts is known to result in feelings of depression and anxiety, and in social isolation. Such anxieties were voiced by respondents in this study, but in contrast to stigma theories, respondents were well aware and able to explain such dynamics. Therefore, many of them had shared their experience of male infertility and intended to share information about DI with their children.

With regard to factors related to the family unit, this study highlights that to date there is little understanding of the specific composition of families built with the assistance of DI. This was illustrated
by the shifting and confusing meanings respondents attributed to the semen provider. This has also been confirmed by other writers who have examined how the parents make sense of the semen provider’s contribution. For many, and especially the male respondents, the semen provider was described as a threat as the biological connection between him and the child was perceived to be stronger than the connection based on social ties between the child and the mother’s partner. In the last 15 years, writers have also investigated the motivations and experiences of semen providers and, more recently, the experiences of teenagers and adults conceived with the assistance of DI. These writers point out that both semen providers and offspring do acknowledge their genetic connection. However, semen providers do not see themselves as being in a parental role, and offspring, although they have been found to use terminology such as the “biological father” for the semen provider and indicate curiosity about him, do not view him as their father. While these findings have been relatively consistent, it must be noted that the terminology remains confusing and there is little evidence that this is changing. Clearly, families built by DI, although not a new phenomenon, lack a coherent understanding for their composition and the roles of the two men involved in building this type of family.

Confirming recommendations of adoption researchers, respondents in this study expected that disclosure was important for children. They assumed that knowing the facts of their conception would make children more stable and feel more confident. Several felt that early disclosure was vital in order to avoid a disruption to their identity development; others thought that disclosure after puberty was more appropriate as children may not be able to cognitively grasp DI at a younger age. There is emerging evidence from offspring conceived by DI that early disclosure does prevent a disruption to identity development and that those who learn of the conception later in life experience bewilderment and confusion and take some time to adjust to this information. Furthermore, disclosure was described by respondents as increasing their confidence about the use of DI, and this is confirmed by both stigma and identity theories. Accepting and acknowledging a stigmatising condition is said to improve confidence and increase self-esteem. Identity development has been argued to be influenced by social interaction; it can therefore be assumed that it is not merely the passing of time, but also an active acknowledgement and coming to grips with DI which is helpful in order to adapt to the notion of family building by DI as an acceptable option.
Furthermore, this study has highlighted that men's and women's experiences are similar in certain areas but differ in others. Whereas their emotional reaction to infertility was equally strong, they revealed different needs and behavioural patterns following the diagnosis. Also, male infertility was perceived to be more stigmatising than female infertility and more strongly associated with a lack of masculinity. Therefore, men were more hesitant in sharing male infertility and their use of DI than women. A further factor revealing gender differences was the perception of the semen provider. Whereas women indicated interest and curiosity, most men felt threatened by his contribution. At the same time, though contact to professional and peer support tended to be initiated by women, both men and women appreciated this support. Also, both men and women found it equally difficult to make sense of a family built with the help of DI. These comments are made at the micro level, but clearly the way men and women view themselves and perceive others to view their infertility and use of DI flows through into the meso and the macro levels.

Factors located at the meso level

This section will analyse and discuss respondents' attitudes towards information management with regard to family members, friends, peers and medical as well as psychosocial professionals. Results suggest not only strong gender differences in the way couples interact with family members and friends, but also typical stigma-related interaction patterns. Furthermore, this section will highlight the need for a biopsychosocial understanding of family building by DI, as well as the importance of peer support to counter social stigmatisation. The lack of information doctors provide about DI services suggests that the stigma also operates for these professionals. This is likely to reinforce stigmatisation for those using DI. Results suggest that both medical and psychosocial services need to be improved.

Gender differences regarding information sharing

Male and female respondents in this study responded differently to both male infertility and family building with the assistance of DI. Whereas only a few male respondents had shared their inability to conceive with family members and friends, all the female respondents had discussed infertility with at
least one person. Men explained that they feared stigmatisation, did not wish to reveal the negative impact male infertility had on their self-esteem, and that they simply did not have the need to share. Women, by contrast, reported requiring the understanding and support of others and therefore, despite their fear of stigmatisation, discussed infertility. Furthermore, both male and female respondents explained that in most cases, infertility was discussed with female family members and friends, as they were perceived to be more interested. Contrary to respondents’ expectations, there were few negative reactions to male infertility. Both family members and friends were supportive and understanding. Family building using DI, however, was associated with stigma, and therefore fewer respondents discussed this with others. Both men and women either feared negative reactions not only towards themselves, but also towards their (future) child, or were unable to gauge others’ reactions.

Results in this study reveal comparable patterns regarding information sharing of male infertility and the use of DI. With both issues, female respondents had more discussions with significant others than did male respondents. As already discussed, both male and female respondents had similarly strong emotional reactions to their inability to have a child. Their emotional needs and behaviour, however, were different. Women not only voiced a greater need to share with others, but also reported that when sharing with other females, they had longer and more in-depth discussions. Men, by contrast, expressed the need to withdraw from social situations and to process the emotional repercussions by themselves. Almost all discussions between male respondents and male significant others, as well as between female respondents and male family members and friends, were brief and focussed on the exchange of factual information; they did not include sharing emotions. Other writers have described similar gender differences (Daniluk, 1997; Lee, 1995; Stanton, 1991) and several attempts have been made to explain these differences.

Nachtegall et al. (1992), for example, contend that gender differences are not only individual responses to infertility, but are based on socially accepted behaviour patterns and roles. Such socially accepted roles for men include the image of being strong, confident and above all, healthy (Brähler et al., 2001b). Both male and female respondents in this study held firmly to beliefs that men suffering from infertility were “not proper men”, suggesting that they feared they would lose their image of being a strong male if they disclosed infertility. Open acknowledgement of such stressful emotions may also result in reactivating the painful emotions men experienced when first diagnosed with infertility. Men may also avoid discussing
infertility in an attempt to avoid re-experiencing these painful and “unmanly” emotions. Furthermore, Daniluk (1997) contends that the medical and biological context results in differences in the reactions of men and women. Traditionally, infertility treatment has been carried out on the female body, independently of which partner was diagnosed with infertility. Although medical interventions, such as surgical removal of semen from the testis, also require the male partner to undergo treatment, once a couple decides to pursue DI, only the female partner is treated. In this study, several men had suffered from testicular cancer and had undergone medical treatment, such as surgical operations and chemotherapy. They were able to recall many details, including the medical treatment, and explained that the impact of the disease was much more severe emotionally than the resulting inability to father a child. This suggests that being subjected to medical treatment can result in higher sensitivity and awareness, and potentially contribute to a higher level of distress, thus verifying Daniluk’s (1997) hypothesis. Greil (1997) adds that distortions may also occur as a result of ignoring issues beyond the immediate experience of infertility. Results of this study also support his criticism. Most male respondents who had suffered from testicular cancer attributed more significance to this than to the subsequent diagnosis of infertility. Understandably, experiencing such a life-threatening disease tends to put infertility into a different perspective. Future research must therefore attempt to capture not only the meaning a particular crisis may have for an individual, but also how individuals make sense of a particular crisis within the context of other life experiences. In infertility counselling, this understanding has been developed, and writers refer to so-called “vulnerable couples” (Wischmann, 2001). This terminology is used to point out that previous crises, especially if unresolved, can worsen the emotional experience of infertility, and these must be recognised when providing infertility counselling. Both this and the previous issues indicate that research that attempts to understand affective and behavioural reactions to infertility is more likely to increase our knowledge if a biopsychosocial approach is applied. This approach includes physical aspects, such as medical treatment, as well as the individual’s life history or context and the resulting psychological meaning attributed to a particular crisis.

Male reactions and behaviour, however, were different in those cases where couples attended self-help groups or consulted a counsellor. Sharing in these situations was described by both partners as helpful and normalising. The typical advantages of self-help groups and of counselling have also been reported by other writers. Self-help groups have been described as important “opportunities for peer support, new
learning, personal insight, and stress reduction” (Shapiro, 1999, p. 117). Their lay character, the informal method of establishing contact with these groups, as well as the low costs involved, have been described as making access to these groups unproblematic (Thorn, 2002). Furthermore, sharing with others in a similar situation has been associated with diminishing the stigmatising nature of a condition (see Chapter 5, pages 100-114, for a detailed outline of social stigmatisation and factors that can alleviate stigmatisation). Men have been reported as showing reluctance to undertake counselling (Beutel et al., 2001; Boivin et al., 1999; McCartney & Wada, 1990). This study has both confirmed and expanded on these findings. Initially all the men had reservations about counselling; however, in retrospect, they welcomed the opportunity to explore psychosocial issues related to infertility and DI. This suggests that a more pro-active inclusion of counselling in medical treatment and an active reaching out to men and couples are required in order to be able to extend this service to men.

In addition to gender differences, the emotional needs of both men and women are likely to change over time. Men in this study voiced a need to withdraw immediately after the diagnosis of infertility. As one man commented, he “wanted to crawl into [his] cave”. Sharing information about this may become more important once men have overcome this stage of shock and denial and have been able to accept the diagnosis and adapt to it, to some degree. This confirms Greil’s (1997) and Mason’s (1993) findings, which highlight the fact that men’s emotional reactions can vary during the various stages of their infertility experience. Only a few women indicated a similar change in their emotional needs over time, but this may have resulted from the fact that most were not affected by infertility.

The experiences of men and women also revealed further differences. Only the female respondents in this study were asked by significant others about their desire or plans for a child. Friends and family members referred to the respondent’s age and length of marriage, indicating that these women were expected to have a child soon. Some women considered these questions intrusive and felt pressured to admit infertility. For others, this seemed a natural issue to discuss amongst women. Men did not indicate that they were asked about their plans to build a family. This suggests that family and children are considered areas that women are in charge of and that women without children are likely to feel more excluded and stigmatised than men without children. The greater level of distress that women have been reported to experience (Greil et al., 1988; Hammer Burns & Covington, 1999) may also be a result of the difference
in the social meaning fertility and infertility has for both sexes. This may be an additional explanation as to why fewer men shared their use of DI with significant others: social expectations for men are such that family and children may simply not be their primary focus in discussions.

In this study, more women than men shared their use of DI with significant others. The gender differences analysed above explain why this is the case. Women have a greater need to share the emotional repercussions of infertility and are more likely to discuss family building in general. As explained earlier, their biological connection to the child is perceived to be secuer than the social connection between their male partner and the child. This is likely to render sharing their use of DI with significant others less threatening for women. In fact, in this study, slightly more female respondents indicated that they will or may share DI information with the child. This raises the question of whether gender difference also operates in information sharing with children and whether women, who have been reported to display more dominance in relationships experiencing male infertility (Goldschmidt et al., 2001), are more likely to disclose information about their use of DI to their children than men. The following examples show that professional recommendations have so far assumed that information sharing with the child is a process in which both parents have equal input. Barran and Pannor (1993, p. 169), when outlining these recommendations, contend that it is “the parents” who “have the responsibility to provide their child with complete information, including the identity of the donor father”. In Rumball and Adair’s study, “Telling the Story: Parents’ Scripts for Donor Offspring”, the authors refer to “parents” when discussing information sharing (Rumball & Adair, 1999). Interestingly, these authors also report that of the 181 individuals who participated in the study, there were 23 female participants whose partners did not respond because they were too busy or believed that their child’s origin was a private matter. Despite the higher proportion of female respondents and the apparent lack of interest of some male partners, the authors conclude that information sharing is a mutual parental decision. In Gottlieb et al.’s (2000) study of the impact of Swedish legislation on disclosure, parents were asked to fill in the written questionnaire together, indicating that authors supposed parental agreement in this area. Also, in Daniels and Thorn’s (2001) paper discussing an innovative family-focus approach to information sharing, the authors refer to parents’ or the couple’s interaction with the child, suggesting that there is similar interest. However, disclosure patterns described in several publications (Barran & Pannor, 1993; Daniels, 2004a) and anecdotal material (Lorbach, 1997) indicate that sharing is, in fact, often initiated or carried out by
mothers. Past research also indicates differences between the male and the female partners. Daniels et al. (1995) report that almost one-third of the 58 couples they interviewed were not in agreement, and a study carried out by Schover, Collins and Richards (1992) also indicates gender differences, although they are less significant. A study conducted more recently reveals that for 18% of parents who had reached a decision regarding disclosure, this was not a joint decision (Lycett et al., 2005). The authors, however, do not provide further information on these gender differences. This suggests that there are not only gender differences regarding information sharing with significant others, but also the potential for differences between the views of males and females regarding information sharing with the child. Therefore, it is important not to assume that information sharing is always a joint decision made by both parents. Future research may provide a better understanding of how gender differences operate in information sharing with the child and how parents manage these differences.

Managing social stigmatisation at the meso level and its impact on information sharing

This study indicates two trends regarding information sharing about the use of DI. One group of respondents feared stigmatising reactions and therefore did not disclose their use of DI. Keeping the stigmatising condition a secret has been described by Goffman (1998) as an understandable management strategy as it seems to be potentially protective. Crocker and Quinn (2000) have expanded this concept and drawn on symbolic interaction in order to explain such behaviour. In their view, by observing and interpreting interactions with others, individuals develop an understanding for themselves. Based on this, an understanding of one's identity and oneself is created by constant comparison to concrete or generalised reactions of others. Results show that the stigmatising nature of male infertility in combination with the deviation from the composition of the biological family, the lack of a coherent understanding of family composition resulting from the use of and, as will be discussed in more detail in the next section, the lack of information and unclear legislation are important factors when presuming possible or generalised reactions of others. Respondents in this study assumed that DI was viewed negatively and that all persons affected would experience stigmatisation if their secret became known. They used strong terminology to describe their perceptions, such as DI being considered “suspicious” or even “disgusting”, and, understandingly, wished to avoid such negative reactions by keeping their use of DI a secret. In addition, respondents indicated the hope that not disclosing DI to others would result in
diminishing the importance of the semen provider’s contribution. This in turn would make their family appear “normal”. Though, of course, they could not hide from themselves the knowledge of having been diagnosed with male infertility or having used DI, and, as already analysed, secrecy was associated with negative psychological implications most respondents wanted to avoid, several hoped that keeping this a secret might facilitate suppression of the acknowledgement of DI. Apparently, not disclosing the use of DI was perceived as a means of controlling or even reducing thoughts about and memories of DI.

Mixed interaction between the stigmatised and the non-stigmatised has been seen to reduce barriers, to improve understanding for the stigmatised and to increase knowledge about particular stigmata (Corrigan & Penn, 1999; Hebl et al., 2000). Miller and Major (2000), however, consider interaction between stigmatised and non-stigmatised about the stigmatising condition unlikely in the case of concealable stigmata, as this would require the stigmatising condition to be revealed. Both male infertility and family building by DI clearly belong in this category; male infertility does not have any observable characteristics and it is not possible to discern whether a woman becomes pregnant after intercourse with her husband or following insemination with the semen of a different male. In fact, this ease of concealing DI has been viewed as facilitating secrecy (Daniels & Taylor, 1993). Despite this and fears similar to those respondents who expected negative reactions, a second, smaller group of respondents shared information about DI with significant others. Many in this group explained that they carefully selected their conversation partners in order to minimise the risk of negative reactions. They also explained that they themselves raised the issue of DI. This group, with very few exceptions, did not experience any stigmatisation or ostracism. In fact their disclosure was greeted with understanding and supportive reactions. Some of those with whom they discussed DI provided them with additional information, and in two cases, family members even offered to donate semen. This suggests that these relatives did not view DI negatively, but as an acceptable alternative for family building. Clearly, for this group, mixed interaction was a positive experience. They reported detailed discussions and recalled that they explained in detail the medical and the psychosocial aspects of DI. In fact, one couple applied a strategy similar to the one suggested by their counsellor for information sharing with children and felt this was also appropriate for adults unfamiliar with DI.
In these examples, it was the stigmatised persons who were pro-active in that they raised the issue associated with the stigma. Evidently, they did not accept the stigma, and instead of silent acceptance, they provided information, candidly acknowledged those issues which others apparently felt uneasy about, and answered questions. This confirms Hebl et al.’s (2000) view that mixed interaction can help to educate others and thus reduce social stigmatisation. Though some respondents experienced so-called “awkward moments” (Hebl et al., 2000), such as others being “dumbfounded”, not knowing how to react or being reserved, these were overcome by the provision of information, the encouragement of questions and the selection of an adequate context for these mixed interactions. What seemed vital for such interaction was the awareness and sensitivity that those unfamiliar with DI required time to process this information. Similarly to sharing DI with children, this suggests that sharing DI with adults does not take place in a single discussion, but requires on-going dialogues to clarify questions and to develop understanding. The fact that male infertility and DI are not visible requires the stigmatised to raise the issue of DI in new situations. In most cases in this study, it was the respondents who initiated these mixed interactions. Nevertheless, in those cases where significant others were aware of the couple’s inability to conceive, they suggested DI themselves and respondents were surprised at their positive attitude towards it.

Jussim et al. (2000) claim that, initially, erroneous social beliefs about potentially stigmatising conditions can lead to their own fulfilment if they are not challenged in interaction with others. They refer to this as the self-fulfilling prophecy of social stigmatisation. Results of this study suggest that such self-fulfilling prophecies operated for respondents. Those respondents who did not disclose their use of DI explained that this was because of their fear of others reacting negatively or attempting to discourage them from the use of DI, or because they were unable to gauge other’s reactions. Respondents also felt that others “block conversations” about DI, suggesting a reluctance to discuss DI. However, those who discussed DI experienced very few negative reactions. This group was able to adjust their perceptions and learn that DI is a less stigmatising condition for others than they had perceived it to be. Those who did not disclose DI to others were not able to experience others’ positive reactions and thus were not able to adjust their perception. In addition, as a result of fearing accidental disclosure, it is likely that they continued to feel anxious in social situations and that others not only felt reluctant to discuss DI because they viewed it negatively, but because they sensed respondents’ anxiety and nervousness. Biernat and Dovidio (2000)
contend that this also operates from the vantage point of the non-stigmatised. Knowing that others suffer from conditions deviating from the norm, they expect this group to be avoidant and distant and therefore behave towards them in a distant way. The stigmatised, in turn, react in a more unsociable and cold way, thus fulfilling the expectations of the non-stigmatised. These dynamics can create a vicious cycle of avoidance in which the avoidance by one group results in further avoidance by the second group, strengthening the need for avoidance and finally confirming the perception of DI being stigmatised and a taboo issue – thus the self-fulfilling prophecy has been created. This process is illustrated in Figure 8.5.

![Figure 8.5. Vicious cycle resulting in a self-fulfilling prophecy](image)

This self-fulfilling prophecy is likely to have further consequences. It not only results in the lack of social support vital to almost all respondents, but also in a lack of mixed interaction which can provide education and information. As this can be viewed as an important strategy for normalising DI, the opportunity to do this is lost, thus reinforcing stigmatisation and taboo.

*The need for a biopsychosocial perspective in family building by DI*

Infertility and the use of DI to build a family have traditionally been located in the medical sphere; Daniels (1986) even goes so far as to contend that these were controlled by the medical profession. This biomedical perspective has limitations as it focusses only on the patient, his or her diagnosis, medical treatment and the creation of a child. In addition, Triseliotis (1993) points out that this focus provides
doctors with greater control and power over patients, and both Annas (1980) and Haimes (1993b) suggest that doctors support secrecy in order to protect their public image. For many decades, patients did not question their doctor’s recommendation to keep DI a secret because they were desperate and grateful for treatment with DI, and because there was a power imbalance between them and their doctor. The status as professionals granted the doctor more authority, and patients had little confidence in questioning their advice. In addition, medical professionals exerted control over research, as they were the gatekeepers to those who might be respondents in a study (Triseliotis, 1993). This biomedical focus was the reason why experience and knowledge from the field of adoption have not been transferred to medical treatment of DI. Adoption was (and remains) located in the psychosocial arena and managed by the welfare services area, whereas treatment with DI remains located in the medical arena and is managed by medical professionals (Brandon & Warner, 1977). It was only at the end of the 1970s and later when social workers (for example: Blyth, 1995b; Brandon & Warner, 1977; Daniels, 1986; McWhinnie, 1986), as well as social scientists (for example: Achilles, 1993; Annas, 1980; Berger, 1980; Burfoot, 1993; Haimes, 1993a, 1993b), started to draw comparisons between adoption and DI, that the challenge to the medical focus occurred. This led to an increase in the recognition of the psychological and social aspects of DI.

A biopsychosocial model for understanding the implications of a physical disease was proposed by Engel in 1977. He advocated taking into account the human factors when diagnosing and treating patients. Based on a systems understanding, his model recognises the interrelations between biological symptoms with psychological and social factors, such as individuals’ affective and cognitive reactions and their relationships with their family and others. In the area of family building by DI, at that same time, Brandon and Warner (1977) advocated for recognition of the psychosocial issues of DI. Drawing strong links to experiences in the area of adoption, they argued for disclosing the use of DI to the child, providing adequate and age-appropriate information, and developing scripts for sharing about DI with children. Though there are indications that both in general medicine (Waldstein et al., 2001) and in psychiatry, where Engel developed this model (Pilgrim, n.d.) the biopsychosocial model is receiving decreasing attention, writers, especially social workers, have explicitly (Daniels, 2000) and implicitly (Blyth, 1995b; Mahlstedt & Greenfeld, 1989; McWhinnie, 1996; Thorn, 2000b) advocated applying this model to family building by DI.
Results of this study confirm the relevance of a biopsychosocial perspective. Respondents placed great importance not only on medical issues, but also on the psychological and the social implications of male infertility and DI. As discussed in the previous section, this was not only apparent regarding the implications DI had for them, but also the implications for their partner and their potential child. The study also indicates that both male infertility and the use of DI impact on extended family members. This study did not aim to examine the experiences and consequences of male infertility for family members, but sought to understand the reactions respondents received from their kin. Though this indirect method has limitations, as respondents may report inaccurate memories or their personal interpretations of family members’ reactions, this is one of the first studies investigating this intergenerational aspect of DI. Clearly, members of the extended families were not indifferent to the emotional pain infertility caused their relatives. Respondents recalled that parents reacted with shock and disbelief when they disclosed their diagnoses. Some parents were reported to have a great desire for grandchildren and to have experienced profound sadness when this seemed impossible. In those cases where male infertility resulted from a childhood disease, mothers were reported as showing a tendency to reproach themselves for not having sought sufficient or timely medical treatment for their sons. They were reported to feel guilty as a result. These consequences bear similarities to the situation of the female partners who are unable to have a child because of their husband’s infertility. This indicates that male infertility has implications well beyond the person physically affected. The reactions of parents reinforce the view that male infertility also has psychosocial implications for the extended family.

Little is known about the meaning of DI for the potential grandparents. Though many studies have indicated that DI is shared with significant others (for example: Baran & Pannor, 1989; Golombok et al., 2002; Schilling, 1995; Snowdon et al., 1985), and this is likely to include the parents of those experiencing infertility, only one study included interviews with grandparents following the use of DI by their sons and daughters-in-law (Hargreaves, 2001). In Hargreaves’ study, grandparents were reported to feel ambivalent about disclosing their children’s use of DI to paternal family members preferring adoption to DI. She concluded that “the decision to procreate using the sperm of an unknown third party [was] fraught with ambiguity and complexity”, mainly because DI challenges cultural norms about the “ideal” way of forming a family and the primacy of a biological connection between parent and child (Hargreaves, 2001, p. 138). She also highlights the fact that family building as a result of DI has
implications not only for relationships between the parents and the child, but also for the relationships between grandparents and grandchildren and for wider kin. Both parents and grandparents in her study anticipated that the relationship with a child who did not share biological ties with one side of the family, "would be qualitatively different from a relationship involving genetic ties" (Hargreaves, 2001, p. 136). Respondents in this study commented on their discussions with family members, and there are interesting differences and similarities to Hargreaves’ (2001) findings. Prior to discussing these differences, it has to be born in mind that in this study, parents and family members’ views were being reported by respondents, whereas in Hargreaves’ study they were directly ascertained. Approximately half of the male and a little over half the female respondents in this study had shared their use of DI with family members. For this group, sharing with kin did not only come naturally but seemed to be desirable. They felt that relatives, and especially the (future) paternal grandparents, had a moral entitlement to know that the child was conceived with the assistance of DI. Similarly to sharing DI with their children, values such as honesty and openness had great significance for them in their decision-making. In addition, they considered the support of family members to be helpful. In contrast to Hargreaves’ (2001) findings, several respondents in this study consulted parents and siblings about their decision to use DI, and discussed the issue of information sharing with them. Consistent with their belief that biological ties are stronger than social ties, respondents assumed that the maternal grandparents were more likely to endorse their use of DI because of the genetic tie. However, once they had shared with their parents, they found little difference between maternal and paternal attitudes towards DI. This suggests, once more, that perceptions about DI by would-be parents may be more negative than in actuality. It also reinforces the necessity of communicating about DI in order to find out others’ actual attitudes so that a self-fulfilling prophecy cannot operate. The different findings between Hargreaves (2001) and this study are even more striking if one takes into account that her study took place in New Zealand, where DI is much more acceptable than in Germany, where this study was located. It is possible that the pro-active attitude of respondents in this study and their open discussion with their own parents resulted in the higher acceptance of a grandchild who did not share biological ties. As described above, conversations and discussions are likely to contribute to a greater tolerance and normalisation of the use of DI. They may also lead to a higher degree of emotional acceptance of the future grandparents towards the grandchild. Though generalising these findings is difficult because of the small number of respondents in Hargreaves’ study (which included eleven grandparents), and the indirect method applied in this study, they indicate
that the use of DI is an important issue beyond the immediate nuclear family and is considered significant for relationships to and within wider family.

The social network of significant others is likely to be important in the decision-making process about DI and can provide support during medical treatment. In addition, the composition of a family built by DI was seen to impact on the relationships within the wider family. Some respondents valued honesty over secrecy and felt that paternal grandparents had a moral entitlement to know about the lack of genetic ties with their grandchildren. Those who refrained from sharing with significant others did so because they feared negative reactions, not because they had different values regarding honesty. Brandon and Warner (1977) link the promotion of a biopsychosocial understanding to social stigmatisation. Referring to experiences in the field of adoption, they suggest that "readiness and openness about the fact of adoption has increased as adoption itself has become an acceptable social procedure. If A.I.D. conceptions increase in number the same acceptance may develop and lead to greater openness" (Brandon & Warner, 1977, p. 339). It is likely that such greater social acceptance is a result of some candidness, which in turn results in further openness and increased acceptance, suggesting that the self-fulfilling prophecy of social stigmatisation can, in fact, also operate in the reverse and promote understanding and acceptance of a condition formerly stigmatised. Brandon and Warner (1977) also suggest that there is a link between promotion of a biopsychosocial understanding of DI and countering social stigmatisation.

The need for a biopsychosocial understanding was also observed in respondents' comments with regard to the medical treatment. On the whole, respondents described doctors' attitudes regarding DI service as hesitant. Some respondents recalled that doctors recommended adoption "because they did not think very highly of DI", others perceived doctors to be sceptical. Information on medical treatment options for male infertility, such as ICSI, was described to be adequate and sufficient. Seeking information on DI from doctors, however, was a frustrating exercise for respondents. In several cases, doctors, such as general practitioners, gynaecologists and urologists, consulted prior to commencing DI treatment did not provide any information about DI or gave incorrect information by explaining that DI was illegal, not available, or a type of treatment no longer carried out in Germany. Respondents also pointed out that doctors favoured either treatment using the husband's semen or adoption, and appeared to be uncomfortable when discussing DI. Several respondents had read medical textbooks but could find little information on DI.
They also reported that leaflets given to them by doctors, if describing DI at all, provided only very limited information. In addition, doctors were reported to neglect any discussion concerning the psychosocial issues related to DI. Respondents, on the other hand, wished to discuss their management of information sharing, fantasies they had about the semen provider, and wanted information about peer support. Many respondents felt frustrated and humiliated when they raised these needs. Doctors were reported to make arrogant or sarcastic remarks, and respondents consequently adjusted and lowered their expectations in order to avoid further frustration.

This illustrates the fact that respondents had many psychosocial issues they needed to discuss, and that doctors operating from a biomedical model could not adequately respond to these. The doctors consulted in this study, however, did not seem to acknowledge the psychosocial implications, but preferred to concentrate on the biomedical aspects of DI. This is in contrast to the results of a survey by Thorn and Daniels (2000a) of the medical practice of DI in Germany. In this survey, all doctors reported that they discussed psychological issues with patients and three-quarters stated that they carried out more than one consultation prior to treatment. Most talked to both partners and, in addition, several consulted with the male and female partner individually. However, when these doctors were asked about specific psychosocial issues, a much smaller number indicated that these were discussed with patients: only one-third discussed the implications of DI for the couple, their feelings about the semen provider, and the question of sharing DI information with the child. On the other hand, all but one doctor reported discussing the issue of sharing information about DI. The authors conclude that “there are comprehensive discussions, the nature of which was not ascertained and will be an important focus of future research” (Thorn & Daniels, 2000a, p. 633). This suggests that in addition to the contrasting experiences of respondents in this study, there is little clarity as to the nature of psychosocial issues. It may well be that respondents in this study defined them differently from the doctors in the survey above and the doctors they consulted. In addition, doctors may also define “discussing an issue” differently. In Thorn and Daniels' (2000a) survey, doctors were not asked how much time they spent in discussion. Many respondents in this study, however, reported their frustration about the lack of time available during medical consultations. Doctors may define having a discussion as raising an issue and suggesting that couples find a mutually acceptable way of managing it, whereas patients are likely to expect longer exploration of their concerns. Furthermore, given that Thorn and Daniels are known to be specialists in
the psychosocial area, it is possible that doctors in the survey above provided answers they thought were expected. Another possible explanation is that these doctors may be unwilling to discuss these issues, as this would indicate that they value psychosocial implications of DI or regard them as important. Given that Annas (1980) and Haimes (1993b) suggest that doctors favour secrecy in order to protect their public image, not raising these issues may also serve to fulfil this need.

At the same time, it must be born in mind that medical guidelines (Bundesarztekammer, 1998) do not help to clarify this issue. Current guidelines define neither the content of counselling, nor the qualification of those who carry out counselling. A revision of these guidelines is being debated at the time of writing this thesis. According to these current debates, medical doctors are to carry out initial counselling and to refer couples to counsellors for any subsequent counselling; there are no indications that the content of counselling will be clarified (Kentenich, 2005). It is unlikely that the division between the role of the doctors and the counsellors will clarify the function of counselling. Counselling has been described as “a notoriously imprecise term” (Blyth, 1995b, p. 43), therefore the risk is high that such a division will not promote a biopsychosocial understanding, but continue to divide biomedical from psychosocial aspects. The implications of medical guidelines will be discussed in more detail in the section reporting factors located at the macro level (see below).

With regard to sharing information about DI, respondents in this study reported a wide range of recommendations given to them by doctors. Some doctors strongly advised against discussing DI with the child or indicated that “anonymity was the fundamental precondition for the clinic”, and even required respondents to sign a document agreeing that they would not talk about DI treatment to anybody. Others did not discuss this at all, and a third group suggested that they share information about DI with the child at some stage. Also, two couples were advised that parents have a duty to share information about DI with the child. These diverse attitudes were also reflected in Thorn and Daniels’ (2000a) survey of doctors, where 36% of those who reported their attitude regarding information sharing considered this to be the parents’ decision, 21% supported information sharing, and 43% favoured secrecy. Findings from this study suggest that these professional recommendations had little influence on respondents’ attitudes. They “listened … but found [their] own way” and commented that it should not be the doctor who decided “what I am doing and what I am not doing”, indicating that such recommendations were felt to be an
intrusion into their parental autonomy. It is possible that the doctors' lack of willingness and/or time to discuss psychosocial issues, including sharing DI information, resulted in respondents' unwillingness to consider their advice in this psychosocial area. Nevertheless, it has to be born in mind that respondents in this study felt confident with their decision regarding sharing, and contrary medical advice therefore did not change their attitude. It is likely that medical advice does influence those who are uncertain about sharing information, because they may perceive doctors as the experts who cannot and should not be questioned.

As discussed earlier, the lack of information about the semen provider was considered a factor for potentially constraining parents from sharing information about DI with their (future) children. In addition, several male respondents and many female respondents indicated interest in being given non-identifying information about the semen provider. According to current medical legislation and guidelines (see Chapter 3 for a detailed analysis of German policy and practice), doctors in Germany are able to provide both identifiable and non-identifiable information about semen providers, but it is not common for them to do so. Though it is permissible, according to current guidelines, for recipients to select semen providers themselves, this is also exceptional. Respondents in this study did not indicate any interest in selecting the semen provider themselves, and only a few had raised a need for information about the semen provider with their doctor. This is likely to indicate the powerful position medical professionals have. Doctors are the gatekeepers regarding information about the semen provider, and the passive attitude of respondents may be indicative of the powerlessness they feel in this professional setting. Interestingly, there was no indication that respondents challenged this role of doctors. This can be interpreted as individual respect or even trepidation they felt for these medical professionals. Furthermore, there are historic reasons specific to Germany that contribute to this behaviour. Robertson (2004), in an overview comparing legislative development in the United States to that in Germany, suggests that a deep aversion of the use of medical science is likely to have been imbued within German society as a result of the eugenic selection practices of the Nazis. Strunden (personal communication, May 5, 2002), one of the medical pioneers of DI in Germany, reports that doctors feared being associated with these practices and that this fear contributed to the secrecy of DI. Respondents in this study also commented that Germans had a negative attitude towards scientific progress and more moral concerns regarding new development than, for example, Americans. It is also likely that their own negative
feelings associated with selection processes accounted for the hesitance of respondents in selecting a semen provider. However, from a moral point of view, there is little difference between doctors' or recipients' selection of a semen provider; in the end, some selection process takes place. Practices in this respect vary between, as well as within countries. In Canadian clinics, for example, recipients can choose between identifiable and anonymous semen providers (Statutes of Canada, Bill C-6, 2004); in clinics in the United States, recipients themselves can also select the semen provider (Scheib et al., 2004). In these cases, they are given so-called pen-pictures containing information about the semen providers' physical characteristics, as well as professional background and hobbies. This is also common in countries such as Victoria/Australia (Szoke, 2004), where legislation stipulates that semen provider must be identifiable, and in New Zealand, where semen providers have been identifiable for the last ten years (Daniels, 2004b). This suggests that recipients in these countries feel more empowered to demand such information, possibly because there is more emphasis on patients' rights and fewer negative associations with such a selection.

The compounding effect of stigmatisation

The non-supportive attitude of doctors regarding DI treatment suggests that DI services are tolerated but not fully endorsed by the medical professionals participants consulted. It is possible that the strong disapproving position of professional bodies between the 1950s and the 1970s, and the moral concerns in Germany at that time have not been completely overcome by current practitioners, or that they find it difficult to view DI as an acceptable way of building a family. This may be reinforced by the ongoing negative attitude of German religious institutions (Lexikon der Bioethik, 1998; Kundgebung, 1987), as well as the continuing general taboo surrounding DI. In addition, medical practitioners may be hesitant because of the uncertainty and inconclusiveness of legislation in Germany. Though there has been some clarification regarding paternity of the father in those cases where married couples seek DI services, several issues, such as the registration period for medical documents and the offspring's right to identifiable information, remain unclear; the implication of this will be discussed in the next section (which looks at factors located at the macro level). It is likely that these unfavourable cultural and legislative conditions have a negative impact on professional service provision. Daniels and Taylor (1993) suggest that doctors also fear stigmatisation and therefore wish to protect their public image. The
German doctors in Thorn and Daniels’ (2000a) survey indicated a great need to reduce the stigma, and results of this current study suggest that they are likely to be subject to similar fears as those of the respondents themselves. This may explain the reservations of medical professionals regarding sharing information about DI. Respondents also spoke out about their wish for doctors to pro-actively contribute to the alleviation of the stigma. However, currently, there are few indications that doctors contribute to raising public awareness about DI. The chair of the German Medical Association for DI has spoken about DI in German television documentaries about DI (for example: Schieder & Kaiser, 2004) and in February 2005, an AKDI member celebrated the 5th anniversary of his semen bank and organised a one-day information event for medical colleagues (Andreesen, 2005). At the same time, it needs to be born in mind that German legislation forbids medical doctors to publicly advertise their services, which places some restrictions on their public activities.

Doctors who fear stigmatisation, feel uncertain or indicate unwillingness to reveal information, may nonverbally and/or subconsciously convey their negative or hesitant views to patients. This confirms patients’ views that DI is stigmatised. As a result of the power difference, the doctors’ influence will be considerable, and therefore any attempt to alleviate the stigma necessarily requires working with those doctors as partners who will then see the need to change the culture and, more particularly, change the stigma.

By curtailing information and recommending, or even, as one respondent in this study reported, demanding secrecy about DI, doctors are in the position of perpetuating the stigmatisation of DI. If they do so in order to preserve their own social standing, they exercise what social stigmatisation theories describe as coalition exploitation (Kurzban & Leary, 2001). In this case, a dominant group, such as professionals, exert pressure on a subordinate group, such as patients, in order to preserve their public standing. Coalition exploitation is said to result in fear and hatred (Kurzban & Leary, 2001). While respondents did not express feelings of hatred, there were many indications that they did not have the courage and confidence to ask questions or to request more detailed information; this is likely to be attributable to feelings of trepidation. Though this did not result in a change of attitude regarding information management for the respondents of this study, it is likely to increase feelings of uncertainty and insecurity, and undermine the confidence of patients. In those cases where recipients feel less
committed to, or uncertain of, disclosure, this may lead parents not to share DI information with others or with their children.

The significance of contact with other couples pursuing DI

Approximately half of the respondents in this study had not only shared male infertility, but had also shared their use of DI with others experiencing infertility and/or pursuing DI. Sharing with peers was described as helpful and supportive. Respondents did not indicate any hesitations in disclosing their impaired fertility and the use of DI, but commented that peer contact fulfilled their need for information and support. In contrast to sharing male infertility and DI with significant others, there was little difference between men and women with regard to sharing with peers. Both appreciated the normalising effect of peer contact.

Those respondents who had been able to meet parents who had used DI and their children, for example while attending a meeting of IDI, the German patient organisation, described this contact as especially supportive. As all IDI members openly acknowledge their use of DI, exposure to this group reinforced respondents’ decisions to disclose their use of DI to their own friends and family. Though in most cases, contact with IDI was initiated by female respondents, again, men indicated that they were as appreciative of this support as their partners. Several men and women believed that it was important for couples considering family building by DI to participate in such groups. They felt that such support was easier to accept from others struggling with similar issues than from professionals, as the experiences of peers were based on real-life rather than theoretical knowledge.

The importance of peer contact was also highlighted by those who had not yet had the opportunity to meet others. During the interviews, several of these couples expressed the desire to be put in contact with other participants. As described in Chapter 7, in one case, two participating couples had established contact before the interviews were completed; in another case, the couple had planned to meet other respondents in their geographical area. Others had planned to attend a preparation seminar, organised by myself, hoping that they “may learn new attitudes … and meet couples in the same situation”.
Decreasing social stigmatisation by seeking peer support

Both writers concerned with social stigmatisation (Ablon, 2002; Corrigan & Penn, 1999; Hebl et al., 2000; Miller & Major, 2000) and individuals experiencing stigmatisation as a result of DI (Franz & Allen, 2001; Lorbach, 1997) confirm that contact with those affected by the same stigma can help to alleviate the difficulties associated with the stigmatising condition. Miller and Major (2000) suggest that peer contact can enhance self-image and general confidence, as well as validate beliefs and attitudes, the latter of which, according to clinical experience, is often referred to as “the normalising effect” of peer contact. In addition, it can provide emotional support (Miller & Major, 2000). As described earlier, however, concealable stigmata are less likely to be disclosed (Miller & Major, 2000), and therefore individuals may experience ambivalence regarding their need for social support and their desire not to reveal their stigmatising condition.

Respondents in this study unanimously valued peer contact. Those who had established contact to others who had considered or used DI realised that they struggled with similar issues, were confronted with comparable questions, and affected by similar emotional reactions. As one male said, this contact resulted in him not feeling like “an exotic ... or an incomplete person”. Others said they felt that they were “not alone” and that they had received “a great wave of support and sympathy”. Clearly, this improved their self-image, validated beliefs, and provided the support they so urgently required. At the same time, not all respondents had established peer contact. In contrast to Miller and Major’s (2000) postulation, there were no indications that this group refrained from contact because of their anxiety about disclosing male infertility or their use of DI. It is possible that this is an important factor for others who feel less confident about DI. Respondents in this study, however, had not established contact because they found it difficult to gain access to others pursuing this way of building a family. They did not know anybody else in the same situation, were not provided with any information by the professionals they had contacted, and did not know how to go about finding others. As previously mentioned, several respondents participated in this study hoping that this would be a vehicle for establishing contact with others.

In addition to the emotional and instrumental support peer contact provides, results of this study indicate a further essential motivation for contacting others in the same situation. Those respondents who had contact with parents who had used DI valued their experience in information sharing, those who did not
have such contact agreed that being exposed to parents who had used DI would be helpful for them. These parents were considered to be “one step further on” and to serve as role models for sharing DI information with children. Respondents explained that they observed interaction between these parents and their children, listened to stories and narratives for information sharing and learnt about their experiences of disclosing DI. Though most respondents intended to share information about DI with their children, this was a theoretical consideration not yet put into practice, either because treatment had not yet been successful, or because of the young age of their children. Role models helped them to consider strategies for information sharing and thus made this more tangible.

Some respondents in this study not only reflected on their own needs, but commented on their (future) children’s needs. They were aware that as a result of their DI origin the children might also feel stigmatised and perceive DI to be a difficult issue. Therefore, they spoke out for them having the possibility of contacting others conceived with the help of DI. Hence, establishing peer contact was also considered helpful with regard to the anticipated needs of the children. Similarly to their own experience, they expected this to be a normalising experience for the children. There is currently no research available on this issue, but consumer groups in several parts of the world have started to organise meetings and conferences, and increasingly, teenagers and adults conceived by DI are using these to establish contact with each other (see for example: Franz & Allen, 2001; Lorbach, 1997).

Psychosocial professionals

Sixteen couples in this study sought counselling; six couples were required to undergo pre-treatment counselling, ten had consulted a counsellor independently of medical recommendations. The other seven couples did not see a counsellor. There is currently no knowledge available in Germany about the number of infertile couples seeking counselling. In Thorn and Daniels’ (2000a) survey, in line with medical recommendations (Berufsordnung, 1998), over half of the doctors recommended counselling. Couples in this current study were recruited from across Germany, thus the doctors they had sought consultation from were located in different parts of the country. According to the proportion of doctors in Thorn and Daniels’ (2000a) survey, a similar number, approximately 50% of respondents in this study, would have reported that they were recommended to consult a counsellor. However, apart from the six who were
required to see a counsellor, no further respondents reported that doctors had recommended counselling. It is unlikely that, relatively speaking, as many couples pursuing DI in Germany consult a counsellor as those in this study. It is more likely that this high uptake of counselling reflects the special composition of the respondents taking part in this research, and, more specifically, that they were interested in and willing to explore psychosocial issues. Their confidence about the use of DI and intention to share this with the child also suggests that they were less concerned about the general stigma surrounding DI.

The provision of counselling for family building by DI

Those respondents who were required to undergo pre-treatment counselling were initially hesitant, as they had not expected this. Some feared that the counsellors were expected to carry out an assessment, which could result in their not being acceptable for treatment; others perceived this to be a bureaucratic hurdle to overcome in order to have a child. Despite these criticisms, all respondents, both male and female, retrospectively appreciated the opportunity to have counselling. Most profited from exploring their motivations and especially appreciated the narratives and stories these counsellors provided for sharing information about DI with children. Though all of these respondents had already decided that they would share DI information, by the time they consulted a counsellor, they not only felt supported in their decision to share DI, but the narratives the counsellors provided made it more meaningful for them and this also reinforced their decision. At the same time, several respondents resented the fact that counselling was required, and they would have preferred to make their own decision for or against counselling. In addition, for several respondents, the motivation of doctors requiring this counselling remained unclear. All of the counsellors were perceived to have a positive view of DI. However, one couple felt that the counsellor fulfilled the needs of the clinic by only selecting couples for their parental suitability, and commented that their own needs for information and in-depth exploration of DI issues were not fulfilled.

The experiences of those respondents who consulted counsellors of their own accord were more varied. Though most of the counsellors viewed DI positively, it was often the respondents themselves who had to raise psychosocial issues related to infertility or DI. Respondents complained that most of these counsellors lacked knowledge in this area and were unable to provide information either about DI treatment possibilities or about information sharing in DI. Some of these counsellors directly or indirectly
suggested keeping DI a secret, others did not raise this matter at all. One couple consulted several psychologists who discouraged them from using DI, explaining that family building with the assistance of DI would be detrimental to the welfare of the child and the family. Only one of the counsellors in this group supported disclosure; none explored strategies for sharing information with children. As a result, respondents were frustrated with the quality of counselling they received. As with the views of doctors, the views of these counsellors did not change respondents' attitudes regarding their planned management of information sharing.

Interestingly, even those respondents who had not taken up counselling indicated a need for it. Though not all explicitly expressed this need, several asked questions during the interviews and accessed my knowledge. These questions referred to sharing DI with children, experiences of adult offspring or families built by DI. Others commented that they took part in this study in the hope that they would have the opportunity to explore their own attitudes once more with a specialist in this area.

Writers point out that couples using DI are likely to have a specific need for counselling (for example: Blood, 2004; Mahlstedt & Greenfeld, 1989; Thorn & Daniels, 2003; Zoldbrod & Covington, 1999). The following issues are considered essential in counselling:

- Managing the emotional repercussions of the medical diagnosis for the male and the female partner;
- Grieving the loss of a child genetically related to both parents;
- Understanding medical and social options;
- Understanding the legislative framework of DI and the right of offspring to access information in those countries where this is the case;
- Exploring the implications of DI, such as the readiness of both partners, and managing information sharing with the child and significant others.

In several countries, such as Canada and Victoria/Australia, pre-treatment counselling is compulsory for every couple; in others, it is offered, but couples are not forced to take it up (see Chapter 4, pages 77-85, for the provision of legislation regarding counselling). Pre-treatment counselling as required in some
countries has not been universally endorsed. Some couples may perceive this, as noted earlier, as an assessment for parental suitability or an unjustified intrusion into their relationship, and therefore they are reluctant to take part in it. Counsellors argue that these perceptions and attitudes may compromise any therapeutic work (Blood, 2004; Daniels, 2002). Such reservations were also expressed by respondents in this study. However, retrospectively, all appreciated the opportunity to explore the psychosocial implications with a specialist, and there were no indications that respondents were less open in counselling. The only criticism from one couple was the fact that the counsellor did not explore the issues they considered relevant, but seemed to raise topics only of relevance for the clinic.

There is no data available as to the level of the uptake of pre-treatment counselling in those countries where it is voluntary. The only figures available are those of people in the general population who are experiencing infertility. In a British survey examining over 900 individuals suffering from infertility, Kerr et al. (1999) report that approximately 71% of respondents felt they would benefit from counselling, but only approximately one-third had already received counselling. As "couples suffered from extreme emotional feelings", the authors argue for legislation to be more prescriptive and insist that all clinics should provide free counselling for all (Kerr et al., 1999, p. 937). On the other hand, Boivin et al. (1999) found that less than 20% of the 143 infertility patients they interviewed considered themselves sufficiently distressed to seek counselling, with those indicating high distress more likely to use this service. Interpreting these results positively, they conclude that those unlikely to use counselling might have an adequate support system. Interpreting these results negatively, they suggest that not all patients would have known how to obtain counselling and, as in Kerr et al.'s (1999) study, may have been deterred by the potential costs. This suggests that counselling should be more readily available for all of those affected by infertility. As those considering DI face additional issues, as described above, there is emerging consensus that pre-treatment counselling should be carried out (Boivin & Kntenich, 2002; Snowdon & Snowdon, 1997; Zoldbrod & Covington, 1999). Results of this study confirm that this recommendation is justified.

German medical guidelines for infertility recommend counselling prior to any AHR treatment (Bundesarztekammer, 1998) but this is not required in the current legislation (ESchG, 1990). There is no data available as to the number of couples consulting a counsellor prior to DI treatment. Clinical
experience indicates that only two of approximately 40 doctors offering DI services require pre-treatment counselling. Only a few couples undergoing treatment with other clinics seek counselling; clinical experience, however, suggests that this number is rising. As infertility has only recently become a specialised field in counselling in Germany (see Chapter 3, pages 54, for the provision of counselling in Germany), counsellors experienced in family building by DI are rare. Discussions during the annual meeting of the German infertility counselling organisation, BKiD, suggests that in addition to myself there are only two other counsellors specialising in this area. Literature dedicated to infertility counselling (Stammer et al., 2004) and counselling for DI (Thorn, 2000b) is just as rare. This indicates a need for more counsellors competent in counselling for DI. It also confirms the need for a biopsychosocial approach in family building by DI. A closer collaboration between medical and psychosocial professionals is required so that doctors are more appreciative of the psychosocial implications of DI and more supportive of counselling.

Until recently, there was no agreement as to whether counsellors should encourage information sharing or whether their advice should be neutral. Whereas Zoldbrod and Covington (1999, p. 332), arguing from an American perspective, recommend that counsellors should “maintain a neutral position in order to ensure client self-determination”, Blood (1998), arguing from an Australian perspective, recommends that couples should be informed of the children’s right to access information about their biological origins. Such diverging positions reflect the social, cultural and legislative framework and, potentially, the degree of acceptance of DI. As will be discussed in the section analysing macro-level factors, it is likely that DI is less stigmatised in those countries with a comprehensive legal framework, which in turn is likely to make information sharing more acceptable. In 2004, the American Society for Reproductive Medicine recommended that parents should be encouraged to disclose their use of DI to their children (ASRM, 2004), and psychosocial specialists are increasingly giving this advice (for example: Blyth et al., 1998; Daniels, 2004b; Daniels & Thorn, 2001; Pettie, 2002). The German organisation, BKiD, has not yet issued formal recommendations for this aspect of DI, but during the last annual meeting in March 2005, members agreed that pre-treatment counselling should be mandatory and cover similar issues to those described in other countries. The subcommittee (of which the author is a member) is currently working on these recommendations.
Several studies indicate that individual and couple counselling can impact on parental management decisions and may result in an increase of parents favouring information sharing. Gottlieb et al. (2000) investigated couples that had treatment in Swedish clinics. All of these had seen a counsellor who actively promoted information sharing. Fifty-two percent of these parents had informed, or intended to inform, their children about their use of DI. Nevertheless, the authors critically commented that though the response rate to this study of 80% was high, “[t]here are reasons to believe that the incidence of telling the child about DI is higher in the group that completed the questionnaires” (Gottlieb et al., 2000, p. 2054). This suggests that the actual number of parents who had disclosed DI or intended to do so was less than 50%. Rumball and Adair (1999) investigated 181 New Zealand parents who had used DI. Again, all had seen a counsellor. Thirty percent of these parents had already shared DI with their children, and a further 54% intended to do so at a later stage, amounting to a total of 84% who favoured information sharing. In comparison to other studies (Brewaeys, 2001; Golombok et al., 2002), these are relatively high numbers, but it must be born in mind that Swedish legislation allows offspring to identify the semen provider, and that New Zealand culture has resulted in a higher degree of acceptance of family building by DI and is also supportive of information sharing. Furthermore, there is no knowledge available of parental attitudes prior to counselling. It may well be that a high number of respondents in both studies already favoured disclosure prior to consulting a counsellor. Currently, there is no knowledge available if or how peer contact by itself impacts on parental attitudes. Thorn and Daniels (2003) reported on group programmes carried out in Germany. These programmes were organised and facilitated by psychosocial professionals, included medical and legal professionals who presented information about their areas of expertise, provided time for establishing contact with others in the same situation and for discussing psychosocial issues such as information sharing. In addition, these programmes provided a role model by including a couple who shared their experience of having children conceived by DI. As a result of attending these programmes, over 90% of participants intended to disclose their use of DI to their offspring. This is a very large number of couples intending to share DI information, especially if the fact that these programmes were carried out in Germany is taken into account, as legislation is confusing, public acceptance of DI is low, and doctors attitudes regarding information sharing reserved. However, approximately 50% of these participants had already felt if not a lot of, then certainly considerable confidence about information sharing prior to attending the group programme (Daniels et al., 2005). The rate of parents who favoured information sharing prior to consulting a counsellor may be similarly high in
the two studies cited above, which suggests that the impact of counselling is less striking than assumed. Furthermore, all three research projects only included respondents who volunteered to participate, which, according to Gottlieb et al. (2000), is likely to attract those favouring disclosure. As most respondents had also favoured information sharing prior to consulting a counsellor, this study does not contribute to any new knowledge in this respect. However, it does point out that the availability of information and guidance literature can be important tools for parents, make information sharing for parents easier and increase the likelihood that the intention to share is put into practice. Though the number of such guidance booklets has increased over the last years, this material is currently only available in English (Bourne, 2002; Donor Conception Network, 1991; Gordon, 1992; McWhinnie, 1996; Paul, 1988; Schaffer, 1988; Schnitter, 1995; Wickham, 1992). There is a need to develop such resources in German and other languages.

In addition to criticising the lack of qualified counselling services, almost all respondents wanted literature written for them as future parents outlining strategies for sharing DI information with their children. The only German literature currently available is the author’s publication (Thorn, 1997). Those respondents who had read this publication felt encouraged to share DI information with their children, and some couples recalled that this was indeed the first time they discussed disclosing their use of DI to their (future) child. Both in Australia (Bourne, 2002) and Great Britain (Donor Conception Network, 1991; Wickham, 1992) counsellors have written booklets parents can use for sharing information about gamete donation with their children. Results suggest that this is an additional area where psychosocial specialists can develop resources to facilitate information sharing.

Clinical experience suggests that a further factor may also be important. Consulting a counsellor or psychotherapist is often associated with admitting a psychopathology and is therefore perceived to be stigmatising. This factor may be more relevant in Germany than in countries such as the United States, Great Britain or Australia, where not only is it more common to take advantage of this service, but where infertility counselling has a longer tradition and is more readily available. This raises the question of how psychosocial services can be delivered so that recipients are encouraged to take advantage of them. It is possible that a service defined as “psychosocial information about family building by DI” is accessed by more couples than a service called “counselling” or “therapy”. It is also likely that the emphasis on
“information” makes it more amenable for men to access this service. Furthermore, results point out that a group programme is preferable to individual or couple counselling and, as analysis reveals, is likely to reduce the stigmatising effect of DI. The educational group programme facilitated by a psychosocial perspective, as described by Thorn and Daniels (2003), seems best suited to fulfil the various needs of recipients. The focus on information and education minimises the negative connotations of a professional counselling service. It implies that those intending to use DI to build their family do not suffer from a psychopathology, but can profit from information and discussions in order to understand the differences entailed in this family type. This seems especially valid given that Boivin et al. (1999) found that counselling with the focus on resolving distress is only required by 15–20% of couples suffering from infertility. Such a group programme has further advantages. Participants can establish contact with others pursuing DI and the inclusion of medical and legal professionals can foster collaboration between psychosocial and other experts and thus promote a biopsychosocial perspective in this area.

Finally, results suggest that the issue of information sharing should be tackled prior to medical treatment. Medical treatment has been described as an “emotional roller-coaster” (Menning, 1980). This term is used to highlight the probing emotional aspects, such as the hope experienced at the beginning of treatment, the waiting period after the insemination has taken place, and the sadness and depressive reactions if treatment has failed. Those respondents who lacked confidence about DI were less likely to share their use of DI during medical treatment. They voiced the need for support and understanding during this stressful time and did not seem to have the emotional capacity to address information sharing at this time. This suggests that once DI treatment has begun, social support for this treatment, as well as empathy for the decision to use DI, is vital. Exploration of readiness to pursue DI and attitudes regarding information sharing should be completed prior to medical treatment.

**Parallels between adoption and DI**

A further group of psychosocial professionals had an important impact on respondents’ decision regarding information management. In this study, many couples had considered adoption. Some had applied to adopt a child with a relevant agency in Germany; others had discussed this option with friends and family members and/or read literature on the topic. Results show that learning about the needs of
adopted children and discussions with adoptive parents who have shared the biological origin with their child encouraged them to disclose DI. Those who participated in preparation seminars for adoption recalled that they were advised to share information about the conception of their adopted children with them as early as possible. This group, though they acknowledged differences between adoption and DI, considered the needs of adopted children and those conceived by DI regarding access to information about their biological origin to be very similar, therefore transferred recommendations from the area of adoption to family building by DI and thus favoured disclosure.

Social scientists, especially adoption researchers, have argued for many years that parallels can be drawn between adoption and DI. As early as 1977, Brandon and Warner, both social workers, argued for taking into account the welfare and interests of children conceived by DI and for medical services to include a psychosocial assessment of those seeking DI. They explained that the "newness of the technique, [and] the social reservations surrounding it" contributed to the lack of relating experiences in the area of adoption to DI (Brandon & Warner, 1977, p. 338). In fact, Triseliotis (1993), a British adoption researcher, describes the secrecy surrounding DI as a *déjà-vu* experience for those familiar with the legislative history of adoption. From a sociological perspective, Haimes (1988) also claims that the similarity between the features of adoption families and those built by DI make comparisons between the two valid. She gives a detailed analysis of the similarities and differences between adoption and DI, pointing out that there are structural parallels, such as the involvement of social parenting, that lead to similar issues in both family types. According to Haimes, the reserved societal attitude towards both family types has played a significant role in the debate about information sharing and has contributed to the stigmatisation of both. In her view, adoption has become increasingly acceptable but DI remains ostracised. Similarly to Brandon and Warner (1977), she points out that adoption is located within the welfare system for which social service providers with a psychosocial perspective are responsible, while DI is located in the medical arena and carried out by doctors with a predominantly biomedical focus. Haimes (1988, p. 48) adds that the unequal power between these two professions results in further disparities: "[W]hatever is decided by the medical profession as being appropriate to their procedures carries much more weight than that of social workers in adoption". More recently, adults who were conceived by DI have also drawn similarities between adoption and DI. Cordray (1999/2000), for example, sees similarities between the plea of adopted children and his own plea to have access to their
biological origin, and consequently, refers to himself as a “DI-adoptee”. On many occasions, adults conceived by DI have spoken out for being granted similar rights as adopted people with regard to this right (see for example: Franz & Allen, 2001; Lorbach, 1997). Throughout the last 20 years, social scientists and psychosocial professionals have continued to stress the similarities between adoption and DI and argue for lifting the secrecy in DI (see for example: Blyth, 1999; Daniels & Taylor, 1993; Triseliotis, 1993; Wiemann, 2001), whereas medical professionals and medical associations, until recently, supported the difference between adoption and DI, secrecy in DI and donor anonymity (IFFS, 2001; Shenfield, 1994). As described in the previous section, change is occurring and some medical associations, such as the American Society for Reproductive Medicine (ASRM, 2004), now endorse information sharing.

Although respondents of this study intuitively compared adopted children to those conceived by DI, they argued that it was much easier to share information about their biological origins with adopted children. This was not only because of the greater social acceptance for, and open acknowledgement of, this family type, but also because there is a multitude of books both for children and parents on information sharing after adoption. This may be a further indication that the stigma of DI is greater than the stigma of adoption, and highlights once more the need for guidance books and resource materials. Also, they confirmed that adoption was more difficult to keep a secret than DI: the latter lends itself to secrecy because the woman becomes pregnant and gives birth to the child. This argument is also brought forward by Daniels and Taylor (1993, p. 158), who explain that the ease of disguising DI “helps to support the pretence that the conception, and therefore the family, is ‘normal’”. Furthermore, respondents argued that access to adoption records was much easier than access to the medical records after DI treatment, as in Germany, adoption documents have to be stored for 60 years and offspring are entitled to access these when they reach the age of 16 years (Adoptionsvermittlungsgesetz, 2002).

One final aspect regarding respondents’ experiences with adoption was their enthusiastic endorsement of preparation seminars in Germany. Those who had attended such seminars for adoption spoke out for offering similar seminars for couples considering or planning to use DI, reinforcing the importance of group programmes for DI.
Summary

As a result of the qualitative design, this study, in contrast to others, indicated that men had similarly strong emotional reactions to infertility as women. Analysing interaction patterns, however, this study revealed that men differed in their behavioural reactions. This study confirmed that male infertility is a stigmatising condition, but despite this, most female and some male respondents shared their experiences with significant others. Interestingly, men appreciated sharing with other men suffering from infertility, as much as women appreciated sharing with other women in similar circumstances, potentially because in these cases, they did not have to fear stigmatisation. This study also confirmed previous hypotheses that medical treatment, for example, can impact on affective reactions (Daniluk, 1997). Those men who had suffered from cancer and undergone invasive treatment reported higher sensitivity and a higher level of distress related to their disease and subsequent treatment than to the need to use DI.

As a result of the stigmatising nature of DI not many respondents discussed their use of DI with others, with even fewer males than females doing so. Given that paternity following DI was perceived to be less certain than maternity, this is understandable. However, this also raises the question of whether fathers are more reserved about information sharing with their children than mothers. This issue has received little attention. Many writers have assumed that sharing about DI with children is a mutual parental decision, although evidence suggests that this is not the case. Both for research and counselling, it will be important to be aware of gender differences regarding information sharing. Furthermore, the stigma perceived by respondents themselves seemed to be confirmed and even augmented by the way doctors offered their DI services. Given that many conveyed hesitant views about DI, respondents were subject to double stigmatisation: their own, as well as that conveyed by the behaviour of doctors.

Writers on stigma contend that social stigmatisation can result in a self-fulfilling prophecy, whereby the stigmatised keep their condition a secret in order to avoid stigmatisation. At the same time, they non-verbally convey uncertainty and anxiety. The non-stigmatised often hold erroneous beliefs about a stigma and are also anxious. This study confirmed that such prophecies operate in the area of DI. Those respondents who shared information about DI did not experience any negative reactions, and both they and the non-stigmatised they shared with were able to adjust their views as a result of this mixed interaction. Those who did not disclose their use of DI were unable to adjust their views.
Family building by DI is often considered a medical issue. Male infertility can be circumvented by using the semen of another man, and if this treatment is successful, the couple's desire for a child is fulfilled. Such a biomedical focus has been criticised as ignoring the psychosocial implications of DI. In this study, doctors were believed to hold a biomedical view when offering DI services while respondents voiced a need for a biopsychosocial perspective in family building by DI. This not only includes exploring the meaning of the different parental status after DI, but also understanding the role of the semen provider and finding an appropriate way to manage information sharing with the child and significant others, such as the extended family. In addition, there was a need to have at least limited information about the semen provider to pass on to children. Respondents raised concerns about talking to children if they could not access even non-identifiable information. The lack of information is a deterrent factor in information sharing.

It has been argued that contact with others experiencing the same stigma can help to reduce the impact of stigma. Such contact can validate beliefs and provide emotional and instrumental support. Results of this study confirm these arguments and indicate that such contact is perceived to be more valuable than exploring the implications of DI in a professional setting with a counsellor. Furthermore, respondents also raised the need for their (future) children to establish contact with other children conceived by DI so that they can benefit from the same support.

This study also indicates a need for exploring the psychosocial implications of DI prior to treatment. Although only a few respondents underwent compulsory pre-treatment counselling, many consulted a counsellor of their own accord. A large number of those who did not have any counselling voiced a need for this, and in fact, several participated in this study in the hope that this would provide an opportunity to discuss their motivation for pursuing DI and to learn about the implications. This confirms the views of psychosocial professionals who support pre-treatment counselling. However, there has been little agreement as to whether such counselling should be mandatory or voluntary. Although respondents of this study had initial reservations about counselling when it was required by doctors, in retrospect, they unanimously agreed that this was helpful. This suggests that mandatory counselling can be helpful and is appreciated. Furthermore, mandatory counselling has the advantage in that it reaches out to everybody.
This aspect is especially important in family building by DI, as individuals and couples using DI face building a family type for which current understanding is limited.

There is increasing agreement amongst counsellors that they should encourage information sharing by couples undertaking DI. Respondents of this study supported this development. They appreciated information and guidance on how to talk to their children about family building by DI and this seemed to affirm their decision and to make it more manageable. Information and guidance literature, although more extensive than previously, is still sparse. This study indicates that there is a great need to develop such literature for families in Germany and in other countries where this is not available. Furthermore, this study also points out that an educational group programme is likely to better fulfil the needs of recipients as it not only provides information and explores the psychosocial implications, but also enables participants to meet others and share their experiences. This is likely to further destigmatise family building by DI.

Factors located at the macro level

Respondents in this study unanimously agreed that family building with the assistance of DI was an issue of considerable misunderstanding and stigma. Respondents' comments provide many examples of stigma located at the macro level. These included the sentiment that DI was a morally questionable activity, and a topic for which it was almost impossible to obtain information or literature. Furthermore, the legal provisions for this family composition were seen to be inadequate and discouraging. Social policy issues, such as the lack of financial reimbursement for medical treatment, were further felt to discriminate and disadvantage those using DI to build their families.

Social attitudes contributing to the experience of stigmatisation

As described in the previous section, respondents did not perceive German society and culture as supportive of family building with the use of DI. In addition to the perception that DI was viewed negatively, respondents pointed out that the public was uninformed and lacked knowledge about DI. In
contrast to other forms of AHR and other family building options, such as adoption, they reported that there was a lack of literature and few reports in the media on DI. This gave the impression that society accepted DI only if it was carried out under a veil of secrecy. Although some respondents assumed that not everybody had such negative attitudes, many felt it was a polarising issue. This was especially so for the older generation, which included the respondents’ parents who were believed to view family building using DI with scepticism. Several respondents made comparisons between the German attitude regarding scientific progress and attitudes in other countries, describing German views in this respect as conservative. Some female respondents also voiced the fear that others may associate DI with an extra-marital relationship, or assume that it was a solution for lesbian couples only. In addition, the public image of semen providers was also perceived to be negative. Respondents believed that the public was unaware of the careful medical screening carried out by doctors before accepting a semen provider.

The fears voiced by respondents bear a similarity to those expressed in Germany in the 1950s, when DI was rejected for moral reasons (Brähler & Meyhöfer, 1986; Fromm, 1959; Krause, 1985; Strunden, personal communication, May 5, 2002; Wille, 1985), those voiced prior to the introduction of the ESchG (Starck, 1986), and again to those in 2000 when a new bill on reproductive medicine was discussed which was to supplement or replace the current ESchG (Bundesministerium, 2001). Critics of DI repeated the fears voiced in the 1950s when they argued that DI compromised the welfare of the child (Baumann-Hölzle, 2001), promoted eugenic thinking (Derleder, 2001), or that procreations should be linked with natural and biological ability only (Miet, 2001). Although more recently, medical (Günther & Fritzsche, 2000; Katzorke, 2001; Nieschlag, 2001), legal (Coester-Waltjen, 2001; Zumstein, 2001) and psychosocial (Thorn & Daniels, 2000a; Thorn, 2001) professionals have argued for regulating family building by DI and thus, implicitly, for more acceptance, it seems as if the general culture surrounding this option has changed little between the middle of last century and today. In contrast to other AHR treatments, there have been very few media reports about DI (Hellmund & Rohde, 1998), and guidance literature for couples experiencing infertility often does not mention DI (Strowitzki, 1998; Winkler, 1994), though some publications dedicate short chapters to it (Köhle, 1997; Schlagheck, 1989; Teut, 2002; Wischmann & Stammer, 2004) others comment negatively (Fechting, 1997). This suggests that the stigma associated with DI and, in part, infertility, remains strong.
Social stigmatisation theorists have suggested different strategies to alleviate stigmatisation. Some have suggested that appropriate strategies must be matched to different levels, for example, individual and couple confidence building at the micro level (Miller & Major, 2000), joining a support group to provide emotional support at the meso level (Ablon, 2002; Corrigan & Penn, 1999; Hebl et al., 2000; Miller & Major, 2000) or exerting political pressure and influence (Miller & Major, 2000) to educate the public and change social policy (Ablon, 2002; Corrigan & Penn, 1999) at the macro level. Others contend that interventions aiming at one level only are likely to fail, as their effectiveness is undermined by lack of change at other levels (Link & Phelan, 2001). The arguments of professionals in favour of DI could be viewed as a strategy to educate and foster policy change in the area of DI. Results of this study suggest that this strategy has not succeeded in reducing the general stigma surrounding DI. The only legal change to occur in the last 50 years was the introduction of the Children’s Rights Improvement Act in 2002. This act provided some certainty for paternity following DI; however, it only protects parties in those cases where the parents are heterosexual and married and even for this group, legal writers do not agree as to whether there is full protection for paternity for the mother’s partner and therefore the child’s father (see Chapter 3, pages 49-51, for a detailed analysis of paternity following DI). It is possible that the general culture has been so unfavourable that these voices have not been sufficient or sufficiently strong to foster change in this climate, thus confirming Link and Phelan’s (2001) contention that a multi-level approach is required to achieve fundamental change.

Writers have also pointed out that self-help or pressure groups can contribute to, or even alleviate, stigma at the macro level (Ablon, 2002; Corrigan & Penn, 1999; Hebl et al., 2000; Miller & Major, 2000). Such groups can strive to gain political influence or engage in public and community education. These actions are likely to change public perceptions and beliefs. Miller and Major (2000), however, note that they are relatively rare and assume that such collective actions are met with resistance from the non-stigmatised because they threaten their control over power and resources. In the current study, several respondents had attended a meeting of IDI, but had not raised the expectation that this group should attempt to influence the public image of DI or exert political pressure. Nevertheless, organisations in other countries engage in such activities. The Australian Donor Conception Support Group, the British Donor Conception Network and the Canadian Infertility Network, for example, have not only carried out public conferences on family building with the assistance of DI (as well as other types of gamete donation), but
have published proceedings of such conferences (Franz & Allen, 2001; Lorbach, 1997), developed written and video educational material, and sought to influence proposed legislation. Such developments in other countries indicate that collective actions do occur in the area of family building by DI. The lack of a similar development in Germany may be explained by several factors. Comparing IDI to groups with similar aims in other countries suggests that such organisations are likely to go through a process of development, the stages of which have different foci. In the initial stage, group work is likely to concentrate on the direct and internal needs of group members. These include the provision of emotional support and opportunities to share experiences and information within the group. Once these needs are met for some key members, the focus is likely to shift to a concern for the larger social issues that impact on the members. IDI is currently developing educational material both for group members and for others (Lüno, personal communication, January 15, 2005), suggesting that this organisation is moving from focussing on internal issues to exploring external issues, such as providing public education. Exerting political pressure and influence is only likely once some members in the group have moved beyond these initial stages. Groups need to foster sufficient confidence for members to have the strength and courage to present their interests in the public arena and to enter public debates. The fact that few members speak out in public or are willing to be interviewed by the media suggests that this is not (yet) the case for IDI. Furthermore, the fact that most respondents in this study did not even know about IDI indicates that this group has not yet moved into the public or social arena. The on-going public efforts of organisations in other countries indicate that they view this as an important tool to educate the public and to contribute towards the destigmatisation of DI. The challenge for such patient organisations or pressure groups is to simultaneously provide information, education and advocacy, as individual members will, of course, have different needs or be wanting to focus on different activities.

Respondents in this study offered several suggestions for bringing about change. Though they did not explicitly explain that such a multi-level approach was necessary, their strategies were clearly located at several levels. As described in the results (see Chapter 7), some had sought counselling in order to increase their own confidence in the use of DI. Some had also sought contact with others or intended to do so in order to validate their experiences. Several had discussed DI with family members and friends, thus attempting to inform those whose knowledge was limited. Almost all respondents spoke out for more general information, literature and especially more media awareness, explaining that “the public must
learn about family building with the assistance of DI. Some were aware that they could contribute to public awareness about DI themselves by taking part in television or radio discussions. However, this latter aspect seemed to be very challenging as respondents voiced considerable fear about the impact this would have on how others viewed them. Several argued that doctors should promote DI in public, maybe assuming that these professionals had both more courage and prestige and their views would therefore have a greater impact. As described earlier, however, few of these professionals do this and those who have taken on this task seemed to have minimal impact or success.

Nevertheless, it seems important to continue to develop and provide public education, and above all, to promote change in other areas as well. Further interventions required on the macro level include an appropriate legislative framework and non-discriminatory social policy.

Uncertainties resulting from an insufficient legislative framework

Results of this study indicate that once respondents had embarked upon treatment, most were aware that DI was legally permissible in Germany. However, many had felt uncertain about the legal status of DI prior to commencing treatment, with several fearing DI was an illegal activity. In fact, one respondent had been informed by a doctor that this was the case and DI was illegal. Other respondents had compared it to the illegal practice of pregnancy termination in the 1970s for which women had to travel abroad. Furthermore, medical information leaflets respondents read after having started treatment gave the impression that DI could be carried out only under exceptional circumstances. Most respondents had consulted a lawyer or a public notary in order to sign a contract between themselves and their doctor; this group was under the impression that even some of these legal experts had little knowledge about DI and its legal implications.

As in other countries, DI was a questionable exercise for many decades in Germany. In the 1950s, several medical societies spoke out against the use of DI (Fromm, 1959), and it was planned to include the use of DI in penal law (Wille, 1985). Doctors who offered DI services ran the risk of being expelled from their professional body and therefore recommended secrecy to their patients. In 1970, the German Medical Chamber only reluctantly accepted DI as a form of treatment for infertility, but did not endorse it
officially (Deutsches Ärzteblatt, 1970). This non-accepting attitude from doctors changed only slowly. Despite detailed recommendations for a legal framework for DI by the former Minister of Justice (Däubler-Gmelin, 1986), these were not implemented when the ESchG, legislation regulating AHR was introduced in 1990. Ambivalence regarding the legal endorsement of DI was voiced again in 2000 during the discussion of new AHR legislation, when some writers argued for acceptance and legal clarification while others supported banning DI (Bundesministerium, 2001). It may be that Fromm’s (1959) fears voiced at the end of the 1950s continued to play an influential role. Fromm felt that the introduction of legislation would be seen as endorsing family building with the assistance of DI. The lack of a legislative framework for DI results in uncertainties for all the actors involved, but particularly professionals, patients and semen providers. It may also convey to some that this way of creating a family is not acceptable. Debates regarding new legislation were discontinued in 2001 when the Minister of Health withdrew. Currently, there is no indication that legislation in Germany will be revised.

Arguing from an international perspective, Blank (1990) suggests that insufficient legal protection for the semen provider renders DI more problematic. It may be that the lack of legal protection for everybody involved results in family building with the use of DI becoming more complicated. The majority of respondents in this study believed that there was a lack of legal endorsement of, and a regulatory framework for, DI, and it may be concluded that this is another example of the stigma associated with family building by DI. Many respondents reported that doctors and legal experts provided contradictory information about the legal position regarding DI. As argued earlier, it is likely that the non-supportive attitudes of doctors, as reported by respondents, may have resulted from doctors experiencing legal uncertainty and fearing stigmatisation. The lack of legal clarification and certainty may also have resulted in contradictory messages for the respondents. On the one hand, they had become aware that DI was not illegal. On the other hand, they continued to perceive DI as morally questionable, were unable to find information or literature about the legal provisions and were given inconsistent information by professionals. Evidently, the lack of a legal framework reinforces the impression that DI is morally wrong, and as a result, the taboo and stigma surrounding it are maintained. This lends itself to the interpretation that a comprehensive legislative framework in Germany has been deferred in order to imply ongoing moral reservations and to discourage its use, or that it is too contentious politically or not regarded as a matter of high priority.
Legal issues arising out of the research

An area of major legal uncertainty was that of paternity following DI. Respondents had differing and sometimes contradictory information regarding the rights and responsibilities of the father and the semen provider. As noted earlier, some legal experts advised them to adopt the child in order to ensure full paternity; others informed them that this was unnecessary. Many men expressed uncertainty as to their legal status in relation to the child. They described themselves to be “practically” the father or explained that “if [DI] is successful, it is as if it was my child”, indicating their fear that the legal framework regarding paternity was insufficient and that the semen provider may be in a position to claim paternity rights. Similar doubts were also expressed when respondents discussed the possibility of contesting paternity. Some couples were informed that the male partner could do so within one year of the birth of the child; others were under the impression that they could do so for a much longer time period. In this context, respondents voiced concern for the semen provider, as he “could be responsible for [many] children” if paternity by the father was successfully contested. The lesbian women were one of the few couples who had taken active measures to provide some certainty in relation to the semen provider’s role. They had placed a declaration of intent with a public notary stating that both mothers should enjoy equal rights, and they had also planned to lodge a similar statement with the relevant Department of Youth and Welfare. At the same time, they realised that such a declaration may only have limited value.

The legal situation for respondents in this study was such that paternity could be contested by both parents and the child within two years after cognisance of circumstances which might appear to cast severe doubts on the paternity of the present father. Social fathers had successfully contested paternity in those cases where consent to DI was legally proven invalid or the husband had separated from the mother and a father-child relationship had not been developed (Müller, 1997a). However, consent for using DI was only required by a woman whose oocyte was used for fertilisation and a man whose semen was used (ESchG, 1990). The AKDI requires member doctors to ensure that for couples contemplating using DI both the male and the female partner gave their written consent, probably in order to avoid paternity contestations and the risk of semen providers having to bear alimony, or the risk of doctors themselves having to provide compensation alimony payments should they no longer be able to identify the semen provider (Schilling & Blonski, 1994). This indicates that the legal situation was such that paternity could have been easily contested if the male partner had not consented to DI.
In April 2002, as the interviews for this research began, the *Children's Rights Improvement Act* was introduced. According to this act, heterosexual married couples cannot contest paternity if the male partner has consented to DI; only the child continues to enjoy this right. Nevertheless, legal writers are uncertain whether paternity, even in the case of married heterosexual couples, is certain. Given that offspring continue to enjoy the right to contest paternity, Keiper (2005) suggests that knowledge of the fact that their father is not the genitor may be sufficient to successfully contest his paternity. Roth (2003) argues that the male partner’s consent may even be invalid in those cases where the male partner had only consented in the hope that a child would stabilise the marriage or where the couple had divorced prior to the birth of the child. There seems to be some agreement that even in those cases, the mother’s husband would have to bear alimony responsibilities (Keiper, 2005; Müller, 2005; Roth, 2003); clearly, paternity as such is not absolutely certain in these cases.

For any other groups using DI, such as de-facto couples, lesbian couples or single women, paternity seems even more uncertain. Legal experts argue that paternity can only be declared after the conception of a child (Keiper, 2005; Roth 2003), and given that contracts with couples seeking DI treatment are normally signed prior to beginning treatment (this was the case with all respondents in this study), these are likely to be invalid. For de-facto couples, this results in the unregulated status of paternity until the child has been conceived and the male partner has declared his willingness to assume paternal responsibility. Keiper (2005) contends that DI for de-facto couples may be problematic although tolerated if an agreement drawn up by a public notary is signed by the intended parents. Müller (2005), however, interprets the *Children's Rights Improvement Act* in a more liberal way. According to her, the male partner cannot step back from paternity if he consented to the use of DI, even in those cases where this consent was given prior to the conception of a child. As medical guidelines prohibit treating lesbian couples and single women (Bundesarztekammer, 1998), Keiper (2005) claims they cannot access DI treatment. Also, for single women there is no other person but the genitor to whom paternity could be extended (Keiper, 2005; Roth, 2003). Müller (2005), however, claims that DI for these two groups is difficult because children have a right to access information about their biological origins and because they have a right to alimony payments from a second parent. Therefore, she suggests that lesbian couples and single women can ensure that the child has access to information about the semen provider by, for
instance, lodging these documents with a public notary. Also, according to her, the social parent in a lesbian family can adopt the child and single women can name another person to whom parental responsibilities are extended in order to provide a second parent for the child. As such cases have not yet been challenged by court, it remains to be seen how they will be determined.

Despite the introduction of legislation, this indicates that paternity following DI may still be contested in the case of heterosexual married couples, and access and the legal provisions for parents in a de-facto or lesbian relationship and for single women using DI, remain difficult. Some jurisdictions have enacted legislation, which clearly prevents uncertainty. Examples of such countries are Great Britain, Sweden, Switzerland, The Netherlands and the state of Victoria in Australia. The certainty arising from this legislation is in sharp contrast to the situation in Germany; almost all respondents in this study indicated considerable concern about the lack of legal certainty this created for them. Furthermore, they believed that this uncertainty impacted directly on their decision to share information about DI with their (future) children. It also contributed to their view that paternity after DI was uncertain, and it is likely that this reinforced their general insecurity and their perception that the use of DI was stigmatising, thus decreasing their confidence in its use.

The offspring’s possibility of accessing information about their biological origin

A second area of legal uncertainty was the issue of records kept about the semen provider, and the recipient couples and the offspring’s right to access these. Many respondents had no information as to how long such records would be kept, assumed that this was dependent upon individual doctors, and believed that semen providers themselves may have an interest in the destruction of these records in order to avoid alimony responsibilities. Others were aware that there was a 10-year period for retaining medical documents and were concerned that their (future) child would not be able to access this information once the records were destroyed at the end of this period.

Although some respondents were advised that offspring had no right to access this information, others had been informed by the legal experts or the doctor they had consulted that children did have a right to this information. Several felt that children should have the legal right to access this information. This
group felt angry and, at the same time, helpless, as they were aware that although their children may have a theoretical right to access information they could not put this into practice in those cases where records had been destroyed. Therefore, one couple had considered filing a court case after the birth of their child in order to ensure that the medical documents would be kept long enough for their future child to have access to these if he or she wanted this.

Several respondents, amongst them some who were undecided about information sharing, considered knowledge of biological origins to be a fundamental right everybody should be able to enjoy and realised that this might be difficult or even impossible for their (future) children. Some questioned the appropriateness of information sharing under circumstances where records no longer existed. They expected their (future) children to be curious and to ask questions to which they could not provide answers. These included voicing the desire to meet the semen provider or wondering about half-siblings raised in different families. Information sharing under those circumstances was perceived to be difficult and respondents feared that it might even be detrimental to their children’s well-being, as they would not be able to access the information they desired. Others spoke out for the provision of non-identifiable information about the semen provider and suggested that there should at least be some tangible information, such as a photo of the semen provider. Comparing this situation to the rights of adopted children, some respondents felt that children conceived by DI were clearly disadvantaged. The view that children have a right to access information about their biological origins has also been voiced by parents in other studies (Golombok et al., 2004; Lycett et al., 2004; Rumball & Adair, 1999). Furthermore, there is emerging knowledge that some offspring who are aware of their conception by DI are in fact curious both about the semen provider and potential half-siblings (Brewaeys, 2001; Scheib et al., 2004) and consider access to this information to be one of their fundamental rights (Cordray, 1999/2000; Turner & Coyle, 2000).

Some respondents considered information about one’s biological origin important for medical reasons. This confirms a trend towards a higher awareness of genetic conditions (Healthcare Heritage Study, 2004; Yoon et al., 2005). It also supports the claims of writers who suggest that access to biological information is important in enabling individuals to adjust their life style to potential risk factors (Annas, 1980; Cooper, 1997; Greenslade, 1998).
The right of offspring to access information about their biological origin has been a matter of great controversy and debate (for example: Blank, 1990; Blyth & Landau, 2004; Daniels, 1995; Daniels & Taylor, 1993; Knoppers & LeBris, 1991; Patrizio et al., 2001). For many decades, moral concerns regarding DI resulted in doctors not only recommending absolute secrecy, but also in destroying the medical records (Daniels & Taylor, 1993). They considered secrecy the best strategy to ensure that the family and the child were protected from stigmatisation, and that the semen provider was protected from any legal responsibilities (Daniels & Taylor, 1993) as well as from potential alimony claims in countries such as Germany where there is no explicit legal exemption with regard to alimony (Schilling & Blonski, 1994).

Several factors have contributed to the policies and/or practices in some countries which specify that records must be maintained so that those conceived by DI can access information about their biological origins. A guiding principle for granting offspring the right to identifiable information about the semen provider has been concerned with the welfare, needs and rights of the child to know his or her biological origins. Several countries, including New Zealand (HART, 2004), Sweden (Lag om Insemination, 1985), Victoria/Australia (Szoke, 2004; Medical Procedures Act, 1984), and more recently, Great Britain (HFEA, 2004) have enacted legislation granting offspring this right. In the case of Victoria/Australia, Szoke (2004, p. 42) reports that the Waller Committee issued the following recommendations as early as in 1983:

> Whether or not a person pursues her or his origins, it should be possible for everyone to discover them. ... The Committee has therefore decided that children born as the result of the successful use of donor gametes in IVF should be able to discover some information about their origins.

In his analysis of the major human rights codes, Blyth (1999), however, argues that none offers any support for this right. He also outlines the ways in which governments in different countries provide different interpretations of these codes. France, for example, when it implemented the Convention on the Rights of the Child (1990), claimed that the notion of the best interests of the child is adhered to if the semen provider remains anonymous, while Australia considers anonymity a major breach of the rights of the child. Blyth (1999, p. 54) therefore argues that the welfare of child is a vague concept, which cannot
"be relied upon to support the case for donor offspring’s rights to learn the identity of the donor". In New Zealand, in addition to considerations of the welfare of children born as a result of DI, it was the recognition of a biopsychosocial model in AHR, respect for Maori culture, and the contribution of social workers and counsellors in clinics which were significant factors in achieving legislative changes (Daniels 2004b). Furthermore, in Great Britain, a human rights organisation supporting people’s rights to learn the identity of their genitor, a court case in which an adult conceived with the assistance of DI, and a mother acting on behalf of her young daughter who desired to obtain information about the semen provider (Blyth, 2004b; Rose v Secretary of State, 2002) are likely to have contributed to the recent changes: as of April 2005, children conceived with the help of DI can access identifiable information about their genitor (HFEA, 2004).

Despite these changes and a universal endorsement of the welfare of the child, many countries, including Germany, have not enacted legislation in this area. In order to avoid an either/or situation and to increase choices for both semen providers and recipients, but maybe also in the hope that it smoothes the progress of enacting legislation, Pennings (1997) suggests a double-track policy for DI. Such a policy makes provision for the semen provider to decide whether he wishes to remain anonymous or become identifiable to the offspring in the future. Individuals and couples using DI would be able to choose whether they use the semen of an anonymous or identifiable man. Given that it is the parents who decide for or against information sharing, Pennings (1997) argues that it is best to let them choose the type of semen provider. Such a double-track policy was introduced in Canada when legislation for AHR was enacted in 2004 (Statutes of Canada, Bill C-6, 2004). However, while this increases choices both for semen providers and recipients, Blyth (1999) rightly criticises this in that it does not pay respect to the autonomy of those offspring whose parents have chosen an anonymous semen provider. If these parents change their attitude regarding information sharing, or offspring's origins are disclosed by others than the parents, and they subsequently want to access information about their genitor, they are denied this possibility.

In Germany, access to information about their biological origins for those conceived by DI is not regulated legally. According to general medical guidelines, as noted earlier, doctors are required to maintain records of all medical procedures for a minimum of only 10 years (Berufsordnung, 1998); there
is no specific regulation for DI records. In one survey, approximately 50% of the doctors indicated that they destroyed their records after this time (Thorn & Daniels 2000a). However, according to the medical guidelines regulating AHR, children conceived by DI “have the right to be informed about his/her biological father, as biological paternity is of significant importance” (Bundesärztekammer, 1998, Appendix 1.4). Also, a principal decision of the Constitutional Court ruled that offspring must be provided with the name of their genitor if this information is available (Deutsch, 1996). The guidelines of the AKDI, currently the only association providing any specific guidelines for DI, make no attempt to resolve this dilemma, but merely refer to “the legal period of documentation” when suggesting the length of time records should be kept (Arbeitskreis, 1996, Spenderrichtlinie F.1). Therefore, the situation in Germany is such that access to biological information is theoretically recommended, but dependent upon the decision of individual doctors who voluntarily maintain records beyond the 10-year period required by their professional guidelines. There is also no regulation regarding the information about semen providers that doctors can or cannot provide for recipients; this is also dependent upon the individual practices of doctors. As of 2006, European Community legislation stipulates that information about organ and tissue donation must be maintained for a minimum of 30 years; this also includes information relating to donated gametes (Europarat, 2004). Member states, however, can determine according to national legislation whether to grant offspring conceived by DI the right to access this information. It remains to be seen whether practices or legislation in Germany will change as a result of this European legislative change.

Although clinical experience suggests that most doctors prefer not giving any information and prefer maintaining semen provider anonymity, there are indications that some provide at the very least non-identifiable information. Also, clinical experience suggests that recipients increasingly challenge anonymity and insist on their doctor maintaining records beyond the 10-year period in order for their children to be able to access this information. A further indication of subtle changes in this respect occurred in 2004, when a medical practitioner helped to establish contact between an offspring and the semen provider. Though this was, to the author’s knowledge, the first time that this had occurred with the mediation of a professional, it indicates a tentative move towards more recognition of the needs of

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24 This doctor had referred the offspring to the author for counselling prior to providing her with the name and address of the semen provider.
offspring. Comparing the legal situation in Germany to other countries, however, it seems to be a vital prerequisite to legislative changes in granting offspring the right to identifiable information to explicitly exempt the semen provider from any paternal responsibilities towards the offspring. The establishment of a consumer group and some tentative shifts in doctors’ attitudes all point to the potential for change in this area. Such change will need to be incorporated into legislation if it is to provide certainty for offspring to be able to access information regarding the genitor. As the results of this research show, this is what respondents were seeking, and they wanted clear legislation that would protect these rights for their (future) child. Such legislation, a macro level change, however, will not be sufficient on its own, as was seen when the policy changes in Sweden and New Zealand occurred. The number of parents who have shared or intend to share information about DI with their children is much higher in New Zealand than in Sweden. Daniels (2004b, p. 162) highlights the fact that “while public policy may provide for, and indeed encourage, information sharing, translating this into parental practice may be an entirely different matter”. In New Zealand, the changes have occurred at micro, meso and macro levels, again illustrating how systems theory adds to the understanding of this area. The parents and semen providers, the professionals and social attitudes (as reflected in the legislation) all have to change and continue to change if the stigma associated with DI is to be challenged and removed. Change in one part of the system without change in the whole system is most likely to lead to DI family building continuing to be regarded as deviant and therefore prone to stigmatising attitudes. Confident parents, who inform their children of the family’s beginnings, need professionals who will support them in their endeavours. This can occur when there is a legislative framework in place that guarantees appropriate protection to all the parties, but treats as paramount the offspring’s right to access identifying information if they wish.

**Government financial provision for DI services**

Several factors regarding payment for DI treatment resulted in respondents feeling frustrated and discriminated against. Many were distressed that they had to pay for medical treatment themselves, whereas other types of AHR treatment were, to a large extent, funded by the health insurance system in Germany. They also felt discriminated against as treatment costs for DI, in contrast to other health-related costs in Germany, were not tax-deductible. Furthermore, they felt irritated and annoyed that doctors were able to determine the fee for DI treatment themselves, and that there was considerable variation in the
fees charged. Respondents reported fees varying from €1,000 to €5,000 for one treatment cycle. Those respondents who knew about these variations considered themselves to be at the mercy of the doctors concerned.

Some respondents felt discriminated against as users of DI, as they were, at least at that time, the only sub-group of those affected by infertility in Germany who had to pay for the entire treatment themselves. When the interviews were carried out, reimbursement for AHR was such that up to eight cycles of inseminations and four cycles of IVF or ICSI with the husband’s semen were fully covered by the health insurance system. Although there have been changes since then, and AHR treatment is not reimbursed to such an extent anymore (Bundesausschuss, 2004), it is still the case that those treatments involving the gametes of both partners are at least partly funded, whereas DI is not funded at all. According to the Social Legislation Code, reimbursement for AHR in Germany is only granted if couples are married and if their own gametes are used (Sozialgesetzbuch V, Para. 27a (1) 4). This excludes DI treatment in general, as well as reimbursement for any group other than married heterosexual couples, specifically. The lack of binding guidelines for DI treatment has resulted in doctors being able to determine the fees for medical treatment themselves, whereas other AHR treatments can only be charged in accordance with fees determined by the Federal Medical Chamber (Gebührenordnung, 2004). Furthermore, health-related costs not reimbursed by the health insurance system are normally tax-deductible; medical costs for DI, however, have been exempted from this. The court decision explicitly referred to the fact that insemination with the semen of a man other than the husband does not heal the husband’s infertility, nor does it diminish the emotional suffering of the husband. The costs of insemination with the semen of a husband, therefore, are tax-deductible as this treatment is considered to mitigate the male partner’s infertility, whereas costs for DI are not (Bundesfinanzhof, 1999). This decision fails to acknowledge that many other types of medical treatment do not heal but only alleviate the symptoms of diseases. Even other types of AHR treatment do not heal or improve infertility but merely circumvent physical factors resulting in impaired fertility. DI, on the other hand, may well alleviate the emotional burden of infertility, as the couple is then able to reproduce. In the current study, this seemed to increase the respondents’ feelings of uncertainty, powerlessness and of being part of a stigmatised and discriminated group.
Writers maintain that social stigmatisation not only occurs at the meso level, which pertains to the interaction between people, but also at the macro level where the structural basis for stigmatisation is located (Link & Phelan, 2001). In this case, a social construct is affixed to a person or a group, which labels and stereotypes them as having undesirable characteristics. From the perspective of the stigmatised, such stereotypical labelling results in losing social status, and being discriminated against and disadvantaged as an individual or as a group. Once such stereotypes are in place and socially accepted, these can lead to individuals suffering from the typical emotional consequences of stigmatisation and being placed in distinct categories such as “us” versus “them”. This can result in status loss and unequal access to social, economic and political power (Link & Phelan, 2001). It could be argued that this is the case with family building using DI in those countries, such as in Germany, where DI is legal but the legislative and/or social policy context remains unfavourable. Those using DI, in comparison to those who use their own gametes for reproduction, have to bear greater financial costs and are not supported by the social security system. Link and Phelan (2001) explain that individuals belonging to such discriminated groups expect stigmatisation and in fact construct their understanding around the associated negative expectations. As discussed earlier, this was the case with respondents of this study. Almost all expected that family building using DI would be viewed with suspicion, even rejected by some. It is likely that this general negative perception resulted from, or is reinforced by, such structural discrimination as government financial policies. Stigmatisation writers agree that this results in typical reactions, such as a decrease in confidence, and an increase in defensive behaviour (Goffman, 1998; Link & Phelan, 2001). This was also found with respondents of this study, both at the micro level and the meso level. They felt uncertain about the meaning of social ties and had difficulties establishing a coherent understanding of a family composition resulting from DI. Most respondents did not share their use of DI with significant others, and there was no indication that they challenged the way doctors provided DI treatment. Although it can be argued that this lack of confidence is a result of individual attitudes towards DI and defensive behaviour towards significant others and professionals, it is also likely to be an indicator of social vulnerability influenced by structural factors in the legal and policy arenas. The structural discrimination is likely to add weight to the self-fulfilling prophecy described in a previous section, as it is likely to be perceived as an additional factor in the negative perception of DI. In fact, structural discrimination may even be a stronger factor influencing the self-fulfilling prophecy than those at the meso level, as discrimination at the macro level is a concrete reality, whereas meso-level factors are based
on self-perceptions in the first instance. Whereas there are personal strategies for managing stigmatisation at the micro and meso levels (such as keeping the use of DI a secret), structural discrimination cannot be so easily managed, or challenged, if there is a desire to do so.

Summary

This study indicates that, in Germany, DI remains a controversial and morally questionable way of building a family. This is not only confirmed by respondents in this study, but also apparent when analysing current social and professional attitudes. Social stigmatisation theory highlights the fact that so-called pressure groups, in this case patient organisations, can contribute to alleviating and challenging the stigmatising nature of a condition. While such a group of individuals and couples who have or are considering using DI exists in Germany, it has not yet sought to work for macro level change. In comparison to patient organisations in other countries, the German group has only recently been established (in 2000). It is likely that this group will engage in more public awareness once it has fostered more confidence amongst individual members and feels more comfortable about raising their needs in the public arena.

The legislative framework is considered an important indicator of the acceptance of AHR and third party reproduction. This study confirms that lack of legal certainty for the actors involved results in maintaining the stigmatising nature of DI. Though recent legislative changes have resulted in increased certainty for paternity following DI, legal writers are not in agreement as to the extent of this certainty, especially in those cases where DI is used by single and lesbian women. Furthermore, access to genetic information about the semen provider is a contradictory and ambiguous issue. Medical and legal guidelines, as well as the ruling of the Constitutional Court, argue for granting offspring this right. Medical documents, on the other hand, can be destroyed after a period of 10 years. Thus, offspring have a theoretical right to this information but cannot put it into practice in those cases where doctors have destroyed these records. The uncertainty regarding offspring’s access to information deterred respondents from information sharing.

In addition to this lack of legislative certainty, respondents reported structural discrimination. In contrast to other types of AHR, DI is neither reimbursed by the German health insurance system nor is the cost
associated with it, in contrast to other health-related costs, tax-deductible. This resulted in feelings of discrimination for the respondents in this study and is likely to corroborate feelings of stigmatisation.

Reflection on the methodology

This section will discuss the methodology used for this study. It will outline the challenges and strengths of carrying out a qualitative piece of research for analysing factors influencing parental decision-making regarding information sharing about DI.

Recruitment challenges

Conducting a study about an issue surrounded by secrecy and associated with stigma has been described as difficult (Golombok et al. 1995; Lycett et al., 2004). This was confirmed once more in this study. It was apparent from an early point that the recruitment process was challenging; the difficulty of finding sufficient respondents was underestimated. These difficulties caused considerable delay in beginning the research study. Being a member of the AKDI, I had assumed that the medical members of this group would actively encourage patients to participate. It remains unclear as to why recruitment using this source was so difficult. One hypothesis is that doctors were sceptical about my views, though I was invited to become a member of the AKDI, and did not support research carried out in what they may consider their own area of expertise. Triseliotis (1993) describes the process of accessing patients carrying out DI as very difficult, as doctors perceive this as breaking confidentiality. Given that some doctors still advise secrecy, my desire to access to this patient group may have been viewed as intrusion into such an intimate and delicate issue. Furthermore, given that the medical profession tends to rely on quantitative research studies (Meryn, 2005), doctors may not have been supportive of a qualitative research approach. A further factor may have been my gender and my profession. Whereas most German doctors providing DI services are male, I am female. I am also one of the few female members of the AKDI and was, at that point in time, the only non-medical member. There may have been reservations about research carried out by a professional enjoying less professional prestige than a doctor, and/or reservations because their medical practice was seen to be under scrutiny. Another factor could be that
some doctors may have felt that what their patients said about them could be critical and therefore I would have been in a position of having knowledge about them that they may not have been comfortable with.

As found in other research (Golombok et al., 1995; Lycett et al., 2004) patients themselves may not wish to reveal their use of DI by participating in research, and in several research projects and surveys, contact with respondents was therefore established through patient organisations (Hewitt, 2002; Turner & Coyle, 2000) or personal contacts (Cordray, 1999/2000).\textsuperscript{25} this entails the risk of distorting the results, as in these cases, researchers investigate those known to prefer information sharing and who have chosen to be vocal about their views. Couples who are less certain about information sharing may require very pro-active encouragement to participate. Given that discussions between doctors and respondents of this study were, as reported, limited, it is likely that such an active and time-consuming encouragement did not take place. More likely, doctors simply handed out the invitation to take part in this research without commenting on it. It is probable that not one single factor but a combination of factors may have had significant impact on the recruitment difficulties, with some factors more relevant in some doctor/patient settings than in others. As access to respondents can be gained through doctors, it seems important for the researcher to establish personal contact with the doctors providing DI services in order to create a sound understanding of, and support for, the intended research project. Furthermore, it seems important to raise awareness amongst the doctors and to know that additional incentives, such as descriptions of the research project and indications that they support this project, are required so that patients are pro-actively encouraged to participate. Further possibilities would be information evenings about DI organised by doctors, which provide opportunities for the researcher to describe their intended study to patients directly and to hand out invitations for participation.

As a result of these difficulties, recruitment strategies had to be expanded. In the pilot study, one couple who had attended an information evening several years prior to this study was included, and in the main study, couples who had read my publication on family building with the use of DI were included (Thorn, 1997). As reported in Chapter 7, having read my publication had raised these respondents' awareness of

\textsuperscript{25} Cordray (1999/2000) does not specify that he recruited respondents via patient organisations, but confirmed that he recruited using personal contacts and contacts he had established through the Australian Donor Conception Support Group (Cordray, personal communication, June 15, 2005).
the issue of information sharing. However, the challenges they associated with disclosing DI did not seem to differ from those of other respondents.

**The strengths of a qualitative study design**

Qualitative research designs have been described as best suited for an exploratory study such as this (Strauss & Corbin, 1998). They capture complex phenomena, such as feelings, thought processes, emotions and perceptions. Both in the area of general medicine (Meryn, 2005), and in the area of infertility (Greil, 1997), qualitative research designs have been said to make particularly important contributions to the study as they analyse a phenomenon within its social and cultural context. This has also proven to be the case with this study; respondents gave detailed and vivid accounts of their affects, behaviours and cognitive processes. It is highly unlikely that similarly rich data could have been accessed with a quantitative study design.

The experience of infertility has been described as a major life crisis for both women and men (Covington, 1987; Lalos, 1999; Menning, 1980). While some writers contend that women experience a higher level of distress than men as a result of infertility (Greil et al., 1988; Hammer Burns & Covington, 1999), Daniluk (1997) assumes that, amongst other factors, methodological approaches may be more suited to elicit the emotional repercussion women experience and therefore distort results. Both Abbey et al. (1991) and Berg and Wilson (1991) confirm her view; they contend that standardised measures may be more sensitive towards the ways in which women express psychological distress. In this study, men reported equally strong emotional reactions to infertility as their female partners. They were as devastated and overwhelmed and revealed shame and loss of confidence in their masculinity as a result of infertility. This open acknowledgement of negative affects can be attributed to the qualitative approach of this study and the open-ended questions respondents were asked. There was no indication that men withheld negative affect during the interviews; instead, as indicated in Chapter 7, they made ample use of the entire range of their feelings. As discussed in the section analysing micro-level factors, this suggests that standardised measures developed so far are not sufficiently sensitive to capture typical male reactions to infertility. This indicates a need for more qualitative research, which can serve as a basis from which to develop tools for quantitative approaches.
Interestingly, and in contrast to Schilling and Blonski's (1994) study where open-ended questionnaires were used, both men and women in this study expressed their fantasies and fears regarding the semen provider. It is likely that this difference results from the fact that respondents in Schilling and Blonski's (1994) study were not asked questions about their feelings towards the semen provider, but in this study they were explicitly asked these questions. Furthermore, respondents were asked to elaborate on some of their answers and as a result, more detailed responses were obtained. Respondents in Schilling and Blonski (1994) study may not have had the courage to talk about their fantasies without being asked and would have needed pro-active encouragement to reveal these. This suggests that this is a sensitive issue and it cannot be expected that respondents will reveal fantasies about the semen provider unless they are specifically asked to do so. This may be similar with other sensitive issues, which are only raised if respondents are asked and given sufficient time and space to respond. In addition to calling for a qualitative approach, this suggests that research in the area of infertility and family building with the assistance of DI needs to be carried out by professionals with insight and experience into these intricate issues.

The strengths of individual and couple interviews

Researchers have questioned the appropriateness of interviewing each partner separately in couples pursuing DI, fearing that this can lead to mistrust between partners (Snowdon et al., 1985). There was no indication that this was the case in this study. Although several potential participants had to be excluded because the male partner was unwilling to be interviewed, once couples had decided to take part in this study, no respondent questioned this procedure or indicated any reservation. It is possible, again, that it was the relatively high level of confidence of this group of participants that resulted in the lack of apprehension. Those with low confidence about DI may have self-selected themselves out. Therefore, the argument that individual interviews can result in distrust between partners may be valid in other cases where respondents are not self-selected. Self-selection, however, does not only impact on the range of differing attitudes towards sharing as it is likely to limit participation to those respondents who favour sharing, but, in the case of interviewing couples, it is likely to affect the type of couples who come forward. It can be hypothesised that those with no or only minor marital difficulties are mainly willing to
participate, as it is likely to be perceived as embarrassing to admit marital strife. Though this limits diversity, it is the only way to conduct in-depth, face-to-face interviews in this area.

Conducting individual and couples interviews in this study resulted in rich data as partners complemented each other in their responses. Any inconsistencies the respondents or I noticed were openly acknowledged and, if relevant, discussed. In addition, given that there was a time span from several hours to two weeks between the individual and couple interviews (in most cases, the couple interview was carried out one day after the individual interviews), this provided the couples with time to reflect and discuss the contents of the individual interviews, and to report this during the couple interview. All of this material was used for analysis and further added richness to the data.

Feedback

The feedback form was administered for two reasons. Acknowledging that carrying out interviews had an exploratory character, I expected that the interviews may impact on some respondents’ attitudes regarding information sharing. While some respondents did indicate on the form that as a result of the interviews, they had discussions about the semen provider with their partner, or shared their use of DI with family members or friends, this did not lead to any new information. Realising the sensitive nature of family building with the assistance of DI, I was also concerned about the well-being of respondents after they had, maybe for the first time, discussed this issue with somebody. I anticipated that for some, this may result in feelings of unease or even distress, which they may have revealed on the feedback form. If this were the case, I would have been in a position to recommend consulting a counsellor. However, given the relative high level of confidence of the respondents, this support did not appear to be necessary. Nevertheless, I felt that this was a useful strategy to apply, as it may be helpful in those cases where respondents are less confident.

Gender issues

Assuming that for many if not most male participants, it was likely to be male factor infertility which led to the use of DI, I was aware that having a female investigating these areas could potentially prove
difficult for them. I expected some male respondents to be reserved about emotional aspects or even unwilling to reveal them to me. In order to capture not only my subjective interpretation of the interview atmosphere and potential reservations, I addressed this issue explicitly as one of the final questions in the questionnaire. I asked all male respondents whether the interviews would have been different for them if they had been carried out by a male researcher. All of the men said that they were indifferent about the gender of the researcher. Some described the gender to be irrelevant, but that it was important for the researcher to understand issues relevant to DI and to be empathetic; others preferred a female researcher as they described women in general to be more sensitive to emotional aspects, which was considered vital in this area. Therefore, retrospectively, my cautious approach perhaps seems to have been unnecessary.

**Issues pertaining to social stigmatisation of and a lack of information about DI**

In all but one case, the interviews for the main study were carried out in the homes of respondents; this was their wish. In one case, however, the couple shared their house with family members. This couple wanted to avoid having to justify my visit and therefore asked to be interviewed at my practice. This couple feared negative reactions from their family members should the latter learn about their use of DI.

Both in the Chapter 7 and in this chapter, the needs of respondents for information and counselling were highlighted. As indicated on many occasions, it became apparent that respondents used the interviews in order to gain information about DI or to explore their attitudes about family building using DI. In fact, several respondents stated that this was their motivation for participating in this research. One potential participant’s need for counselling seemed so great that she initially pretended to be single so that she could participate. As explained earlier, during the interview, she revealed that she was in a stable relationship with a male partner, but that he refused to carry out DI. When I realised that her need to explore the different attitudes between her partner and herself was the reason for her wanting to participate in this study, I discontinued taping the conversation and referred her to a counsellor; this material was not used for this study. In a sense, this indicated the stigma associated with DI and the lack of available information and resources even before I had started to analyse the material for this study.
Managing different roles in the area of infertility and family building with the assistance of DI

As described in the introduction to this thesis, my roles in the area of infertility and DI have been and still are manifold and diverse. Most respondents considered me an expert on DI with extensive knowledge in the area. I was able to use my expertise in constructive ways, such as recognising the counselling needs of the woman who initially pretended to be single, establishing linkages between respondents when requested, and above all, providing information about different aspects of family building by DI during and after the interviews. Though these are not inherent parts of social science research, they were acknowledged and greatly appreciated by the respondents of this study. In several cases, respondents indicated that they had carefully considered whether they would participate in this study and only consented in the hope that they would benefit from participating. They had hoped for two potential benefits: in the short term, they had hoped to access my knowledge and experience, in the long term, they hoped that this study would further knowledge about family building with the assistance of DI and result in a book for couples considering this family building option. Respondents realised that they personally would not benefit from these potential long-term consequences, but nevertheless wanted to contribute in the hope that this would help to alleviate the stigma and taboo associated with DI. In a sense, this research has had a synergetic effect: it has furthered scientific knowledge and it has provided information and support for the respondents who took part. For me, personally and professionally, this was a very rewarding aspect of this project.

Undertaking this research, especially carrying out the interviews with respondents, was a powerful experience for me. I heard about the distress, the stigma and the difficulties respondents experienced and I felt privileged that they openly shared these emotions and experiences with me. As already noted, this was a particularly confident group of couples. In this respect, they differed from clients I commonly see as a counsellor. The struggle clients go through tends to be greater because they feel less confident. Also, the struggle of those that do not volunteer to participate in a study or approach professionals as clients may be even greater. This once more highlights the need to offer psychosocial support to everybody considering family building using DI.
Summary

Given that family building with the assistance of DI is surrounded by stigma and taboo, recruiting sufficient respondents for this study was challenging and the recruitment strategies had to be expanded. It will be important to consider creative methods of recruitment in future and to avoid going through patient organisations only, as this can distort results. The qualitative design of this study resulted in rich and vivid material, which could be drawn upon in order to understand parental decision-making. It also emphasised that current knowledge about the emotional implications of male infertility may not be fully understood, and that quantitative approaches do not necessarily capture all aspects of this; therefore, qualitative and quantitative studies must go hand in hand in order to further knowledge. In contrast to the fears voiced by some researchers, the administration of individual interviews did not result in mistrust amongst couples, but instead in more comprehensive data as each partner’s contribution complemented the other’s. In contrast to my own concerns, men did not hesitate in revealing their vulnerability towards me as a researcher of the opposite gender. The stigmatising nature of DI, however, became apparent even before the interviews: one couple did not wish to be interviewed in their home as they did not want to have to justify my visit to the family members with whom they shared the house. In addition, the lack of information and support available to couples considering or using DI became apparent at an early stage.

Many respondents participated in this study not only in order to access my knowledge and experience of the topic and to explore their decision to use DI, but also in order to contribute knowledge to the area of family building with the use of DI from their own experiences.
Chapter 9

Conclusions

This study was undertaken in order to understand the factors influencing parental decision-making regarding information sharing in families built with the assistance of DI in Germany. As a social worker providing counselling and psychosocial support for individuals and couples using DI, the issue of information sharing became a major focus of my work. Clinical experience made it apparent that a multiplicity of factors impacted on parental decision-making. This study has not only described these factors, but revealed how and why they are interrelated. On the micro level, individual factors, such as the level of confidence in managing a family composition deviating from the social norm and the challenge of making sense of a family formation for which understanding is only emerging, were factors that impacted negatively on the desire to share information about the use of DI. At the same time, the wish to be open and honest, and the realisation that keeping a secret is difficult and can impact negatively on family relationships were important factors in favour of information sharing. On the meso level, the fear of social stigmatisation for both the offspring and the parents and the lack of and/or inaccurate information about, and guidance for, information sharing were deterrent factors. Not having the opportunity to share with others using DI and the non-availability of role models discouraged acknowledgement of the use of DI. At the macro level, the negative social attitudes towards family building with the assistance of DI, the lack of comprehensive legislation, as well as discriminating social policy, were factors impacting negatively on parental decision-making.

Knowledge that best helps the understanding of interdependencies between the factors located at the micro, meso and macro levels can be located in systems theory and in the application of a biopsychosocial perspective. Applying a systems understanding made it possible to analyse how, for example, an individual’s level of confidence can be influenced by the provision of counselling and guidance for information sharing, as well as by negative social attitudes and the lack of comprehensive
legislation. The latter not only impacted on individuals using DI, but also on medical professionals providing DI services. Negative professional attitudes were also found to impact on individuals' attitudes and decision-making, thus reinforcing a negative attitude towards information sharing. Using a biopsychosocial perspective facilitated the understanding of the long-term implications of the use of DI for all actors involved – the offspring, the parents, the semen providers, and the professionals. It also highlighted the differences in attitudes between individuals using DI and those of the medical professionals. By using social stigmatisation theory, this thesis has contributed to a better understanding of the factors leading to marginalisation and its consequences. It has highlighted patterns typical of interactions amongst individuals experiencing stigmatisation and between stigmatised and non-stigmatised individuals. The results of this thesis corroborate current social stigmatisation theory according to which change at all levels is required in order to alleviate discrimination and stigmatisation and to achieve enduring change. The implications are clear: to achieve a change of attitude in the dominant pattern of secrecy surrounding family building using DI, efforts must be directed at the micro, meso and macro factors and their interaction as outlined in this thesis.

Finally, this thesis, being located in the field of social work, has a practical and applied dimension in that the results obtained will be of benefit to professionals providing medical and psychosocial services in the area of family building using DI.
Appendices

Appendix A - List of abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AHR</td>
<td>assisted human reproduction</td>
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<tr>
<td>AID</td>
<td>Artificial Insemination by Donor</td>
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<td>AIDS</td>
<td>Auto-immune Deficiency Syndrome</td>
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<td>AKDI</td>
<td>Arbeitskreis für donogene Insemination e.V. (German Medical Association for Donor Insemination)</td>
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<td>ASRM</td>
<td>American Society for Reproductive Medicine</td>
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<tr>
<td>BGB</td>
<td>Bürgerliches Gesetzbuch (Citizens' Legal Code)</td>
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<tr>
<td>BKiD</td>
<td>Beratungsnetzwerk Kinderwunsch Deutschland e.V. (German Infertility Counselling Network)</td>
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<tr>
<td>CICA</td>
<td>Canadian Infertility Counselling Association</td>
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<tr>
<td>DGGG</td>
<td>Deutsche Gesellschaft für Gynäkologie und Geburtshilfe (German Society for Obstetrics and Gynaecology)</td>
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<tr>
<td>DI</td>
<td>Donor Insemination</td>
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<td>ed.</td>
<td>Edition</td>
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<td>Ed.</td>
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<td>Eds.</td>
<td>Editors</td>
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<tr>
<td>e.V.</td>
<td>eingetragener Verein (formal acknowledgement of a charitable organisation in Germany)</td>
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<tr>
<td>ESchG</td>
<td>Embryonenschutzgesetz (Embryo Protection Act)</td>
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<tr>
<td>FRG</td>
<td>Federal Republic of Germany</td>
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<tr>
<td>FSA</td>
<td>Fertility Society of Australia</td>
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<tr>
<td>GDR</td>
<td>German Democratic Republic</td>
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<tr>
<td>GST</td>
<td>General Systems Theory</td>
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<tr>
<td>HART</td>
<td>Human Assisted Reproduction Technology Act (New Zealand)</td>
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<tr>
<td>Acronym</td>
<td>Definition</td>
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<tr>
<td>HFEA</td>
<td><em>Human Fertilisation and Embryology Act/Authority</em> (Great Britain)</td>
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<tr>
<td>ICSI</td>
<td>Intracytoplasmatic Sperm Injection</td>
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| IDI     | Information Donogene Insemination  
|         | Information Donor Insemination – German patient organisation for DI |
| IVF     | In-Vitro-Fertilisation |
| NADIR   | Nationales ADI Register  
|         | (National DI Register of the former German Democratic Republic) |
| RTAC    | Reproductive Technology Accreditation Committee (Australia) |
Appendix B – Individual Questionnaire

A Male infertility
1. When did you learn about your/your partner's infertility (or the factor that contributed to you using DI)?
2. What impact did this have on you both and how did you respond?

B Building your family with DI
1. How did you learn about DI?
   What were your views on DI as a treatment for male infertility?
   What had contributed to these views?
2. Can you tell me what happened when your doctor suggested DI to you?
3. Why was it important for you as a person to use DI?
   How did you/your partner respond to this?
4. How long did the decision-making process to use DI take?
5. Were both of you equally in favour of DI?
6. Did you talk to anybody about DI as part of your decision-making?
   What was it like for your partner when you discussed this with others?
   At what stage did you discuss DI with others?
   What were their reactions?
   What was helpful/unhelpful in these discussions?
7. How did the discussions impact on your decision to talk/not to talk about DI with your child?
   How did the discussions impact on your decision to talk/not to talk about DI with your family/friends?

C Stigma and power
1. How do you think male infertility (or whatever factor led you to use DI) is viewed by the public?
2. How do you think donor insemination is viewed by the public?
3. What were your personal experiences?
   What were the reactions of your family/friends towards you?
4. What do you know about the legal situation of DI in Germany?
5. What do you know about the current medical practice of DI?

D The family resulting from DI
1. How do/would you see yourself in relation to other types of families?
   How do you think your partner sees this?
2. What does it mean to you to be a father/mother after DI?
   How do you think your partner sees this?
3. What does it mean to you that your child was/will be conceived by DI?
   How do you think your partner sees this?
4. Were there any discussions between you and others about these issues?
   If yes, who initiated these discussions?
   If yes, what was discussed?
   What did these discussions mean to you?
Semen provider
1. Can you describe what you think and/or feel about the man who provided his semen?
2. Can you describe what you think your partner thinks about him?
3. What do you think he thinks about you and the children he helped to create?
4. How do you see him in terms of a place in relation to your family?
5. How have these thoughts impacted on your decision about sharing the nature of the conception?
6. How much do you know about him?
   What information did the doctor give you?
   Would you like to have more information about him?
7. How has this information (lack of) impacted on your decision about sharing the nature of the conception?

Professional and peer support
1. What did the doctor recommend to you in terms of disclosing the nature of your family building to the child/others?
2. Did you see a counsellor?
   What did you discuss with counsellor (alone, together with partner)?
   What were his/her views?
3. Did you discuss these matters with any other professionals (nurse, scientist, etc.)?
   Who and what did you discuss them with?
   What were their views?
4. How did these discussions influence you?
   How influential do you think professionals should be?
   Did you feel you had to accept the advice?
5. Did you seek/receive any peer support?
   How helpful was this?
6. Which of these discussions with professionals/peers were helpful for you?

Information sharing
1. Have you considered what you might want to do in relation to sharing/not sharing?
2. When did the issue of sharing/not sharing first occur to you?
   Who or what motivated you to think about this?
3. What decision have you come to?
   How did you arrive at this decision?
   What is the origin of your views?
   Did you have any doubts or insecurities?
   At what stage did you make the decision?
   Did others have an impact on your decision?
   What helpful/unhelpful discussions did you have with others?
4. If you were conceived this way, would you want to be told this by your parents?
5. Was the issue of a family secret relevant when you decided for or against information sharing?
6. Has your decision changed?
   Which circumstances may affect your decision in the future?
7. Do you and your partner share the same views?
   If not, how do you manage this?
8. How are you managing sharing/not sharing in your every-day life?

Final questions
1. What would have been helpful for you so that you could have made this decision more easily?
2. What other issues were important for you but were not covered by my questions?

Additional questions asked in the pilot study
1. Did the letter you receive before the interview prepare you well for the interviews?
2. Were you able to understand all my questions?
3. Did you find any questions difficult?
   Would you suggest any changes to any of the questions?
4. Are there any additional comments you would like to make about the interview?
Appendix C - Couple Questionnaire

A Male infertility
1. What did it mean to you as a couple to be confronted with male infertility (or whatever contributed to you using DI)?
2. What impact did this have on your relationship?

B Building your family with DI
1. Why was it important for you as a couple to use DI?
2. What issues did you discuss with each other while you were deciding whether to use DI or not?
3. Was one of you more strongly in favour of DI than the other? How did you manage this?
4. How did these discussions impact on your decision for or against information sharing?

C Stigma and power
1. How do you think male infertility (or whatever factor let you to use DI) is viewed by the public?
2. How do you think DI is viewed by the public?
3. How did you as a couple decide whether to talk about male infertility with friends/family?
4. How did you as a couple decide whether to talk about DI with friends/family?
5. How did the reaction of others impact on your decision?

D The family resulting from DI
1. What does it mean to you to be parents after using DI?
   How do you think others see you/would see you (if they knew)?
2. What does it mean to you as parents that your child was/will be conceived by DI?
   How do you as parents think others see/would see your child (if they knew)?
3. Were there any discussions between you as a couple and others about these issues?
   If yes, who initiated these discussions?
   If yes, what was discussed?
4. How have the discussions impacted on your decision to share/not to share?

E Semen provider
1. Do you as a couple talk about the semen provider?
   If yes, what do you discuss/share with each other?
2. Has this impacted on your decision to share/not share the nature of conception?

F Professional and peer support
1. What did you as a couple discuss about the doctor’s information?
2. What did you as a couple discuss after you had seen a counsellor?
3. What did you as a couple discuss after contact with any other professionals (nurse, biologist, etc.)?
4. Did you seek/receive any peer support as a couple?
   What was helpful for you as a couple when you talked to others?
5. How did these discussions impact on your decision?
   Were there any differences between you?
   If yes, how did you manage these?

G Information sharing
1. Which of you first initiated a discussion about sharing the nature of the conception?
   What did you discuss together?
2. What decision have you come to?
   How did you arrive at this decision?
What is the origin of your views?
What doubts/insecurities (if any) did you have?
At what stage did you make the decision?
Did others have an impact on your decision?
What helpful/unhelpful discussions did you have with others?

3. Did the two of you share the same views when you first discussed this?
   If no, how did you manage this?

4. Have your views changed?

5. Are you in agreement about information sharing?
   If not, how do you manage this?

6. How are the two of you managing sharing/not sharing in your every-day life?

Final questions
1. What would have been helpful for you as a couple so that you could have made this decision more easily?

2. What other issues were important for you but were not covered by my questions?
Dear

Thank you very much for assisting me with the research project. It was very helpful to have your and your partner's views. As indicated on the Information Sheet you were handed before the interviews, I am now asking you to report in writing on any thoughts and discussions you may have had after the interview. Please complete the attached form without reference to your partner.

Once you and your partner have completed the forms, please feel free to share your responses with each other. If as a result you think there is important information that you would like to share with me, please write about this on a separate sheet. I will look forward to receiving your completed forms within the next 2 weeks. If you have any questions about completing the forms, please do not hesitate to contact me. An addressed and stamped envelope is included.

It would be very helpful if I could discuss the issues in the Feedback Form with you again in approx. 5 years, as this would provide very valuable information. If you are willing for me to contact you in 5 years, please tick the box on the Feedback Form.

Yours sincerely,

Petra Thorn
Appendix D – Feedback Form (incl. accompanying letter)

Feedback Form
Please use additional sheets if required

1. I have had the following thoughts and ideas after the interviews:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

☐ I had no thoughts or ideas.

2. As a result of the interviews, my partner and I discussed the following:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

☐ There were no discussions between my partner and me as a result of the interview.

As a result of the interviews, I discussed the following with friends or family members:

________________________________________________________________________
________________________________________________________________________
There were no discussions between my friends or family members and me as a result of the interview.

Follow-up study

I am willing to participate in a follow-up study in approx. 5 years.
Appendix E – Recruitment letter to doctors

Research Project
Sharing the nature of the child's conception in families formed as a result of donor insemination - A study of the factors influencing parental decision-making

Dear Dr.

I am currently carrying out a research project studying parental decision-making in families that are formed or will be formed with the help of donor insemination. The aim of the study is to understand the factors influencing the parental decision in terms of sharing or not sharing the nature of the conception with the child and others.

I plan to interview approx. 40 individuals and these will include heterosexual and lesbian couples as well as single women who plan to undergo donor insemination, are currently in treatment or have conceived a child this way.

I would very much appreciate if you could pass on the enclosed letter, information sheet and consent form to patients who fall into the above categories and with whom you have had contact in the last 3 years. I have included 10 copies. Please feel free to make copies should you need more or ask me to send you more.

Should you have any further questions about this project, you can contact me at any time.

Thank you very much for your cooperation.

Yours sincerely,

Petra Thorn
Appendix F – Follow-up letter

Research Project
Sharing the nature of the child's conception in families formed as a result of donor insemination - A study of the factors influencing parental decision-making

Dear

Several weeks ago, your doctors informed you of the above research project. Since then, several couples have established contact with me and indicated their willingness to participate. The issue of information sharing is likely to be of interest to your and to your family. I would appreciate it if I could include your experiences in this research and if you would be prepared to be interviewed.

If you would like to have further information, don't hesitate to telephone me. The best time to reach me is between 9 am and 4 pm, as well as between 7 pm and 8 pm. Should you not be able to talk to me personally, you can leave a message on my answer-phone and I will ring you back.

Yours sincerely,

Petra Thorn
Appendix G - Letter of invitation

Research Project
Sharing the nature of the child's conception in families formed as a result of donor insemination - A study of the factors influencing parental decision-making

Dear Sir and Madam,

I am grateful to your doctor for passing on this letter and the attached information about the above research project. I am a member of the Arbeitskreis für donogene Insemination e.V. (Association for donor insemination, the German association of physicians who carry out DI) and have regular meetings with the doctors who are members of this association.

I myself am not a doctor. I am a social worker with a particular interest in donor insemination and the well-being of children and families. I am currently carrying out a study investigating the factors influencing parents' and would-be-parents' decision to share the nature of their (future) child's conception.

I would like to establish contact with individuals and couples who plan to use donor insemination, who are currently in treatment or who have a child as a result of donor insemination. I would like to carry out interviews asking about their experiences with donor insemination. If you are interested in participating in an interview, I would be very grateful if you would contact with me by telephone, in writing or by email.

Attached you will find detailed information about the research project; should you have any more questions, please don't hesitate to contact me.

Yours sincerely,

Petra Thorn
Appendix H – Description of the research project

You are invited to participate in the research project:

Sharing the nature of the child's conception in families formed as a result of donor insemination - A study of the factors influencing parental decision-making

The aim of this project is to find out what factors influence parents and would-be parents in terms of sharing the way they built or intend to build their family with their (future) child and social network. This is an area that professionals know little about and your participation will assist professionals to offer a more comprehensive service to those using donor insemination in the future.

If you agree to participate in this project, I would like to interview you individually for approx. 1 hour. If you are married or in a stable relationship, I would also like to interview your partner and both of you together as a couple. The couple interview would take approx. 1 hour. I have chosen this procedure because I would like to capture the different experiences between men and women as well as the views of couples. The joint interview will focus on your experiences as a couple. The interviews can be carried out in your home or any other place you nominate. As a follow-up of this interview, you will be asked to report in writing on any discussion you and your partner may have had after the interview. You will also be asked if you are willing to participate in a follow-up study approx. 5 years from the time of this first interview.

The results of the project may be published in professional journals and presented at conferences, but you may be assured of the complete confidentiality of data gathered in this investigation: the identity of participants will not be made public and any comments that you make will not lead to your identification by any other person. To ensure anonymity and confidentiality, all names and places will be coded and only the main researcher (Petra Thorn) will have access to this code.

Your decision to participate or not to participate will have no impact on the treatment you may be involved in at present or will contemplate in the future as your doctor will not know if you are taking part or not.

The project will be carried out as a requirement for a degree of Doctor of Philosophy by Petra Thorn under the supervision of Assoc. Prof. Ken Daniels (Department of Social Work, University of Canterbury, Private Bag 4800, Christchurch, New Zealand, Tel. 0064 33642 447, Email: k.daniels@sowk.canterbury.ac.nz) and Prof. Dr. Marlies W. Fröse (Department of Social Work, Post-Graduate Studies, Evangelische Fachhochschule Darmstadt - Protestant University of Applied Sciences -, Zweifalltorweg 12, 64293 Darmstadt, Tel. 0049 (0) 6151 879 847, Email: froese@efh-darmstadt.de). Either Prof. Daniels of Prof. Dr. Fröse can be contacted at any time should you wish to discuss the project with them.

The project has been reviewed and approved by the University of Canterbury Human Ethics Committee.
Appendix I - Consent Form

Research Project
Sharing the nature of the child's conception in families formed as a result of donor insemination - A study of the factors influencing parental decision-making

I have read and understood the description of the above-named project. On this basis I agree to participate as a subject in the project, and I consent to publications of the results of the project with the understanding that anonymity will be preserved. I understand also that I may at any time withdraw from the project, including withdrawal of any information I have provided.

Name__________________________________________________________________________

Address_______________________________________________________________________

Telephone number______________________________________________________________

________________________________________
1. Partner signed date

________________________________________
2. Partner signed date
Appendix J - Contact Summary

Name/code

Date

Type of contact

Summary of information

Atmosphere

Anything to bear in mind for study
References


Daniels, K. (2004a). Building a family with the assistance of donor insemination: 'It wasn’t our ideal way of having a family but it is our ideal family'. Palmerston North, NZ: Dunmore Press.


Donor Conception Network. Nottingham, UK: http://www.dcnetwork.org


Information Donogene Insemination [IDI]. Darmstadt, Germany: http://www.spendersamenkinder.de


Infertility Network. Toronto, Canada: http://www.infertilitynetwork.org


Manseau, F. (2004). Infertility counselling and the new Canadian legislation on assisted human reproduction. In J. Haase & J. Takefman (Eds.), *Course 1: Global perspectives on infertility counselling. Developed in Cooperation with the International Federation of Fertility Societies (IFFS) 18th World Congress* (pp. 54-58). Montreal, Canada.


**Legislation: Austria**

Legislation: Victoria/Australia


Legislation: Canada


Statutes of Canada, Bill C-6 (2004).

Legislation: Europe


Legislation: Germany


Kindschaftsrechtsverbesserungsgesetz (2002). (Children’s Rights Improvement Act).


Legislation: Great Britain


Legislation: The Netherlands

Wet Donorgegevens Kunstmatige Bevruchtting (2002).

Legislation: New Zealand


Legislation: Sweden


Legislation: Switzerland


United Nations Declarations


