

6 Empowered by choice?

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At the heart of the right to know and the right not to know debate is the right to choose, which is predicated on the right to information, and other relevant resources, to enable a choice to be made. In many areas of everyday life choices have proliferated; in affluent countries there are more TV channels and types of eggs, ways of serving coffee or listening to music than ever before. Many of these choices may be trivial, but patients and parents are also increasingly bombarded with information and advice on more serious matters concerning health and child rearing. Patients and parents can obtain information to help make a choice of where to go for hospital treatment or which school they would like their child to attend. Hospital and school league tables and websites provide information on outcomes (e.g. survival rates after different types of surgery or examination pass rates), staffing levels and other factors that might influence decisions (hospital car parking or school uniform policy). Even in societies with universal health and education provision, it is acknowledged by providers that the more ‘informed and articulate’ have more choices, including the choice to go elsewhere into the private sector.

This chapter first discusses the choice agenda in health and the effects of choice on the chooser. Next, the possibility and desirability of changing the focus from individual autonomy and ever-increasing choice is considered and discussed through the example of the genetic screening of embryos and children.

The assumption is frequently made that the individual will be empowered by choice, and more empowered when more choices are offered. In a study of an attempt to ‘empower’ the lives of elderly people living in long-stay hospital wards, empowerment was said to be about:

people’s ability to control their lives and act as autonomous individuals. It is about people being able to define their own needs, rather than their needs being defined for them

(Ahlquist 1997, p. 4)

Empowerment was a means to improve the quality of individuals’ lives. In any society there is a relation between power and status on the one

hand and the choices available to people on the other. The impoverished are not only economically poor but will generally have fewer choices and control in all areas of their lives than the more affluent. Although increasing choice for all does not necessarily reduce these inequalities, the centrality of choice in education and health in the UK stresses an equal opportunities agenda.

Choice has always been available to some people. Some have had the resources to opt out of the NHS. Others have proved informed and articulate enough to access choices within the NHS that are not routinely available to others.

The Government believes that all patients should have the advantages of choices over their healthcare. The NHS should develop as a personalised service, open to everyone

(Department of Health 2000)

The NHS Plan quoted above went on to stress the importance of a diversity of provision from which choices can be made to meet different needs. 'Equity and Excellence' was the title of the government white paper (Department of Health 2010). Decision making, it stated, is to be shared with patients who are to have information, choice and control. This is said to result in increased efficiency and higher standards in the health-care system. The subsequent consultation on the proposals had a 'vision of informed, empowered patients making personal choices' but acknowledged that there are 'major challenges in making sure that everyone can exercise choices that do not cause problems for them or the NHS (Department of Health 2010, point 7).

Choice alone, even in the absence of economic costs, does not ensure equality. In health care, and others areas such as education, the active, information-seeking, articulate parent or patient is both a problem, because their success in getting the best service impacts on others, and the model to emulate.

While it could be argued that what people really want is access to a good local hospital, rather than more choices, the assumption is that increased choice leads to greater satisfaction. Where there is more choice, fewer people are likely to get their first choice because the hospitals and facilities considered to be the best will tend to be oversubscribed. A report on the ethics of rationing in the NHS makes the case for 'nudging' patient choice:

Patients should be 'nudged' towards preferred uses of NHS services, through the provision of clear information and making it easy for patients to make the 'right' choices

(Rumbold *et al.* 2012, p. 44)

Since the hospitals considered to be the best will be the most difficult to access, it seems likely that the existence, if not the reality, of choice will

widen inequalities because those with the most social capital will find out the criteria to be given priority and endeavour to fulfil them, whatever they are.

In the commercial sector companies endeavour to persuade consumers to choose their products and be satisfied enough with their choice to purchase them again. Public providers hope that, in taking on responsibility for choice from the professionals, individuals will be both more satisfied and more engaged in the process.

There is extensive research into the effects of an ever-increasing range of choices on the chooser. While this is mainly in the field of consumer behaviour it has been applied to other fields, including choices in higher education (Arterian 2007) and health (Botti *et al.* 2009). Some key findings of these US studies are that:

- Being able to make choices has a beneficial effect on motivation and performance in research where participants are asked to complete tasks, including creative tasks and at work where people have some control over their physical environment.
- There are class and cultural differences in the value accorded to being able to choose.
- Greatly increased choices in consumer goods can lead to confusion and indecision resulting in people being reluctant to choose at all (Chua and Iyengar 2006, p. 56).
- Being offered choice between undesirable options causes stress, anxiety and conflict in the chooser (Chua and Iyengar 2006: p. 54). In these circumstances those for whom a choice is made are more satisfied than those who choose for themselves.
- Those who explore every option before choosing ('maximisers') tend to have high expectations which are unlikely to be fulfilled and they suffer from dissatisfaction and stress (Schwartz 2004).

These studies begin to differentiate between choosers and subdivide them into groups according to personality traits, assessed by psychological tests, by culture and socio-economic status. The findings confirm that having choices is valued by those who are well educated, in a middle class or professional occupation and from a Western cultural background that valorises individualism rather than interdependence (Chua and Iyengar 2006). As Matravers argues, in western societies to be an adult is to be an agent, with the ability to choose and liable to be held to account for the choices made (Matravers 2007, p. 4). Stephens, Markus and Townsend argue that choice is associated with agency but that agency is more central to the middle classes than it is to the working class, for whom conformity to the group is important to well-being (Stephens *et al.* 2007, p. 827).

Choice and responsibility

In making a choice individuals become responsible for the outcome. It is their choice, whether good or bad. Of course not all choices can be lumped together and when it comes to choices that have a tragic consequence (e.g. the death of a newborn baby) parents who made the choice for themselves were found to cope less well with the outcome. An ethnographic study comparing parents with new-born children on life support in France and the USA found that decisions to switch off the machine were left to the physicians in France, whereas in USA parents had to make decisions themselves. The researchers concluded that 'when confronted by tragic choices individuals are likely to be better off if those choices are either physically or psychologically removed from them' (Botti *et al.* 2009, p. 349).

The authors do not use their findings to call for a return to paternalism but rather to argue that it is too simple to say offering choice is best when dealing with 'messy realities' and that the demand for participation will vary between parents (Botti *et al.* 2009, p. 350). Bearing the responsibility for choice was a burden for parents in those circumstances; they felt they were being asked to choose for their child to die, and to be able to follow expert advice provided support and made them feel better about the decision.

Similar findings were made in a qualitative study of UK women making decisions in pregnancy about antenatal screening (Ahmed *et al.* 2012). In the UK health professionals are required to provide the information necessary for patients to make 'autonomous, informed decisions' by providing the necessary value-neutral information and be non-directive (Ahmed *et al.* 2012, p. 2). While some have long argued that the ideology of genetic counselling does not, or cannot, be realised in practice (Clarke 1991; Mitchie *et al.* 1997) this study by Ahmed *et al.* found that women wanted advice to help them come to a decision about screening. The women interpreted 'advice' in different ways: as information alone, as guidance and support and as providing direction. Most understood that professionals did not want to give an opinion for ethical reasons, and the fear of being sued, but they would have valued their advice in order to help them come to their own decision (Ahmed *et al.* 2012, p. 6).

The problem with making choices in the real world is that outcomes are not predictable and so however much information is available it cannot answer the crucial question: will **my** baby be healthy? If I undergo one more course of IVF will **I** have a successful pregnancy? However small the risk, your baby may be the one in a thousand that has the condition; however many courses of IVF you have had there is a chance that

the next one will be successful so how can you make the decision to stop? While the ideal situation is one in which 'the individual is free to select whatever action she or he desires...' (Paton 2007), in practice individuals live in particular social and cultural contexts that impinge on their decision making. Where IVF treatment is publicly funded treatment will usually be limited; in England and Wales the recommendation is that three cycles should be offered for women who meet the criteria (National Institute for Clinical Excellence 2004). Women who can pay for private treatment have more choices. In Peddie *et al.*'s study of women who had undergone IVF without success, the psychological, emotional and social costs of prolonged and unsuccessful treatment were clear but the decision to end treatment was difficult. Two themes in the findings were unrealistic expectations of success and social and media pressure; the social obligation to keep trying new technology and the constant promises of new breakthroughs that might offer new hope (Peddie *et al.* 2005, p. 1946). In this example women are being asked to choose between undesirable options: stopping treatment and so acknowledging that they will almost certainly never give birth or continuing expensive treatment which affects their health with a diminishing chance of success after unsuccessful cycles.

The choice discourse is convenient for service providers and difficult for individuals to resist. However, as discussed, ever-increasing choices in consumer goods and health care do not ensure consumer or patient satisfaction or happiness. Rather, a 'proliferation of options seems to lead, inexorably, to the raising of expectations' (Schwartz 2004, p. 186). In a publicly funded health system, there will inevitably be dissatisfaction among those who find that the choice they made is not in fact available.

Choosing as self-expression

The act of choosing is not just important because of the value attached to autonomy and the association of choice with freedom but because making choices is an expression of who we are (Iyengar 2010). We define who we are in relation to other people, so choosing is actually a social act that communicates to others what sort of persona we want to portray. As we choose we ask 'What kind of individual am I, and given who I am, what should I want, and given what I should want, what do I choose?' (Iyengar 2010, p. 272).

In this self-conscious model of the individual, we constantly monitor the reactions of others and modify our behaviour and choices accordingly. In the classic social constructivist account human beings construct their social world through interactions with others and then perceive

it as objective reality which in turn constrains their actions. The ability to shape our environment could mean that human beings were overwhelmed by the constant choices that had to be made. As discussed earlier, the multiplication of choices can lead to confusion and anxiety and the way of resolving this is to limit the need for decisions by establishing standards, routines and habits that reduce the need for choice (Schwartz 2004, p. 114).

In every society there are socially acceptable ways of doing things that remove the need for individuals to decide how to act in every situation; their actions become habitualised: 'Habitualization carries with it the important psychological gain that choices are narrowed ... This frees the individual from the burden of all those decisions' (Berger and Luckmann 1967, p. 71).

In many modern societies choices have multiplied in areas where there were once strong norms and sanctions for those who broke them, for example, sexuality, family life and gender roles.

Removing choice

As 'choices' are burgeoning in both the public and private health sectors, is there an alternative to the stress on choice; could choices be restricted on ethical grounds that would be socially acceptable? The idea of simply removing choice has been discussed in relation to participation in medical research and to organ donation, both areas where informed consent must be obtained (Evans 2004; Harris 2003). The value attached to informed consent makes any suggestions of compulsion controversial. Evans (2004) argues that, in a publicly funded health-care system, there is a moral duty to take part in research in some circumstances. He limits this to cases where the patient has sought treatment for a condition and is eligible to be enrolled in research into treatment, the research is not expected to harm the patient and it may benefit others. In these circumstances enrolment should be automatic:

And because not everyone can be relied on to do their duty, in clinical research ... then responsibility for the decision must be given to others. You should be entered into the research automatically, and if you want to obtain treatment in these circumstances then you should no more have a veto over taking part in the research than you should have a veto over paying your income tax

(Evans 2004, p. 202)

The argument is that those currently having treatment benefit from those who took part in medical research in the past and thus have an obligation to help others in the future.

In the case of organ donation many European countries have some form of opt-out system where the onus is on those who do not want to donate to make their wishes known. However, in practice, even in Spain, which has the highest rates of cadaveric donation, organs are not removed unless the family agrees (Navarro-Michel 2011, p. 160). Compulsion even in limited circumstances is controversial. After all, the emphasis on informed consent and the frameworks for ethical review of research involving human subjects followed the abuses carried out in the name of medical research in the 1930s and 40s. Abuses in human medical research have often involved subjects who are neither high status nor powerful. So, looking at the analogy Evans draws with income tax payment above, there are ways in which the elite may minimise their tax payments with the help of experts, while most UK employees have tax deducted by their employer. No doubt there would also be ways of avoiding compulsory enrolment in research for those with the resources to seek alternative treatment.

Imposing compulsion in an attempt to reach a desired end in health care – a wider cross section of medical research subjects, more organs for transplant – might not be workable in a democracy. Would the media soon be reporting on tearful relatives whose loved ones' organs were taken against their wishes or on people refusing treatment because they did not want to be enrolled in medical research? But what about alternative ethical framings that are less individualistic? There have been criticisms of the value accorded to individual autonomy and a counter move in ethics to more communitarian values such as solidarity, reciprocity, dignity and prudence (Hayry 2003; Knoppers and Chadwick 2005). When discussing donations to biobanks, population genetic databases established for research purposes, the argument can be made for a solidarity-based approach rather than one based on individual autonomy (Prainsack and Buyx 2012). However, in other areas such as genetic testing, a solidarity approach seems less tenable because it would require people who are making choices about what is best for themselves or their children to focus on broader issues.

Genetic tests, treatment and enhancement

For the individual, genetic tests are available for an ever-increasing range of traits that carry elevated risk of developing a disease or behavioural condition. Most people are probably unaware of the profusion of genetic tests but those who are pregnant, undergoing IVF or have a family history of a specific disorder will be offered a limited range of tests. While access to genetic testing will be restricted for publicly funded patients,

and may vary according to their location, privately funded patients have more choices, which in turn puts pressure on the public health service to increase availability. Since 2009 UK clinics that offer fertility services have been licensed to test patients for specific genetic traits through pre-implantation genetic diagnosis (PGD), rather than having to apply on a case by case basis. Since 2010, traits that indicate lower penetrance and late onset conditions can be included, meaning that a percentage of those with the trait will never develop the condition and others will develop it only in adulthood. These include BRCA1 and BRCA2 mutations that carry an increased risk of breast and ovarian cancer and early onset Alzheimer's disease. For UK women with a breast cancer trait, their lifetime risk of developing breast cancer is raised from around 12 per cent to over half. The Human Fertilisation and Embryology Authority (HFEA) undertook a consultation entitled 'Choices and Boundaries', before introducing PGD for these conditions (HFEA 2006). A response from Genewatch UK objected to the use of the term 'choice' rather than 'decision' in the title of the consultation, on the grounds that it 'tends to turn the process into one of marketing, not serious deliberation' (Genewatch UK 2006). The particular imperative to emphasise choice in genetics is of course the shadow of eugenics in the sense of state-enforced controls over births. Wachbroit and Wasserman argue that this legacy of abuse is why those patients who are offered genetic tests and disease screening are seen to require specialist counsellors. The official role of genetic counsellors is non-directive; they are to offer individualistic, client-centred therapy that allows patients to make their own decisions (Wachbroit and Wasserman 1995, p. 238). As has been pointed out, the cumulative effect of individual choices can, like state-enforced controls, also lead to societal change. For instance, preferences for boys over girls have resulted in distorted sex ratios in parts of India and China (Hesketh 2011).

Regulation within a country may limit access to PGD, prenatal testing and childhood testing but direct-to-consumer testing operating in less regulated environments opens up availability. Is individual choice in this area empowering and, if so, who is empowered?

Savulescu supports a broadening of PGD to non-disease traits. In his view, parents should have information about non-disease traits through genetic testing, be able to freely choose which child to bear through PGD and be provided with 'non-coercive advice' on which child has the highest chance of having the best life (Savulescu 2001, p. 424–5). Using the Internet and international market consumers can currently purchase tests for themselves and their children either individually, as a package, or arrange an entire genome scan. They can investigate their genetic risk for all sorts of physical and mental disorders, including

complex multifactorial disorders, for their genetic ancestry, can identify those genetically related to them or check out their child's 'inborn talent'. Companies based in the USA that offer hundreds of tests and even whole genome scans include 23andMe, deCODEme and SeqWright, all easily found by a web search engine. The California Department of Public Health wrote to thirteen companies based in the state requesting that they 'cease and desist' from offering testing to California residents (Magnus *et al.* 2009). The State of California requires companies offering such tests to be licensed and patients should not access tests without a physician's order (*ibid.*). The companies that replied made three arguments: that genetic information is a fundamental part of a person and individuals have a right to it; that the tests are not really genetic because they give information on genetic predisposition; and that people should have access to their own health information directly, without having to involve a physician (*ibid.*).

The company 23andMe markets DNA testing as 'a "one size fits all" perfect gift' that will allow the recipient to: 'Gain insight into your traits, from baldness to muscle performance. Discover risk factors for more than 200 health conditions with the assurance that the list grows each month'. These 'health conditions' include serious diseases like breast, stomach and lung cancer, Parkinson's disease and Alzheimer's disease, so it might not be a 'perfect gift' for all! For those testing newborn babies or toddlers who cannot yet spit, there is the opportunity to send for a special test kit that requires only a quarter teaspoon of saliva to be collected. No restrictions on parents testing their children are mentioned here.

Although the arguments evoke individual autonomy and the right to know, company websites may also appeal to solidarity and community in their marketing. The 23andMe website contains research findings and in a section entitled 'core values' has the following message to potential patients:

you're joining in a community of motivated individuals who can collectively impact research and basic human understanding. In today's connected information age, it's no longer just about me. Instead it is about how we can change our understanding of ourselves by joining together

Another group of companies target their products specifically at parents of young children. Companies such as talent4me and My Gene Profile offer a raft of genetic tests claiming to reveal your child's 'inborn talents'. Parents are told that they will find out whether their child has a particular sporting talent or is musical so that they know how to best direct their child and avoid the frustration and failure that comes of encouraging participation in a type of sport in which he or she will not succeed. Parents

can replace the hit-and-miss approach of giving their child all sorts of enrichment classes and instead take scientific direction, know where the child's talents lie and 'spend money wisely' (My Gene Profile).

Leaving aside the question of the validity and reliability of the tests and how many parents have actually used them, it is clear that the website material plays on parental insecurities and competitiveness. Your child can only succeed by having the edge over other people's children:

These advertisements describe complex, confusing, and anxiety-producing genetic concepts for the consumer. Drawing on themes of 'choice,' 'hope,' 'fear', and 'peace of mind,' these advertisements validate patients' worries about their genetic risks and appeal to their desire to assert control over potential outcomes (Golhurst *et al.* 2002)

The advertisements are designed to create desires and demands in parents, increase the numbers using genetic testing and provide 'solutions' to problems that parents did not previously know they had (Genewatch UK 2006). The view of genes conveyed in the brochure (English version) is that they are static things that can be read off to see whether or not a child has a strong 'leadership gene' or 'performance gene' so that parents can have scientific direction rather than a hit-and-miss approach to helping their children.

If parents took up the opportunity to access these tests to get the edge for their child, or prospective child, weighing up what to do with the results, whether using PGD or discerning a child's 'inborn talent' may not be straightforward. The more tests that can be performed the harder it will be to decide which the 'best' potential child is, or, which inborn talent to pursue. The embryo with the predisposition to aggression and criminal behaviour seems an obvious one to discard but if the increased risk is only in cases where the child is maltreated (Caspi *et al.* 2002) then perhaps this is better than a predisposition to alcoholism. If your child's inborn talent test reveals a talent for rugby football and susceptibility to alcohol addiction then perhaps the responsible parent would not encourage the child to play rugby because of the temptations of post-match alcohol consumption in later years!

While parents might struggle with information and choice overload the effect of free choice at the social level also has to be considered. Fukuyama argues that there will be in effect a 'genetic arms race' with parents forced to 'choose' to prevent their child being disadvantaged (Fukuyama 2002). Currently parents only have a choice from available embryos for specific traits but if many people chose, say, taller and more intelligent children (if such a thing became possible), then the average height and IQ would simply rise. As an enhancement becomes normal then it is no longer

advantageous and so those who wanted their child to have the edge would need to seek another 'improvement'. As Hirsch wrote: 'If everyone stands on tiptoe, no one sees better' (Hirsch 1977, p. 5).

As research continues and more tests are developed there are also concerns that a right to know may become a routine requirement for parents to gain access to welfare services or insurance-based health-care systems. In a report on behavioural genetic tests, personalised information on behavioural predispositions was seen as valuable but:

key concerns are that individuals remain free to choose whether or not they provide this information and suffer no discrimination or disadvantage from withholding their genetic information, and that any use of genetic information is equal and equitable – advances in behavioural genetics should not benefit one group in society more than another

(Dixon 2005, p. 15)

If the behaviour in question is illegal, stigmatised or imposes significant economic and social costs on society these 'key concerns' that focus on individuals would have to compete with concerns about protecting the public. As the range of available tests continues to increase what limits will there be to individual responsibility? Hearing of a child born with a condition for which there is routine prenatal testing, such as Down's, people might ask whether the mother 'took the test', but parents who choose to continue with the pregnancy are not necessarily condemned (although there is evidence in Britain of an increase in negative attitudes to welfare recipients in general and there may be an assumption that the disabled will be claimants) (Park *et al.* 2013, p. 30). However, in the case of tests for behavioural conditions the parents' decision could be seen as a public rather than a private matter. The child with a genetic trait associated with aggressive behaviour, addiction or impulsive behaviour might engage in behaviour that negatively affects others. While research indicates that these behaviours have multifactorial causes, evidence on genetic traits has already been presented in criminal courts, usually by the defence, and has in some cases resulted in reduced sentences (Calloway 2009; Farahany and Coleman 2006). Such evidence might also be used to argue that these individuals are particularly dangerous and likely to reoffend so should have a harsher sentence, particularly if they knew their genetic risk (Levitt 2013).

Parents, especially mothers, have choices to make that were unknown in previous generations and this undoubtedly increases anxiety. For some parents choosing PGD is empowering; they may be able to choose to implant an embryo free of a specific genetic disease or have a child who is a tissue match for a sibling (a so-called 'saviour sibling').¹ But when it

comes to non-disease traits or mild conditions are there any lines to draw or should all decisions on their children's genetic make-up be the responsibility of parents, however much further our knowledge and techniques develop? At the very least, if there is to be a free market then parents would need some way of managing the options available; perhaps expert choice advisers and packages of tests with computer-assisted decision-making programmes. Although parents are focused on their own children, it is conceivable that some will see a shared interest in coming together to resist testing, selection or enhancement in particular areas and/or to promote it in others.

Choice

The picture that emerges is of the modern individual being bombarded with choices accompanied by more or less subtle messages about what the good parent or the responsible person should do. The right to know has become the responsibility to know. In the field of health care and especially genetics, what was considered to be part of nature that humans could not change is being opened up to choice. As discussed in this chapter, in specific circumstances choice can be a burden from which people would like to be relieved; it can lead to stress and confusion or if the available choices do not meet expectations, to disappointment and regret. Faced with a long and complicated menu at a restaurant, or another familiar set of choices, we can fall back on habit and have what we always have or opt for something new and unknown; the consequences are probably trivial. When it comes to choices made over our own or our children's health we are more likely to be in an unfamiliar situation where we have no experiences or habits to fall back on, yet our choices could have serious consequences. In this context choice and individual autonomy seem to be an insubstantial ethical framework that increases responsibilities but does not give us the means to choose well.

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NOTES

- ¹ There is also the possibility of parents wishing to select an embryo with what others would consider a disability. This was prohibited in 2008 in the UK by an amendment to the UK Human and Embryology Act (section 13, subsection 10). This amendment was probably a response to the highly publicised case in 2002 when a lesbian couple selected a sperm donor with hereditary deafness, and subsequently had a deaf child. However, they did not make use of PGD as their donor was a family friend.