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# **Reproductive Genetics: From Choice to Ambivalence and Back Again**

Anne Kerr

## **Introduction**

### *Setting the scene*

Genetics, genomics and society has burgeoned as an area of social and cultural scholarship alongside new technologies of diagnostics, databanking, treatment and genetic modification. In the late 1990s, as the Human Genome Project produced ever more detailed draft maps, and genes for the most common single gene disorders were identified and linked to the range of phenotypes through which these diseases are manifest, a number of prenatal genetic tests were developed by scientists and clinicians. Initially these tests were aimed at families who had already experienced the birth of an affected child, with conditions such as cystic fibrosis or Duchenne Muscular Dystrophy. Tests were also developed for so-called 'late onset' disorders, such as Huntington's disease, which affect people in adulthood. Although many have welcomed these new tests, families do not always want to take the test or abort when the results are positive (eg in the case of cystic fibrosis – see Lafayette et al, 1999). These tests for specific genetic disorders have not tended to develop into more general forms of antenatal screening for a range of financial, ethical and organisational reasons. Antenatal screening is mainly offered for more common chromosomal disorders as Down's Syndrome. Ultrasound anomaly scans can also pick up a range of defects in the fetus, some of which are the result of genetic mutations. Together prenatal genetic testing and screening or prenatal diagnosis (PND) can be considered to be a 'suite' of measures which involve technological intervention in pregnancy to diagnose genetic and chromosomal disorders in order that prospective parents can be offered a termination should the fetus be shown to be adversely affected.

As these technologies developed, considerable attention was devoted to the reproductive choices associated with this new and not-so-new genetic knowledge. Abby Lippman's famous paper (1992) on the social and cultural constraints on informed choice set the scene for a range of critical analyses including those from disability studies scholars such as Tom Shakespeare (1998) which challenged the implicit framing of disability as a medical problem to be avoided through genetic tests and termination. Teresa Marteau (1995) and colleagues' studies of the interpersonal dynamics of genetic counselling, together with the impressive historical analyses of US scholars such as Diane Paul (1998) clearly demonstrated the ways in which a range of social and cultural conditions affect the processes through which women come to be offered particular prenatal tests and make reproductive choices. Other important work from an anthropological perspective, notably Rayna Rapp's (2000) study of amniocentesis in America, also gave a rich insight into the complex tapestry of choices around reproduction in the clinic, the family and the community. Linking micro-level decisions in the clinic, with larger social and cultural forces, these authors have shown the implicit and sometimes explicit ways in which the termination of affected fetuses is privileged over other choices, including the choice not to partake of tests in the first place. Genetic counsellors and clinical geneticists have also reflected upon these processes. For example, Angus Clarke in the UK (Clarke, 1991) and

Barbara Biesecker (Biesecker and Peters, 2001) in the US, have also actively engaged with the politics of reproductive choice and disability and sought to improve their services to take account of the social model of disability. This has led to a number of projects, such as the Answer (Antenatal Screening Web Resource) initiative in the UK, co-ordinated by Shakespeare, which focus upon providing more balanced information to prospective clients of genetic testing, and exploring experiences of living with genetic disease for individuals and their families.<sup>1</sup>

Assisted conception technologies evolved in parallel with these prenatal genetic tests and screening programmes, within a context of considerable public suspicion and concern, particularly around the creation of embryos for research purposes, and the use of these technologies by same sex couples, older or single women. Clinicians and scientists' early technical efforts were focused upon improving sperm selection and embryo storage and grading, in order to increase the success rate of this complex and difficult work. They also built an enormous market for assisted conception amongst infertile couples, gradually extending the client base to women who were unable to conceive for a range of medical and/or social reasons. A range of mainly US and to a lesser extent UK scholars have explored these issues, from feminist (Steinberg, 1997; Throsby, 2004), historical (Pfeffer, 1993) and anthropological (Franklin, 1997; Cussins, 1996; Thompson, 2005; Konrad, 2005) perspectives in particular.

In the early days of assisted conception, little critical attention was paid to the discarding of affected embryos – clinicians in particular saw it as obvious that couples would only want a 'healthy' baby. In the early 1990s prenatal genetic diagnosis and assisted conception met in the arena of Preimplantation Genetic Diagnosis (PGD) (see Roberts and Franklin, 2006). Here scientists and clinicians worked together to find ways of selecting non-affected embryos for couples with a history of genetic disease. These couples had often endured several rounds of PND as well as the death of their children in infancy due to genetic disease. Although PGD has never been offered on a wide scale and the chances of embryos implanting and pregnancies going to term remain low – it became the focus of intense critical scrutiny in the public realm. Meanwhile, affected families formed intense partnerships with clinicians and scientists developing the techniques. In the UK, Roberts and Franklin's ethnographic study of PGD (2006) and Williams and colleagues' interview-based studies (Williams et al, 2007; Ehrich et al, 2006, 2007) detail the complexities of ethical discussions and decisions that both patients and professionals have negotiated in the course of developing and accessing these treatments. This work has demonstrated that families and clinicians are ambivalent about embarking upon PGD and about how to handle the information that it generates and the decisions that they must make about which embryos to select and which to discard. In contrast to much of the work on PND, the emphasis here has not been upon the poverty of ideal of informed choice that belies the realities of restrictions and limits on choice, but upon the symmetries of ambivalence for both service providers and service users, and the strange comfort which women and their partners experience when experts acknowledge their doubts and *lack* of knowledge, as they make their way through the PGD process. This ambivalence and moral pioneering has strong echoes in the work of Rapp in particular.

To set these developments in a wider context, it should be noted that legal, cultural and organisational systems concerning both PND and PGD vary from country to

country in complex ways. In some European countries with a strong Catholic tradition PND and PGD are restricted, in others the technologies are more readily available. The middle classes in rapidly industrialising countries such as India and China have readily adopted these technologies and ultrasound scans are also widely available (and used for sex selection as well as the identification of disabilities). There are also differences across the English-speaking countries that this chapter focuses upon. In the UK antenatal services are predominantly offered through the National Health Service, where genetic counselling is given via clinical geneticists, and termination is legal to term in cases of serious disability. Assisted conception services tend to be offered through private assisted conception clinics although NHS services are available on a limited basis. There is a well-organised regulatory system to control the types of tests and screening services on offer through licensed clinics. Although there are criticisms of termination and the disposal of defective embryos from pro-life and a disability rights perspectives, abortion and assisted conception legislation is not under threat because the majority view in parliament and public surveys is pro-choice. In the US, the situation is more complex, with most women coming to these tests and screening programmes through private health care in pregnancy, where screening is more widespread and routinised. Specialist services for affected families are also organised differently, with genetic counselling being provided by a distinct professional group, largely drawn from a background in social psychology. The politics of reproduction are also more complex, in the sense that abortion laws vary according to state, and the pro-life voice is much more influential in public and in policy processes and in limiting women's reproductive choices in the clinic..

### *Querying choice*

Looking across these socio-technical developments in the area of reproductive genetics, choices are a key concern for a range of groups, not least women and their partners. This is true for both arenas of PND and PGD. Choice is a central concern in discussions amongst scientists, clinicians, patients, prospective parents, scholars, critics and regulators, and even in the public understanding of genetics where 'drawing the line' around what reproductive choices are offered to whom has always been a persistent metaphor and cognitive resource for thinking through the social implications of genetics (Kerr et al, 1998). The types of choices that should be offered, the right to choose, and the conditions which influence and restrict choices are key to these discussions. When we turn to the growing fields of bioethics and disability studies and their engagement with reproductive genetics, we also find a strong emphasis upon choice, alongside a strong imagination about what choices might become available in the future . This work often focuses upon the rights and wrongs of termination on the grounds of less serious disorders or social conditions/disabilities including sex (Birch, 2005; Parens and Asch, 2003). The ethics of selection for positive traits, including 'saviour siblings' has also been discussed in depth (Boyle and Savalescu, 2001). This is where a couple with an affected child uses PGD to conceive a sibling that can be a tissue donor. The right to choose is often held to be paramount, especially by those writing within a liberal tradition where the individual is sacrosanct. This also extends to some arguments by disability studies scholars, who argue that disabled people should be able to deliberately select fetuses affected with their genetic impairments, eg deafness, although this is explicitly condemned by some authors (see McLellan, 2002). Visions of a better 'more equal' world and balanced, informed even free choices around reproduction, jar with these

increasingly prescriptive versions of what women *should do* when facing these difficult choices. Paradoxically, the idea of choice is at once idealised and ultimately restricted by critics and advocates of reproductive genetics alike.

This suggests the need for further reflection on the conditions of uncertainty and ambivalence under which reproductive genetic choices manifest and evolve. There is the need for a more thoroughgoing analysis of how ambivalence frames and indeed constitutes particular choices at particular times, and how choices echo through the social world rather than evaporate at the point at which decisions are made. The open-ended, even elusive nature of choice, for the many parties that these technologies touch, directly and indirectly, also requires further analysis. And there is a need to reign in dark imaginings or potentially frivolous thought experiments about choices that might become possible in the future. We need to concentrate upon the messiness and complexity of the present in a time of uncertainty, or else we risk losing sight of what really matters to people in the business of reproduction. Greater empirical precision that recognises the important differences between reproductive genetic technologies, and the actors that engage with them would also be worthwhile. Although there are clear parallels, the elision of PND and PGD in some of the more broad ranging bioethical and/or disability studies discussions is especially problematic given that the work done to constitute (and dispose of) embryos and fetuses, both discursively and materially (within and out with the body), is so radically different in these arenas. At the same time as we must unpack these wider dynamics and dare I say ‘realities’ of choice, we must also move beyond a discussion of choice to consider reproductive genetics as something more than a set of problematic choices for those most directly affected by these technologies. Technologies have a broader cultural life beyond the material – functioning as representations and points of cultural resonance for particular social groups and actors. In addition to considering the public, policy and media discourses around reproductive genetics, we must also explore what is absent from their accounts and the ways in which they reify choice whilst failing to confront the ambivalence through which it is mediated.

In this chapter, I will explore these themes in more depth, with the aim of unpacking some of these complexities in the hope of contributing to and perhaps somehow bridging academic, activist and policy discussions about these important issues. I begin with a fuller account of choice and ambivalence, drawing on a range of empirical studies and more theoretically oriented writings concerned with contemporary practices in reproductive genetics. I will then move on to consider the wider socio-cultural place of reproductive genetics, before returning to draw some conclusions about how we understand and analyse reproductive genetics in the era of genomics.

### *Introducing ambivalence*

My focus here is upon sociological rather than cognitive or psychological ambivalence (although the two are obviously not mutually exclusive). What happens when individuals and social groups or cultural discourses hold apparently contradictory views in parallel and are the tensions produced by these contradictions paralysing or productive? Drawing on the ideas of Bauman (2003) and previous collaborative work with Sarah Cunningham-Burley and Sarah Franklin (Kerr et al, 2007; Kerr and Franklin, 2006) I am interested in the extent to which ambivalence or

doubt can be a positive aspect of morality or ethical reflection about reproductive genetics, for individuals and society as a whole. Bauman argues that the facilitation of individual reflexivity alongside public spaces for citizens to challenge and debate and disagree about the good life and how to live it is key to a new ethics that avoids the barbarism of modernity and the nihilism of postmodernity. Although we are used to thinking of choices as good because they can resolve ambivalence one way or another, this is not necessarily always a good outcome, or even a genuine outcome. Making a choice can generate other choices that can involve yet more ambivalence. Choices may also be a burden rather than a benefit, especially when there are too many of them. Ambivalence is therefore not necessarily something to be avoided – at times it may be a resource or even a comfort. However, there is also a need to be aware of where ambivalence is expressed and how it is foreclosed, avoided or disposed of in particular discursive contexts. It is especially important to think through the dynamics of choice and ambivalence at the level of the individuals, the clinic, and policy as they are likely to play out differently in these various contexts. Individuals may find choices burdensome and ambivalence welcome in the context of treatment, but clinics need to offer choice and micro-manage ambivalence to enable the service to continue, and policy needs to allow for ambivalence but also foreground choice: a difficult circle to square.

### **On choice and ambivalence: frames, echoes and context**

Setting aside the rather sterile debate about what has changed since the hey day of eugenics, it seems clear that the conditions under which contemporary reproductive genetic tests are offered to prospective clients are shot through with uncertainties and inter-dependencies which make the notion of individual informed and/or rational choice just that: a notion. This is captured in the following excerpt from Nikolas Rose's *The Politics of Life Itself*:

[Today's] counselling encounters entail intense bidirectional affective entanglements between all the parties to the encounter, and indeed generate multiple "virtual" entanglements with parties not present – distant relatives, absent siblings, potential offspring. In these entanglements, the ethical relations of all the subjects to themselves and to one another are at stake, including the experts themselves. The consultation acts as an intensifier of ethicality. It mobilizes affects of shame and guilt, and of the respective claims, scope and limits of freedoms for the self and obligations to others. It activates the conflicts within the counsellors between the ethics of care and the ethics of guidance. It requires the counsellors to fold into themselves in a way that is by no means trivial or transient, some of the anxious and fateful undecidabilities that possess those whom they counsel.

(Rose, 2006, 74).

Ambivalence in the sense of uncertainty and indecision is the contemporary hallmark of reproductive genetics, at the same time as the rhetoric of informed choice marks it as significantly different from the eugenics of the past. Counsellors and counselees fashion a choice from their encounters, but the complexities and ambivalence within this process are simply not captured in the notion of 'informed choice'. Panning back from the clinical encounter, for people with a family history of genetic disorders, the dilemma of procreation is not simply solved by the choices offered by PND or PGD.

The existence of these technologies factors into their thinking and discussions, but there is no inevitable momentum towards an actual encounter with them. Not only is their provision often limited (because of a lack of specialist services or high costs), people do not inevitably choose to take them up even when they are available. In the case of late-onset disorders, many individuals prefer to remain in a state of 'knowing ignorance' that also has implications for their reproductive behaviour. As Claudia Downing (2005) has written in her study of families facing Huntington Disease (HD), the same risk information can be interpreted quite differently, even by members of the same family, and 'negotiating responsibility' for taking a diagnostic test and/or having and/or passing on the disease evolves over time. For family members that choose not to be tested in or prior to pregnancy, making it known to their families that they had sought genetic counselling could be enough to engender their support, even if they considered themselves unable to take the test, in some cases because 'they needed to retain the hope associated with uncertainty to function as responsible parents' (231). For others PND raises new uncertainties as the complexities of the accuracy of the genetic information and its relationship to phenotype must be interpreted. Even with a 'positive' diagnosis, choosing an abortion or choosing to give birth to an affected child does not dispose of ambivalence. The option of PGD is also far from open or easy for many families. There are considerable costs involved – financial, emotional and physical - and the meaning of the information provided about the embryo's 'risk status' is often far from unambiguous. Even when PGD is deemed a success and unaffected embryos are given a 'trajectory to life' in the womb, that trajectory is always open to interruption, especially since diagnosis often needs to be confirmed through PND at a later stage in the pregnancy (Roberts and Franklin, 2006). This means prospective parents and their care givers are often ambivalent about the value of PGD and about how to interpret the minutiae of the information it generates.

It would be wrong, however, to consider the various risks and uncertainties associated with PND and PGD as there to be overcome in the interests of some ideal of choice, be that a matter of the 'wise' choice or the choice made wisely. Drawing on Onora O'Neill's discussion of trust and accountability, Roberts and Franklin contextualise their study of PGD with a discussion of the ways in which accountability accumulates as clients and providers work out what to do. 'Good information' is constituted through open dialogue so that the meaning of that information is actively constructed in a partnership between 'expert' and client (2006, 204). As Roberts and Franklin note, 'it is impossible to know which answers or decisions are "right" and best practice must be based on the quality of the decision-making process which in turn relies upon its perceived trustworthiness or accountability' (209). This relational, evolutionary model of accountability also makes sense in relation to choice in its own right - in the best case scenario reproductive genetic choices unfold through critical, open dialogue. The emphasis here is upon relational rather than individual rational autonomy: choices are inter-subjective rather than objective and agency is co-produced by a range of social and material actors not individuals acting alone. As Ehrich and colleagues also note in their study of practitioners' ethics of PGD (2007), relational autonomy came to the fore when their participants talked through the prospect of taking a test with affected couples and reflected upon their own values on a more personal note. In both studies, practitioners tried to address the wider context of reproductive choices, including their social implications. The process of addressing these wider contexts offers a means though which to bridge 'professional knowledge, individual autonomy and wider social, ethical and professional values' (8).

Sadly, it seems that the small intensive scale of PGD and the meaningful partnerships between providers and their clients upon which the service is often based contrasts rather sharply with the 'industrial' end of reproductive genetics: antenatal screening for conditions such as Down's Syndrome. Here there is precious little time for staff or couples to critically engage with risk information, even although it is far from easy to interpret, as both groups experience screening and subsequent diagnostic testing like a conveyor belt that is difficult to get off (Raffle, 2001). Ideally, reproductive decision-making should be reflexive: notions of risk and disability should evolve in exchanges between counsellors and clients (Biesecker and Peters, 2002). However, the limited time for screening discussions, discomfort around termination and sometimes the lack of expertise on the part of counsellors means that underlying negative attitudes about conditions like Down's Syndrome are often implicitly reproduced through the consultation (Alderson, 2001; Al-Jader, 2000). Nonetheless, there is evidence that some practitioners are more reflexive about the limits of choice. A study by Williams and colleagues documents practitioners' ambivalence about the apparently inexorable logic of progression in antenatal screening and the dangers of 'too many choices' (Williams et al 2002a and b). Practitioners in this study were concerned about women's opportunities to decline testing and feelings that they might be judged to be irresponsible if they declined. They also expressed discomfort with their own role in shaping clients' decisions within a health care culture of screening and market values. A strong critique of choice emerged in the context of this ambivalence yet these practitioners' 'day job' was to facilitate these very choices. However, studies of peoples' experiences of being found to have an affected pregnancy also show how a lack of dialogue with staff exacerbated patients' feelings of loss and grief, especially when facing late stage terminations or perinatal death (Lalor et al, 2007; Malacrida et al, 1999; see also Rapp, 2000). As Williams and colleagues (2001) have suggested in a study of fetal medicine ethics, practitioners may deny engagement to protect themselves from the emotional pain of their job. Practitioners' lack of sensitivity to clients stemmed, in part, from their ambivalence around death – particularly when the imperative to 'do something' to avoid natural or prolonged death meant that they actively intervened to hasten the death of the fetus in the later stages of pregnancy. Presenting these interventions as a matter of 'no choice' can be helpful to some clients as well as to staff. As Rapp notes, for some women in her study of amniocentesis, 'the very notion of "choice" is unbearable and must be abolished from the vocabulary of grief' (2000; 225) as a means of bracketing the pain of ambivalence surrounding their decision to abort. Ambivalence is clearly expressed differently, depending upon the context of care and the actors involved. In the case of PND, ambivalence is not used effectively in clinical situations; practitioners and their clients do not have a means of sharing their concerns in a way that benefits both parties. Ambivalence here is darker and more corrosive. A focus upon choice is not a good way of managing these difficulties either – instead it can seem to make them worse as it heightens people's sense of responsibility, guilt and grief.

It is also important to note that there is a distinct lack of available counselling for people affected by the birth of a child with a genetic disorder. Parents who have experienced the birth of a child who might have a genetic disorder do not always get genetic counselling. Sikkens and colleagues note in a study from the Netherlands that nearly 40% of parents who experienced the birth of a child with congenital abnormalities and were suitable for referral to the genetic clinic did not receive



genetic counselling, although it is not clear whether this was an active choice on their part (Sikkens et al, 2002). There are also limits on the availability of screening and counselling services for some ethnic groups with high prevalence of particular genetic conditions like sickle cell (Atkins and Ahmed, 1998). This suggests that for some their ambivalence is within a context of too few not too many choices.

Moving back from the clinic once again, reproductive choices are not made in isolation from wider families and communities. Once made, they reverberate beyond the individuals concerned. Even if they keep their choice a secret, clients must consider the consequences of their choices for those around them as they may reveal information about their risk status too. Finding out ones' status as 'risky subject' can have implications for other family members that can be especially pertinent to those engaged in or contemplating reproduction. Mothers, sisters and daughters seem especially bound up in these risky relations. This cannot be understood in simple terms such as the geneticization of kinship (Finkler, 2000) as knowledge, choice and responsibility are negotiated in complex ways. Monica Konrad has pointed to the ways in which families affected by HD come to know and understand their kinship through establishing and updating tentative genealogies (2003). When new knowledge of connections to someone at risk emerges, especially when parenthood has commenced, this can cause profound feelings of ambivalence in the sense of doubt and uncertainty about whether or not to contact them with this new information and change their identity in the process.. Affected individuals also face a 'burden' of deciding when to tell their children. The individual's choice to know involves them in considering and trying to manage the consequences of their choice for their children's sense of genetic and social identity. This can result in conception secrets for those who choose non-disclosure, secrets which Konrad notes, 'live on, even beyond their repeated telling and retelling' (2003, 349). Hallowell's studies of how women with a family history of breast cancer negotiate reproductive choice and responsibility also show how a sense of connection with and potential guilt about one's daughter and her daughters to come frames treatment decisions not just reproductive decisions (Hallowell, 1999).

Drawing on Parson's and Atkinson's (1992) study of the ways in which women tested for carrier status for Duchenne Muscular Dystrophy translate their risk status into their personal 'stock of knowledge' as a way of thinking about their future reproduction, we can also imagine that some clients of reproductive genetic services translate their experience of testing and/or termination into the everyday patterns of their life to manage to live with the consequences of their choice. Similarly, in a study of women's and men's responses to genetic risk information about breast (and in women's case ovarian) cancer, d'Agincourt-Canning noted,

Some participants responded to their positive results with feelings of uncertainty. Their mutation status put them into what some have called a 'liminal' state that is a position of being neither ill nor perfectly well. This state of uncertainty did not define the way they conducted their lives. Rather than feeling threatened, these participants accepted their genetic risk as any other risk that needed to be dealt with. While worrisome at times, it became part of their awareness and part of their routine lives. (469-70).

Although this research is not around reproductive genetics, it does hold clues for how people might learn to live with genetic risks in the long term, including their previous decisions related to reproduction that these risks had coloured. For some there will be a process of bracketing and forgetting which enables them to live the rest of their lives without reference to the troubles of their past. A sense of having made the right choice and of having acted responsibly in the interests of their family and their unborn child has been found to be important in enabling people moving on from their decision to test and/or terminate (Rapp, 2000). At other times, a recognition of ambivalence might actually enable people to live with the choices they have made. Garcia and colleagues (2007) found in their study of patients' experience of being offered PND for Down's Syndrome that all of the participants felt that their choices may have been different in different contexts. This is not to say that they regretted their decisions, but that they recognised their socially situated logic. For all of the participants, whether they accepted or declined PND, there was considerable diversity of opinion and/or ambivalence as they thought about what it would mean to have a disabled child in their lives and that of their families. Perhaps this recognition of ambivalence helped them to come to terms with the test results and the choices they made in response.

These processes of negotiating responsibility beyond the immediate choice to find out about and manage the risk status of oneself or one's unborn child are also part of a wider process of identity work that genetic technologies can involve. Novas and Rose (2000) discuss the postings to an HD support groups on the web, noting that reproduction is a key area of concern, and suggesting that

these informal processes of mutual disclosure around such issues among those who identify themselves with a virtual community are significant because they constitute a new form of authority based on ... experience ... Within such life strategies, the governance of risky genes is intimately tied to identity projects, the crafting of healthy bodies, and the management of our relations with others (503).

Prospective and previous reproductive choices thus form part of people's constructions of identity, in environments where they can share their experiences with similar others. This does not only apply to the virtual realm, but to more grounded communities in a range of contexts, from condition-based support groups to parenting networks. Revealing and hiding reproductive choices and disease status are also part of how people account for their identity amongst colleagues, friends and in their engagements with service providers with an interest in their health. This can involve opening up, sharing and/or managing ambivalence and helping people to make or avoid particular choices about what to know.

To sum up, informed choice is an ideal not met in practice in the sphere of reproductive genetics. Sometimes this is because patients do not have access to diverse and nuanced information and appropriate space for contemplation and decision-making. At other times, there is a lack of opportunity, desire or motivation to make a choice, or even a lack of ability to face choices or to live with their consequences. However, choices still get made - sometimes this is experienced as a resolution, at other times there is regret and guilt, for clients and practitioners alike. But a condition of ambivalence can also prevail in a more positive sense - seeing that the possibility that other choices could have been made can be comforting rather than

distressing for affected individuals. Practitioners too can experience offering and facilitating patients' reproductive choices as giving them the best chance of a healthy baby, or as a form of closure when faced with abnormality or a source of more difficulty and uncertainty for their patients and their own moral selves. Sometimes there are too few choices and sometimes there are too many. Choices are variously revealed and hidden as people construct their identities in various contexts. Choices and lack of choice have the potential to create and/or mitigate ambivalence in complex ways.

Individuals, families and clinics' engagement with PND and PGD are characterised by a lexicon of choice and ambivalence that the ideal of informed, or individual choice does not capture. Ambivalence here can mean uncertainty, indecision and dilemma, but also knowing ignorance and the conditions of hope for the future. Choices in these contexts are highly variable and context specific, based on relational rather than individual autonomy. They cannot be understood in isolation from ambivalence. It seems that the people who are closest to these processes know this most acutely, be they affected individuals or practitioners. Yet these conditions of ambivalence seem to get lost on the wider public stage where reproductive genetics is invariably reduced to a matter individual choice.

### **The sociocultural places of reproductive genetics**

This focus upon individual choice means that the choices which are made in the process of facilitating the testing or screening service overall get lost from view (Lippman, 1992). These are choices which pregnant women and families affected by genetic disease do not traditionally play a role in. Yet there is no intrinsic logic to any technology, despite how we sometimes feel as recipients and practitioners. Instead, technologies and their applications are socially accomplished through a combination of material and human agency, as much of the work in the sociology of technology has amply demonstrated. In the area of reproductive genetics it seems that a limited range of actors participate in these processes and operate with a narrow, often economistic version of the public health in mind (Kerr, 2004, chapter 4).

However, the recent opening up of genetic and embryo research and assisted conception to wider public scrutiny has created some spaces for affected women and their families to become more involved in shaping the agenda of diagnostic and treatment facilities and public policy more widely (see Rabeharisoa and Callon, 2004). In the UK this is especially true in the smaller more 'craft' based areas like PGD where a range of public consultation events have taken place and have shaped the regulation of this technology. Patients groups have become increasingly effective at putting their agenda for better diagnostic and treatment services across, including the case for stem cell research. Families with genetic disorders, especially those who have experienced the death of a child in infancy, can expose their private reproductive ambivalence in public as a means of demanding greater reproductive choice. Parents' key role in establishing a demand for PGD is often highlighted by clinicians in this field, and the model of partnership is also stressed by other pioneers of antenatal diagnostic testing for conditions such as cystic fibrosis. However, the more radical or questioning agendas of some of the disability rights organisations who are also part of these consultations is less influential. Their calls for investments in service provision

over ‘cure,’ and their accounts of how it feels to confront a test that is designed to make sure that people like them are not born, have not had much of an impact on reproductive genetics beyond the general level of public debate. Their concerns are expressed and then bracketed by regulators, parents and innovators alike, in other words their ambivalence is managed away. The rhetoric of individual choice has more institutional leverage and support from diverse groups with a stake in reproductive genetics.

Choice also looms large in the wider public’s ethical discourses around PGD, but in a way that is intimately tied to ambivalence. Scully and colleague’s (2006) study of lay views on sex selection using PGD noted a high degree of ambivalence about choice because of the perception that it placed a burden on people, especially in conditions of uncertainty about knowledge, a tendency to individualise responsibility for health and negative value judgements about disability. Ideals of good parenting and the personal liberty of the child profoundly shaped these accounts, in a model of relational autonomy, as with the case of professionals involved with the provision of PGD as reported above. Although necessarily situated within a strong discourse of ambivalence, choice was nonetheless a key organising concept for how participants thought about the morality of PGD being used for social rather than more obviously medical reasons in Scully and colleagues’ study. Interestingly, there was also a strong theme of the need to relinquish choice as a part of parenthood, to deal with the reproductive dice as they are thrown and to accept children, however they turn out. Participants found it difficult to establish where these choices ought to begin and end in relation to the spectrum of disorders that the tests might be used to identify, as have others in similar studies of genetic testing as a whole (Kerr et al, 1998b), but the need to make a choice was paramount. In a focus group study on reproductive genetics in the US, Kalfoglou and colleagues (2005) also found an interesting diversity in participants’ notions of choice, including appeals to the importance of accepting God’s choice and a despair about people’s capacities to make wise choices, born of a general scepticism about humanity. As they noted, ‘These participants were concerned that greed, vanity, and prejudice would drive both individual and policy choices’ (1617). Yet, in common with other studies, the authors found that the majority of participants bracketed this ambivalence in favour of individual choice, based on a sense that couples directly affected by these conditions should make their own decisions.

We must also remember that there are some important cultural differences in how reproductive choices are related to perceptions of good motherhood in particular. The UK-US ambivalence around choice is often resolved, for regulators and a majority of publics alike, in the right of couples to choose but this carries with it a profound ambivalence about whether or not these couples are acting like good parents in trying to choose ‘healthy’ children. We can see such ambivalence on global as well as local stages. In countries with a more barbaric history of state-sponsored eugenics, Germany in particular, women can be shamed if they take up reproductive genetics because it is seen as selfish, whereas in other societies where reproductive genetics has been embraced, notably Israel, it might be considered selfish not to take the test (Hashiloni-Dolev and Shkedi, 2007). Both extremes in their different ways, constitute a model of motherhood in terms of relational autonomy - German *and* Israeli mothers are expected to limit their autonomy in the interests of the child. At the same time, it

is reproductive choice (or lack thereof) that becomes the focal point of social judgement.

Key actors in policy discussions about reproductive genetics also foreground choice in conditions of ambivalence. As Mittra (2007) has argued, the recent report by the UK House of Commons Science and Technology Committee, entitled *Human Reproductive Technologies and the Law* (HOC, 2005) used reproductive autonomy as a battering ram against the Human Fertilisation and Embryology Authority's previous decisions to limit PGD to serious disorders by emphasising the precautionary principle (although the HFEA have also been criticised for their wide interpretation of 'serious' in making licensing decisions). The committee emphasised the need to devolve decision-making to clinicians and clients, except in cases where evidence of harm to individuals or society was compelling. Considerable attention was devoted to drawing a distinction between the eugenics of the past, with an emphasis upon coercive population improvement, and individual choices to improve health and avoid disease and disability in the present: discourses promoted by an unlikely alliance of pro-technology, pro-medicine and pro-choice activists. These arguments sit alongside, but not necessarily in dialogue with, anti-abortion and disability-activists' problematisation of individualism, information and choice and their concerns about the consequences of negative representations of disability, as perpetuated by antenatal testing and screening, for people living with disabilities (see Kerr and Shakespeare, 2002). The more recent UK Human Genetics Commission report entitled *Making Babies: Reproductive Decisions and Genetic Technologies* (2006) attempted to bridge this divide by privileging reproductive autonomy at the same time as promoting better service provision for people with disabilities to enable couples to 'make a real choice to have a child with a genetic condition if that is what they so wish' (11). The HGC also recognised a relational dimension to reproductive autonomy and accepted that reproductive decisions are made in context and may have effects beyond the couple and their potential child, including society as a whole. Yet the HGC defaulted to reproductive autonomy as a means of resolving these tensions, whilst also stressing other vaguer notions of 'genetic solidarity' and protecting children's interests alongside the principle of individual choice. It seems the best that can be done is to line up a set of principles, with choice top of the list, without tackling the ways in which these principles entwine and contradict each other. The appeal to 'real choices' emphasises choice once again, in such a way that it dominates when cast alongside much more tentative appeals to precaution and the need to think about 'drawing the line' at selection of trivial traits such as myopia.

Individual choice dominates in a range of public discussion and pronouncements about reproductive genetics. Although ambivalence is often recognised and expressed individual choice is a kind of default position for regulatory bodies, members of the public and even patient advocates. An important reason for the dominance of choice in these various public discourses around reproductive genetics is the backdrop of anti-abortion and anti-embryo research politics against which they play out. Although in the UK these are the views of a vocal minority, it is a minority that nevertheless plays an active role in public discussion and debate about reproductive genetics, presenting a range of legal and moral challenges to regulators and parents alike (see Mulkay, 1992). These groups seek to close off ambivalence around the 'meaning of life' by arguing against a gradualist, transitional model where the potential for life grows rather than is established at the moment of conception. At the same time they

seek to open up ambivalence on other fronts, around the extent to which women are being offered 'real choices' and about the values we place on disabled lives. Scientists and pro-research advocates have tended to mobilise choice to counteract these claims, but also to open up ambivalence of their own about what the moment of conception might be, for example.

These strategic aspects of ambivalence should not be underestimated when considering the politics of reproductive choice writ large. However, there is little critical reflection of their role in debate in mainstream press coverage of reproductive genetics, where we repeatedly see reproductive genetics presented as a debate between 'pro-life' versus 'pro-science' positions. The focus upon particular events such as new discoveries and applications also feeds this dichotomous format. From press reporting around cloning and stem cell research, to genomics more broadly, there is a consistent lack of attention to the realities of women's choices and the complexities of risk information and interpretation with which they must engage (Williams et al, 2003; Petersen, 2002; Nerlich et al, 2003; Kitzinger et al, 2002). Although fictional representations and dramas about reproduction and genetics tend to explore ambivalence in more depth, these cultural products often sensationalise by foregrounding 'sex and death' (Henderson et al date). The ironic play of particular frames around reproductive genetics in the press also needs to be recognised. Just as readers do not believe all that they read, journalists do not believe all that they write (Petersen, 2002). However, there is still a tendency to focus upon imagined futures of prospective treatments and cure, a tendency that potentially undermines wider and deeper discussion of the one key area where genetics has had an impact upon clinical practice: the area of reproduction.

## **Conclusion**

We understand now that uncertainty is not a temporary nuisance, which can be chased away through learning the rules, or surrendering to expert advice, or just doing what others do. Instead it is a permanent condition of life. We may say more – it is the very soil in which the moral self takes root and grows....

[We must recognise] the intimate connection (not contradiction!) between autonomous, morally self-sustained and self-governed (often therefore unwieldy and awkward) citizens and a fully-fledged, self-reflective and self-correcting political community. They can only come together; neither is thinkable without the other. (Bauman, 2003, 36)

Bauman argues that there ought to be a process of translating between productive and positive situations of personal ambivalence and public spaces where ambivalence can be freely expressed. This could, in his view, form the basis for a better kind of private and public existence in late modernity. This is an intriguing possibility. Given the conditions of ambivalence that we can trace in the area of reproductive genetics, especially in affected couple's, publics and professionals' responses to testing and screening more generally, is there any possibility for drawing upon them to improve dialogue and policy making in this contested realm?

Perhaps it is time to dismantle the ideal of informed choice in reproductive genetics and to put a more modest and provisional version of choice in its place that works with rather than against conditions of ambivalence. Drawing from Roberts and Franklin, it seems that the best types of decisions are made in the context of meaningful relationships between experts - affected families, embryologists, clinicians and counsellors – where ambivalence is openly acknowledged. An exploration of ambivalence clearly requires time. This underlines the importance of timely service provision and space for reflection with supportive counselling for affected couples. This is not an argument about reducing choices in the interests of the community rather than the individual. Rather it is a call to move beyond the ideal of choice as a matter for individuals alone through supportive dialogue rather than condemnation or restriction. More generally, there needs to be time for policy makers and service providers to attend to the sociotechnical contexts through which tests and screening services evolve and the choices and ambivalence therein and a wider range of people need to be involved in these processes.

There is also a need for more creative thinking around choice in the public and political spheres. Too often, it seems, we shy away from allowing people their choices for fear of infringing their freedoms, at the same time as we leave them *alone* with their responsibility to choose. We need more widespread recognition of the ways reproductive choices are framed and limited, and how they are not necessarily always welcome or comforting for those who must make them. We also need better support and empathy for people making reproductive choices - resisting the urge to stand in judgement while loudly proclaiming 'it's up to you'. The typical policy move of resolving tensions around reproductive genetics by appealing to individual choice is far from satisfactory. Perhaps other values like compassion and goodness could take its place. It certainly seems that policy maker, activists, affected families, practitioners and professionals as well as scholars and writer could benefit from actively seek to talk beyond and around choice. This draws upon the sophisticated understanding of reproduction and disability that many groups of the public have already, media rhetoric notwithstanding. The lived realities of having and raising children, caring for sick and elderly relatives, and negotiating responsibilities for oneself and ones' family are intrinsic parts of what we all do, whether we are touched by genetic disease or not. If our political community is to build upon this lay understanding, as well as the many rich and varied studies we have of people's direct experiences of reproductive genetic choices and responsibilities, we need to protect and even foster a range of unwieldy and awkward scholars and citizens of genomics. Challenging ambivalence is as important as fostering it.

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<sup>1</sup> <http://www.antenataltesting.info/default.html>