

Got to get you into my life: Offspring of donor insemination challenging confidentiality rules

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ABSTRACT

A sperm donor is the biological father but not the social father of a child conceived through donor insemination. What is the significance, if any, of the genetic connection between the donor and donor offspring? How do the various stakeholders perceive the significance and how does the variety of views influence legislation? Initially, donor insemination was an informal arrangement between doctor and patient in which the genetic connection with the donor was downplayed or even concealed. As the practice became formalised through specialist clinics, the anonymity of donors was maintained. As donor-conceived children reached adulthood, however, some of them challenged the policy. The ensuing debate has resulted in significant legislative changes.

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Introduction

The concept of the family is significant in public policy, in political ideology, in law and in people's lived experiences. In a narrow conception, a nuclear family comprises a heterosexual couple and their biological children. Thus the family is a social arrangement based on biological/genetic connections. Changing or loosening the genetic connections poses challenges to the regulation of the social arrangements along with the concomitant responsibilities and expectations of citizens and family members. Assisted conception, in the form of donor insemination (or more complex assisted reproductive technologies) poses challenges to the genetic foundation of the notion of family. One of the challenges is the issue of the anonymity of sperm donors, which has resulted in numerous reports, policies and changes in regulation in the forty or so years since donor insemination became a recognised practice in Australia (Parliament of Victoria Law Reform Committee 2012; Victorian Law Reform Commission 2007; Waller Committee 1983; Legislative Assembly of NSW Committee on Law and Safety 2012; NSW Department of Health 1997; NSW Law Reform Commission 1986; Legislative Assembly of Western Australia 1999; National Bioethics Consultative Committee 1989; Family Law Council 1985). Controversies and inconsistencies have unfolded both in citizens' opinions and state regulations.

Over time, the controversies have become more complex as both technology and social mores change. Early in the debate, comparisons with adoption were drawn (National Bioethics Consultative Committee 1988; Winkler & Midford 1986; Cushman 1983). More recent arrangements other than the nuclear family, such as lesbian couples and single women, have been a matter for debate (Dempsey 2008; Millbank 2006; McNair 2005; Victorian Law Reform Commission 2005; Cannold & Gillam 2002; Walker 2000). Various papers have argued the merits of differing positions in the controversies. Rather than promoting a particular view, our purpose in this paper is to outline a range of stakeholders' opinions and sketch out how differences in views have been reflected in the development of policy and legislation. We confine our focus to influences on regulations concerning the anonymity of sperm donors in Australia between 1983 and 2012.

To this end, we first outline the debate concerning the significance of genetic connectedness in conceptions of personal identity. We then contrast this approach with the view that kinship is a result of social relationships. Next we describe some concerns that donor offspring have expressed about their lack of medical history. Finally, we describe some concerns donors may have about moral and legal expectations. In each section, we comment about how stakeholders' perceptions bear upon policies and regulations.

Initially, the processes used in donor insemination were intended to maintain the social model of the family and to minimise the genetic paradigm, or, at least, to

minimise the stress on the social model by concealing the genetic intervention. Donor insemination was offered to heterosexual married couples seeking to create a family. Doctors matched the donor's physical characteristics with those of the prospective social father and adequate records of the procedure were generally not kept (Johnston 1980; Kirkman 2005). In law, the child was presumed to be the child of the marriage and the husband was registered as the father on the child's birth certificate (Finlay, Bailey-Harris & Otlowski 1997). To protect donors from any legal action relating to maintenance and inheritance, they were guaranteed anonymity (Johnston 1983). Potential donors who were seen as 'unusually interested in their progeny' were rejected, and the donors who were selected were not informed of the use or results of their donation (Johnston 1980, pp. 14–15). In 1984, by virtue of section 60H, the *Family Law Act 1975* (Cth), was amended to make provisions for families created by donor assisted conception. Accordingly, a child born as a result of donated gametes or embryos is deemed to be the child of the woman giving birth and her husband, provided each consented to the procedure. State and territory provisions across Australia also stipulate that donors are not legal parents to children born as a result of their donations.¹ However, if a woman giving birth to a donor-conceived child does not have a husband/partner, a sperm donor can be recognised as the legal parent of the child evidenced by the recent Family Court case *Croth v Banks* [2013] FamCA 430.

As the children of donor insemination grew to adulthood, some of them did not accept the down-playing of the genetic role in their paternity. Some became interested in knowing more about their genetic fathers, their characteristics and even the donor's name. They demanded a change in the policy of donor anonymity and advanced a number of arguments to justify the significance of the genetic link (Taylor 1998; Johansen 2002; Hewitt 2001; Narelle 2003; Grimm 2005; Burns 2013; Adams & Lorbach 2012). These arguments have resulted in numerous reports, debates and consequent legislative changes, including provisions that enable donor-conceived people a prospective right to access identifying information about their donors and the establishment of voluntary information registers.² The National Health and Medical Research Council (2007, p. 34) guidelines on assisted reproductive technologies also stipulate that donor-conceived people 'are entitled to know their

¹ These include: *Status of Children Act 1984* (Vic) ss 10A–10E, 13–15; *Status of Children Act 1966* (NSW) s 14; *Status of Children Act 1978* (Qld) ss 17–19, 21, 22, 23; *Family Relationships Act 1975* (SA) ss 10A–10C; *Artificial Conception Act 1985* (WA) ss 3, 5–7; *Status of Children Act 1974* (Tas) s 10C; *Parentage Act 2004* (ACT) s 11; *Status of Children Act 1979* (NT) ss 5A–5F.

² The legislative changes include: *Assisted Reproductive Treatment Act 2008* (Vic) ss 59, 69–72; *Assisted Reproductive Treatment Regulations 2010* (SA) ss 8(2)(a)(4)(c); *Human Reproductive Technology Act 1991* (WA) s 49(2d); WA Department of Health n.d.; *Assisted Reproductive Technology Act 2007* (NSW) s 37(1); *Assisted Reproductive Technology Regulations 2009* (NSW) s 15.

genetic parents’ and that ‘clinics must not use any procedures that allow genetic parentage of persons conceived to be confused’.

Some of the debates hark back to adoption policy while some are being superseded by modern genetic technology. Some are concerned with practical financial implications, while others attempt to grapple with subjective notions of personal identity.

Knowing me, knowing you: Debating personal identity through genetic connections

Some donor-conceived adults have argued that knowing the identity of their genetic father is essential to their sense of personal identity. The personal identity model of genetic connectedness was widely used in the context of adoption during the 1970s and falls into two strands—psychological and sociological. While there are differences between adoption and donor insemination, there is a similarity in that the offspring in both cases has a genetic connection to a biological parent that is different to their connection to their social parent (Golombok 2009; Haines 1988). The genetic connection view holds that genes create unique individuals, as well as connect them to others who share the same DNA. Therefore, issues of identity do not simply rest with the individual, but also with their genetic family and kin. As Haines (1987, p. 368) puts it, the notion of identity is not simply a question of ‘Who am I?’ but also ‘Who are they?’ Further, as Grotevant (2005, p. 2) writes, ‘adoption provides a living laboratory in which we can probe questions about the significance of biological connections in the meaning of family and the development of personal identity’.

The term ‘genealogical bewilderment’ was first used in the 1950s and 1960s to define a state of confusion and uncertainty experienced by children who either did not have knowledge of, or only had uncertain knowledge about, one or both of their ‘natural’ parents. This confusion and uncertainty about a person’s genetic parentage was said to fundamentally undermine their sense of security thereby affecting their mental health (Sants 1964). This assertion, however, was not found to be based on research findings but ‘from a distillation of clinical experience and literary insights’ (Humphrey & Humphrey 1988, p. 65).

During the 1970s, the link between knowing one’s biological parentage and psychological health was also propounded by the much cited English social worker, Triseliotis whose extensive research on adoption and foster care led him to assert that:

[T]here is a psychological need in all people, [which] manifests primarily amongst those who grow up away from their original families, to know about their background, their genealogy and their personal history if they are to grow up feeling complete and whole (Triseliotis 1984, p. 38).

In the United States from the early to mid-1970s, psychiatrist Sorosky and social workers Baran and Pannor provided arguments using language ‘that bore the incontestable cachet of social science and medical authority’ (Carp 2002, p. 446) in favour of open adoption records. According to them, adopted people searched because there was something psychologically wrong with them (Carp 2002, p. 447). As Carp (2002, p. 450) notes, however, most studies of adopted people’s psychological problems relied on small, poorly selected samples.

Studies on reunions between adopted people and their birth parents show that by meeting face-to-face, ‘the adopted person could see someone to whom they were biologically related and who might well look like them’ (Howe & Feast 2001, p. 362). Along similar lines, the Australian media frequently features stories about donor-conceived adults wishing to know more about their donors. For example, in one media interview a 21-year-old female is quoted as saying:

I think that it’s a key element to developing a complete sense of personal identity is to know where you come from, and part of that is to know who my donor is, and to know something of him beyond the bland physical description that I’ve got, which I’m, really lucky to have, but my gosh, I’d love to have his favourite colour, his favourite book, you know, why he decided to donate? What motivated him? Did he have friends that were infertile? Did he need money? (Hewitt cited in Hardaker 2004, p. 1).

Knowledge about the donor was also important to another 31-year-old male’s identity as well as his daughter’s identity. Conceived in the 1970s, and therefore without information about his donor, he states:

It’s an important part of who I am and who my daughter is—we lack part of our identity. I don’t need another father figure, I don’t need another family, I do not need money or some other material or tangible assets. I don’t need anything except who I am (Adams quoted in Williams 2005, p. 1).

The emphasis on the bloodline, and its connection to identity, was also a common theme in a number of other media interviews with Australian donor-conceived adults who sought out more information about their donors, or who wanted to put a ‘face’ to the donor (Harris 2007; Cohen 2005a; Negus 2003; Singer 2002). What they may discover, however, is difference rather than similarity. For example, Frame (1999) was adopted as an infant in Australia and embarked on a search in his 30s to find his birth parents. Having found and met his birth mother on several occasions, he writes about how ‘the effort has not been wasted but the whole thing matters very little to me’ (Frame 1999, p. 129). He further adds about his birth mother:

[She] was not the mother I wanted to find. I am nothing like her; not even vaguely reminiscent. It would be easier for me to believe that I was someone else's child. There is not even the most remote similarity in appearance. We do not share anything in common, and on this point she agrees. We do not choose each other's company. We are absolutely strangers. I am confused rather than enlightened (Frame 1999, p. 129).

Frame's experience differs markedly from the widely circulated Australian media reports of the reunions between donor-conceived adults and their donors. For example, the story of Danielle, who reports that on first meeting her donor, she felt 'this instant connection' and could 'see' herself in the donor (quoted in Hayne 2009, p. 39). Another example is Walker who, having found her donor, stated: 'I no longer wake up in the morning wondering who I am ... I am still a donor-conceived adult, but I have solved one puzzle in my life which gives me a sense of whole identity' (quoted in Rudebeck 2002, p. 8).

According to Haines (1987), expressing curiosity about one's genetic parents and kin does not necessarily translate to a psycho-pathological crisis, as Sants and Triseliotis suggest. Instead, she uses the concept of 'social identity' to explain why adopted people seek information about their past. Based on semi-structured interviews with 45 adopted people, Haines and her co-researcher Timms found that 'issues of identity in adoption have more to do with constructing a narratable self than with a crisis' (Haines 1987, p. 366). That is, some adopted people need to know who else played a part in their story, in order to provide them with 'a more accurate enriched biography of their own place in the world' (Haines 2006, p. 266). Along similar lines, and based on interviews with thirteen self-selected adopted people who found and made contact with their birth kin, social anthropologist Carsten (2000, p. 687) stated that 'the reunions can be understood as reflections on personal biography and the completeness or incompleteness of personal histories'.

While it could be argued that donor-conceived children are placed in a similar social position to people who were adopted as infants, unlike adoption, where a child is relinquished, donor insemination provides individuals or couples with the opportunity to create a child. Therefore the lack of information about donation differs to adoption in that donor-conceived people 'did not experience a relationship with a genetic parent that was later broken' (Golombok 2009, p. 224). Consequently, the psychological consequences are likely to differ (Golombok 2009). Deech (1998, p. 705) goes further to suggest that unlike adoption, which has 'a paternal and maternal story worth knowing', the same cannot be said about donor insemination. As she argues about donor insemination:

[There] is no history that is relevant except the purely genetic one. No other story, other than fertility, lies behind the non-paternity of the

obvious man. There is presumably, no story to be told ... save the simple and possibly embarrassing one of the impoverished student who becomes an anonymous donor (Deech 1998, pp. 705–706).

According to Deech (1998), this makes a child born by sperm donation, more akin to a child born as a result of ‘a one night stand’, where the parties to the procreative act barely know each other. The presumption that there is no ‘story worth knowing about’, however, is challenged by some of the social science research that includes the views of donor-conceived adults who consider information about the donor as being important to their sense of identity, echoing sentiments that are similar to those of the adoption community from the 1970s (Beeson, Jennings & Kramer 2011; Marquardt, Glenn & Clark 2010; Cushing 2010; Kirkman 2004; Turner & Coyle 2000).

Novas and Rose (2000) note that there are many views of identity and only some of these are biological. Some donor-conceived people may yearn to know about their donors, as they consider it important to their sense of identity. However, other donor-conceived people’s perspectives suggest that having personal and social information about their donor has no impact on their sense of identity at all (Corderoy 2011). Indeed, as Topp (1993) alludes, her accomplishments in life are the most important aspects to her sense of identity. These rarely reported perspectives/accounts are different from those who regard information about their donor to be important in the way they construct their personal identities. The dominant public voice of donor-conceived people tells us that detailed information about their donor is important to their sense of personal identity.

In summary, the personal identity model of genetic connectedness is based on the assumption that there is a psychological or emotional need to have detailed information about one’s genetic parents and other kin, and that this information leads to a sense of a complete, or healthy, sense of identity. This view, however, is not universal, nor can it be empirically validated. Based on the limited available empirical research, for some donor-conceived people, having detailed information about their donor is very important to how they construct their personal identities, but for others, the genetic connection has little or no bearing (Blyth et al. 2012; Ravitsky 2012).

Sense of belonging: Debating the social versus genetic family models

The underlying premise of the dominant family model is that the genetic link between individuals predetermines family and kin relations. Karpin and O’Connell describe the concept of the genetic family as: ‘[A] model of relatedness in which the genetic tie between individuals comes to be invested with particular significance,

layered over and intersecting with other models of family based on legal and social connections of contract and choice' (Karpin & O'Connell 2002, p. 65).

According to social anthropologist Strathern (1995, pp. 351–353), the 'naturalness of family life' in the industrial world was based on the understanding of the procreative process as a 'fact' of biology. This led to an understanding of kinship as a relationship based on genetic relationships. And, 'though parents were not born kin to each other, the child was born kin to both of them', creating 'closeness, defined in the way familial and kinship relations overlapped'.

In the case of donor insemination, the genetic bond between the 'natural' father and offspring does not coincide with the bond between the social father and offspring. Concealing the existence of a donor may ameliorate the threat to the social bond, but it also has the effect of acknowledging the significance of the genetic tie. The threat was seen by some members of the South Australian and Victorian parliaments, as more significant if the social bonds were weakened by the acceptance of de facto relationships. Roach-Anleu (1993, p. 5) argues that the absence of a genetic link between the child and one or two parents signalled an 'erosion of the family' and the only way 'to stem the tide' was to make marriage a pre-requisite for admission into assisted-conception programs.

In contrast, the Waller Committee which was set up by the Victorian government in 1983 stressed the need for donor-conceived people to discover something about their genetics origins. In addition to pointing out that donor-conceived people ought to be able to access some non-identifying information about their donors, the committee stressed that 'honesty and integrity are crucial to the creation of happy families' (Waller Committee 1983, p. 26). These views were reflected in the first laws and regulations governing assisted conception.³

From the mid-1990s, donor-conceived adults, their support groups, academics and professionals argued for the right of donor-conceived people to access identifying information about their donors (Allan 2011; Adams & Lorbach 2012; Schneller 2005). Victoria was the first state in Australia to give adult donor-conceived people a legal right to know the identity of their donor. This was followed by Western Australia, New South Wales and South Australia (Hammarberg, Johnson & Petrillo 2011). The right to know the donor's name, however, can only be exercised, of course, by those who know that they are donor-conceived.

³ These were the *Infertility (Medical Procedures) Act 1984* (Vic) ss 23(2)(3); *Human Reproductive Technology Act 1991* (WA) ss 46(3)(a); *Reproductive Technology (Code of Ethical Clinical Practice) Regulations 1995* (SA) s 11(4)(ii)(b).

From the point of promoting the cohesion of the social family, it was left up to the parents to tell their children about their donor origins. Research suggests however, that many parents do not tell and a main reason is disruption to the parent-child relationships (Golombok 2009; Loughnane 2006). As an impetus for parents to tell their children about their donor origins, in 2008, section 17(2) the *Births, Deaths and Marriages Registration Act 1996* (Vic) was amended to allow for an addendum to be placed on the child's birth certificate to indicate that they were donor-conceived, and that further information about the donor is available. The NSW Parliament is proposing to follow its lead (Legislative Assembly of NSW Committee on Law and Safety 2012, p. 56).

A number of donor-conceived people and their supporters have also used the adoption analogy to claim a retrospective right to know the identity of their donors (Allan 2011; Adams & Lorbach 2012; Donor Conception Support Group 2011; TangledWebs Inc. 2011). Although retrospective laws are uncommon in Australia, in the 1980s, adopted adults in all Australian states were granted retrospective access to the name of their birth parent (Allan 2011; Marshall & McDonald 2001).

Message in a bottle: Debates concerning the need for medical information

The medical/health model of genetic connectedness is premised on the importance of knowing about one's genetic origins/history for medical and health purposes. When people present to their doctor with a perceived medical condition, it is considered good medical practice that the doctor takes a family medical history in addition to performing a physical examination and other diagnostic procedures (Guttmacher, Collins & Carmona 2004). As Finkler, Skrzynia and James (2003, p. 405) argue, 'every time doctors take a family history, they reinforce the notion that there is an association between kinship and health'. A person's family medical history is also a valuable clinical tool in assessing the risk one carries for a variety of disorders that are known to be inherited. For example, a family history of adenomatous polyposis would include performing a colonoscopy and the subsequent removal of colonic growths. Such procedures are claimed to have saved lives.

Even though part of family culture has long been the recognition of the inheritance of illnesses and diseases (Richards 1996), rapid advances in genetic research in recent decades, and the forecasting of the alleviation of disease, have fuelled an interest in the topic in the media, and in the lay community (Finkler, Skrzynia & James 2003; Lebner 2000). Ironically, in 2004, the US Centers for Disease Control and Prevention conducted a survey of 4,000 Americans and found that while 96 per cent of those surveyed believed that knowing their family history was important to their health, only one-third of the sample had ever tried to gather and organise their family health histories (US Department of Health & Human Services 2004).

This may have prompted the US Department of Health & Human Services to declare Thanksgiving Day as the National Family Medical History Day. Accordingly, US citizens are now encouraged to use their family gatherings as time to collect their family health histories to benefit all family members (US Department of Health & Human Services 2004).

Donor-conceived people and their families are no exception in the cultural milieu. As one Australian adult donor-conceived person, Hewitt, stated:

One of the effects of not knowing my family medical history is that I am paranoid about my health. I put my hand up for any available health check, because I don't have prior knowledge that would enable me to take preventative health measures (quoted in Wilde 2005, p. 7).

Another said:

Had I known that cancer is in my family I could have been scanned and tested for these years ago? The choice would have been mine and this is the most frustrating thing in all this ... Maybe it could have been caught early, giving me the hope of beating it (Grech 2011, p. 1).

Against this argument is the fact that modern genetic technology can now identify the risk an individual has in developing a wide range of genetic diseases (US Department of Energy Genome Programs n.d.). People already have the option of undergoing predictive genetic testing and before long the cost of a blueprint of one's personal genome will be affordable for many people without the need for contact between the genetically related (Mahmoud 2012). The universal availability of preconception genetic testing and screening, as recommended by the UK Human Genetics Commission (2011, p. 1), would also go some way towards addressing the risk of inheriting genetic conditions.

Aside from the need or desire to have a full family medical history, another health related issue centres on the potential for unwitting incest between donors and their donor offspring, or between donor half-siblings (Cahn 2009). The term 'incest' is defined as 'the actual sexual act between family members (however family is defined)' (Cahn 2009, p. 60). Donor-conceived people who know about their donor origins, however, can inquire about a potential sexual partner and are thus able to avoid the risk of forming intimate and sexual relationships with their donors or donor siblings.

Limits have also been placed on the number of families using the same donor to reduce the risk of consanguinity (Sawyer 2009). Notwithstanding this, a cause for concern is the revelation by a sperm donor in New South Wales, that he donated sperm 318 times at several different clinics, including 270 times 'at one prestigious

clinic' (Cohen 2005b). It is not known how many children were created from his donations or whether any of them know they are donor-conceived.

Money matters: Concerns about financial responsibilities

A practical implication of genetic connectedness refers to financial imperatives for uniting parents (mostly fathers) with their biological offspring. This imperative is associated with child maintenance/support; inheritance (property or money), and the commercial interests of the genetic testing industry. In Australia, the federal government is a major consumer of DNA paternity testing, which is mostly used for securing child support for unmarried or un-attached mothers. There is also a private market for DNA paternity testing and consumers include 'alienated or suspicious husbands' and sometimes their new partners (Gilding 2006, p. 91).

In the context of donor conception, section 60H of the *Family Law Act 1975* (Cth) and state and territory provisions across Australia stipulate that donors are not the legal parents of children. This means that legally, donors cannot be held liable for child support, nor can donor-conceived people claim inheritance from the donor. Also, donor-conceived adults' narratives either do not mention money or inheritance, or make it clear that they are not interested in these matters. Yet, as one Australian donor, who consented to exchange information with two girls born as a result of his donation, said: 'I was a little worried they (might have) turned out to be ratbags and wanted to pursue me for money. Whatever the laws, politicians can always change their mind' (Lunn 2006).

Although there is no legal responsibility imposed upon Australian donors for financial support, donors may feel a moral sense of financial responsibility for the children that have been conceived using their gametes. In a study on the experiences of donors (mostly from the United States) who had made contact with their donor offspring/families, the researchers' findings suggested that some of the donors 'feel a moral obligation to support any donor offspring who may contact them and are in need of financial or emotional support' (Jadva et al. 2011, p. 644).

Conclusion

How significant is the genetic connection between donors and the offspring of donor insemination? How do various stakeholders perceive the significance? What are the implications of the level of significance to policy and law? How important is the anonymity of the donor?

For some stakeholders, the genetic connection is insignificant. It is reasonable to infer that the doctors who provided the service and the women recipients of donor insemination did not consider the genetic connection to be a significant obstacle to using the process as a means to produce a family. Some donor-conceived adults too,

have expressed indifference about relating to their genetic fathers. If the connection is insignificant, then there are practical reasons to conceal it and the identity of the donor. Confidentiality keeps the relationship between donor, doctor and offspring simple, allays fears of social or financial complications in the future and increases the supply of donors.

If the connection is seen as having some significance, this too provides reasons for maintaining confidentiality. A genetic connection between donors and donor-conceived people can be seen as competing with the social father and to constitute a threat to the family. For this reason, some arguments were advanced that donor insemination should be available only to families that were socially strong in the sense of a formal marriage rather than less formal de facto relationships. Some doctors and recipients took pains to choose donors who bore physical resemblance to the social father to help conceal the donor insemination.

In contrast, some donor-conceived adults, along with some theorists and some policy makers, consider that the genetic connection is very significant. As a result of this view, they have pressed for law and policy changes that prevent medical clinics from accepting donors who are not prepared to have their identity released to donor-conceived adults. The current situation in Australia is that all states grant donor-conceived adults a prospective right to access the identity of their donor. In 2012, Victoria seemed to heading in a different direction to all other states when the Parliament of Victoria Law Reform Committee (2012, p. 76) recommended that all donor-conceived adults be granted retrospective access to their donor's identity. This recommendation, however, was rejected by the Victorian government in 2013 (Parliament of Victoria Law Reform Committee 2013).

Other legislative changes include the establishment of voluntary registers in Victoria, Western Australia and New South Wales. Victoria has also legislated for the inclusion of addendum on their birth certificates stating they are donor-conceived. These reforms, however, are not consistent across all states and there are current calls for uniformity (Senate, Legal & Constitutional Affairs Reference Committee 2011).

The long term effects of the changes in law and policy are not yet realised, but one possible outcome could be a fall in the number of sperm donors (Turkmendag 2012). Whether or not donor-conceived people have or have not experienced psychological or social benefits is yet to be shown empirically. Indeed, it may remain impossible to determine whether the changes were ultimately worthwhile.

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