Well:Nzgenesbull   published in Bulletin of Medical Ethics. 176:13-18, 2002

The promise or threat of the new genetics to children

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Rapid advances in genetics promise to being great benefits, through effective prevention and treatment of disease and suffering, and through increase of knowledge, skill and prosperity. This paper reviews how children are the first main group to be affected by the promised new DNA-based genetic knowledge and techniques. Whilst assuming that the embryo and fetus do not share the full moral status of the child, this paper questions how attitudes towards prenatal existence and new developments in embryology and fetal genetics might alter attitudes towards babies and children and also parent-child relationships.

Almost all reports of plans for genetic interventions on children imply that their interests are totally aligned with those of their benevolent parents. Closer analysis of child-adult relationships reveals inter-generational conflicts. (1) Parents can control children's lives, their enjoyments, knowledge, resources and life chances. The new genetics will enable adults to control children's identities in previously unimaginable ways, along with change in social attitudes and structures that prepare for genetic services to be widely available, as this paper reviews.

Presenting the new genetics

The Human Genome Project (HGP) that reveals the structure of DNA has been presented to the public in quasi-religious terms, as if it provides essential answers to the great questions about humanity, for example: `It is a complete manual for building and running the human body. We'll be the only species who knows how to build ourselves, to know who we are and where we came from'. (2)

One approach, through which geneticists gain considerable financial and political support, is by the use of the alarming comparison, when they compare their intentions with a more alarming alternative that makes current plans seem safe in comparison. For example, a decade ago research on human somatic (body) cells was justified as much less dangerous than taboo research on germline (reproductive) cells. The latter cells irrevocably affect all future generations, and scientists undertook never to tamper with them.(3) A few years later, human cloning and other germ-line interventions were being developed, and laws to regulate them being passed. Again, some scientists present their preferred development as safer than a rejected alternative, thus appearing to combine scientific innovation with judicious prudence and public benefit. They use the reassuringly positive phrase `therapeutic cloning' to describe cloning for research purposes, although the meaning of `therapeutic' word is stretched to denote not immediate therapy but experiment which might possibly one day produce effective therapies. This is contrasted with the dangers of `reproductive' human cloning, that would allow the cloned embryo to develop into a child.

The argument illustrates the moral shift over a decade that now assumes the public will more readily accept the use and destruction of certain embryos for research, than their subsequent birth as children. Such complex changes in the public psyche may be impossible to explain, but part of this process appears to involve: changes in language from `pre-term baby', to `fetus', to `embryo', that distance human origins from humanity and blur moral debates; and old popular myths that link childhood to deficiency and deformity, (4) mingled with fears of monstrous birth. Scientists appeal to public fears by claiming that their embryo research will reduce and prevent such births. They describe `tragic' families who `desperately need' these new technologies to prevent their children from inheriting genetic conditions. Less explicit, but perhaps more influential subliminally, are images of very abnormal children, in magazines and television programmes on genetics. The narrators' tones mingle pity with hints of disgust; the whole child is lost in the emphasis on certain deficiencies.

The journalism conveys inter-related messages: this `suffering' can be prevented; it is kinder and better to prevent such intolerable lives and therefore to prevent such beings from existing; the embryo stage is not only morally neutral in terms of enabling embryos to exist or to die, it is becoming morally desirable to intervene; these interventions may be for the benefit of the particular embryo and parents through treatment, or for society through research; it is progressive to regard some embryos as research material, provided the adults concerned consent or do not refuse. Current legislation internationally (5) illustrates the gradually shifting legal and moral boundaries, away from prohibition and towards controlled human germline research. Some governments require that only `spare' embryos from infertility treatments may be used, and no embryos may be produced solely for research purposes, another use of the alarming comparison argument mentioned earlier. To understand debates about the new genetics involves examining how argument, language and euphemism are presented. The questions missing from public debates include asking how public images and general fears about deficient, imperfect babies and children are being fostered, and what latent irrevocable new futures we might bequeath to future generations.

Developing the new genetics

Britain now allows `therapeutic' cloning of human embryos .(6) Germline research has been conduced for years on animals and human embryos in countries without legal restrictions, including the US, which regulates only publicly funded research. Some doctors are cautious about how these advances might affect children, (7) but others dismiss criticisms as irrational, sometimes in a paradoxically emotive way: `To be hysterical about the use of embryos for tissue engineering does not make any sense if you are going to save a life`.(8)

In 1990, there were promises of `gene therapy cures' within a few years, but a decade of trials has produced almost no effective treatments. Recent reports assert that the Human Genome project may have grossly underestimated the total number of human genes, and call for the meaning of the still invisible `gene' to be defined.(9) However, with the 30-40,000 plus human genes, that are all copied into the millions of cells in each body, attempts to alter our gene structure are immensely complicated. Gene therapy is likely to be most successful when it alters genes in the pre-embryo's 32 or so cells, though at this stage it is easier and cheaper to select out `faulty' embryos or select in preferred ones, than to attempt to correct them. British couples can now select in vitro embryros to delete those with a full condition or carrier status and also ones likely to provide compatible samples to treat a diseased relative.(10) There are concerns that these children will be seen as means, rather than ends in themselves, with the risk that they will be rejected if the treatments to which they contribute are unsuccessful.

At present, genetic knowledge is used to reduce disease and disability in two main ways: offering life-style advice to (mainly middle aged and older) people at higher identified genetic risk, or offering termination of affected pregnancies – an intergenerational approach. New DNA-based genetics as yet hardly affects the health services, but structures, routines, skills and attitudes are in place (11) that will allow genetic knowledge and techniques to flood into the health services as soon as they are available, without public or professional debate and deliberate decision making.(12) One example is the aim to isolate fetal cells from maternal blood that it already routinely collected in prenatal clinics; 4-500 genetic conditions could then be screened for relatively quickly and cheaply, once the technique is developed.

Attitudes towards the new genetics

British public opinion about GM (genetically modified) plants and animals has generally swung from lack of interest towards hostility and fear. Human genetics, however, tends to be seen as the silver lining to the genetic cloud. The mass media promote enthusiastic beliefs that human genetics will, indeed already does, relieve suffering in new miraculous ways that justify all manner of animal experiments.

Genetics enticingly promises doctors Science Based Medicine - precise knowledge of the etiology, diagnosis and prognosis of disease - in contrast to the lesser consequentialist science of Evidence Based Medicine. Convinced of such promised benefits, in 2001 the British government set up a Commission to ensure that human genetic services will be fully used and equally available to all. Whilst being equitable, such a programme can become a drag net, (13) when services which very much benefit a few people at high risk are gradually offered routinely to everyone, with increasing pressures on practitioners to offer them and patients/clients to accept them. Examples include prenatal screening, and screening of IVF embryos before implantation.

Science, industry, commerce, the law, especially patent law, and governments aim to exploit immensely profitable genetic research and development. The vast sums invested raise questions about whether public benefit or profit is the prime motive and guiding value. When economic market values determine policy, children can be very vulnerable: they cannot vote or own property and others are appointed to make decisions for them. For example, all children born in Iceland are enrolled into the DeCode genetic databank unless their parents object; children cannot withdraw until they are adult. Even then, they cannot backdate their withdrawal, (14) and their childhood data will always be used. It has been argued that children have no right to genetic privacy, their genes belong to the family gene pool and should be common knowledge for all the relatives.(15) Ethical discussions about genetics are mainly confined to adult-centred issues of consent, confidentiality and insurance, in which children's concerns tend to be over-looked.

Another crucial kind of vulnerable childhood dependence is that children's work at school, at home, and in their communities, is seldom recognised as `work', or valued or paid for, and instead they are expected to `earn' their place by the `emotional labour' of being pleasing and compliant.(16) The United States has the only government in the world to refuse to ratify the UN 1989 Convention on the Rights of the Child, which respects the `worth and dignity' of every child. US writers on ethics especially magnify and endorse parents' rights, in effect, to treat their children as property rather than persons: `to shape and guide their child's future lifestyle and life plans' because `rearing a child in an environment in which their [parents'] values and beliefs flourish is a principle reason for becoming parents'.(17) While there may be some benign truth in this remark, it could be read as an illiberal attempt at moral cloning. The comment dangerously denies children's early propensity to develop their own beliefs through their own unique experiences. It suggests an arrogant intolerance, not only towards children's thinking and values, but also to the moral struggle for children and adults to live with peace and justice in very mixed societies, and in global `environments' not dominated by the parents' personal values. This entails some respect for other values and beliefs which the parents' supposed rights seem to exclude. The comment also implicitly denies that, though not always easy, parenting and its rewards involve relating to children as persons, not simply as things to be `shaped'. The most ominous aspect of promoting an ethic of parental power is that it could validate parents' future far greater potential powers over the genetic make up of their children, for good or ill.

Contemporary geneticists distance themselves from eugenics, which they define as a past history of state enforced abortion, sterilisation and euthanasia programmes on resisting people But this obvious, `front door' eugenics is contrasted with `back-door' or `consumer eugenics',(18) when states achieve similar results though `therapeutic' abortions and promotion of parental prenatal choices.

Genetic interventions that affect the next generation include pre-partnership/marriage, preconceptual, pre-implantation, and prenatal tests and counselling. Abortion is frequently justified as less distressing than a child's impaired life. Pre-implantation genetic diagnosis (PIGD), that selects which embryos to implant in the uterus, is promoted as less distressing, and less of an ethical issue, than abortion. As already mentioned, doctors can modify embryos and add or delete cells. It is currently debated, for example, whether to select out only embryos and fetuses with a full genetic condition, or also to withdraw those with the carrier trait (that will not affect the child but might affect the child's children). Should embryos with a late onset condition not be implanted? And how many healthy years before the condition develops constitute a worthwhile life 60, 40 or only 20 years? These calculations tend to discount childhood as a worthwhile time in its own right.

Couples can now choose to implant an embryo that will be a compatible `donor' of tissue to treat a diseased relative. The new techniques relieve and prevent much distress, but can also pose painful, bewildering, sometimes regretted choices,(19) and concerns that children will be valued as the means towards other ends, rather than for themselves. The techniques contribute to geneticisation,(20) when causes, processes, prevention and treatment of disease and disability are all reduced to genetic terms. There is then the danger of ignoring other vital and remediable factors such as social inequalities, which can so greatly increase or reduce disabling constraints on all people's lives, whether they have genetic impairments or not. Further, in emphasising solely biological problems and solutions, geneticisation denies strengths in parents and children, such as human agency and ingenuity in overcoming problems. It thus implicitly and insidiously dehumanises and disempowers them.

Genetic services contribute to the privatising of parental responsibility.(21) Whether women decide to end or continue with their pregnancy, they carry new explicit responsibility and potential guilt for their conscious `choice' about whether or not to have an impaired child. Formerly, when the event used to be regarded more as a blameless matter of chance, there was stronger case for shared societal responsibility for, and inclusion of, these children. Now, however, negative accounts of disability tend to influence prenatal counselling(19) and midwives raise parental expectations (demands?) when they assert that `everyone wants a perfect baby'.(12) This does not encourage tolerant, inclusive attitudes towards the next generation. Although hard to measure, it is also hard to believe that the effects of mass prenatal services, checking almost every pregnancy for fetal pathology and for potential termination, do not affect individual parent-child relationships and social inter-generation attitudes. Certainly, rising maternal tentativeness has been demonstrated during the impressionable months of pregnancy,(22) and linked to fetal tests. Might this more provisional, tentative parenting continue after birth? Reported intolerance, exclusion and abandonment of children from schools and homes are markedly increasing. By Spring 2002 in Britain, local taxes were considerably increased to pay, it was argued, for the rapidly rising numbers of children removed from their parents' inadequate care, and also for treating these children's complex problems. Among other powerful influences on children's lives and health and on inter-generation relations, the impact of current and likely future trends in the prenatal and genetic services urgently needs to be reviewed.

The new genetics promises, further, not only to reduce disease but also to enhance future children.(23) Enhancements for height, athleticism, intelligence and other features are not yet possible genetically. Yet the current selecting out of fetuses likely to have low intelligence (Down's syndrome, fragile X) or low stature (achondroplasia) with trends, such as the widespread use of prescribed drugs to modify children's mood and behaviour, pave the way for social acceptance of genetic modifications when they are possible. Should parents be allowed to enhance their children genetically, and how could that affect generational politics? Will enhancements inevitably become acceptable, partly through global market competition, when clients and scientists travel to countries that permit such endeavours, and pressure their own governments to allow them? Arthur Caplan, official ethics adviser to the US HGP, predicts that doctors will routinely make total DNA scans, advise on healthy life-styles, select and enhance embryos. Routine brain scans will enable doctors to control behaviours and learning difficulties, and enable employers to select new staff. `The rush to use eugenics will be amazing with parents competing to give their kids the best start in life`, death may be deferred indefinitely. `Many parents will leap at the chance to make their children smarter, fitter and prettier.' Technology which `simply makes for better children' will overtake ethical concerns. `In a competitive market society, people are going to want to give their kids an edge....a genetic edge is not greatly different from an environmental edge....You might download French into the 3-year-old's brain directly.`(24)

Will parents come to feel careless, negligent, callous, if they refuse genetic enhancements for future children? When enhanced children fail to live up to costly expectations how will they fare? When unenhanced children are ill or disabled, whose fault will it be, and who will pay for their care

Although a decade of human single gene research has brought few results, experiments to insert a whole chromosome that can carry thousands of genes have succeeded, for example, in mice. The mice offspring inherited the extra chromosome, and the technique opens the possibility for numerous irrevocable preconceptual choices to create designer babies. Human babies, occupying an ambiguous position between humans and animals,(26) are likely to be among the first candidates(3) for such advances. New genetic treatments may simply be accepted as better routine versions of current best practice, instead of being critically debated, not least for their impact on childhood. Behaviouralist interventions often imply that the child is the problem, and aim to fit the child to adult-centric requirements. For example, `attention deficit disorder' describes children who do attend, but to things, and in ways, which adults do not want them to. The power to alter children through genetics instead of drugs will be immensely greater.

This raises profound ethical questions, about the meaning of human existence, identity and intergenerational obligations. Far from examining these questions, current ethics attention turns to the putative benefits for wealthy adults rather than to potential problems for children and society. Scientists' claims, mentioned above, that genetics provides quasi-religious *knowledge* extend to assumptions that the *morality* and virtue endorsed by the `selfish gene' (selfish parent) replaces morality with ancient roots in religion. `[N]o one has the guts to say it [but]: If we could make better human beings by knowing how to add genes, why shouldn't we? What's wrong with it?...Evolution can be just damn cruel, and to say that we've got the perfect genome, and there's some sanctity? I'd like to know where that idea came from, because it's utter silliness.'(25) `The right to a custom made child is merely the natural extension of our current discourse of reproductive rights. I see no virtue in the role of chance in conception, and great virtue in expanding choice.'(26) `[O]ver the next two centuries, the number and variety of possible genetic extensions to the basic human genome will rise exponentially...Extensions that were once unimaginable will become indispensable...to those parents [the `generich' 10% of people] who are able to afford them.'(27) The extensions will include cross-species genetics, that picks desired characteristics from animals to create `post-humans'. The question we have to ask first is: Can children and global society afford these genetic changes, which treat children as consumer artifacts to alter according to other people's whims? `Where love, compassion, altruism and justice have failed, genetic manipulation will not succeed'(28) - and is likely to erode these essential intergenerational virtues that sustain human life. To assess the promise or threat to children of the new genetics involves moving beyond medical and genetic questions to include social and political questions as well.

Acknowledgements
I am grateful to the Wellcome Trust for funding `Cross Currents in Genetics and Ethics at the Millennium' 1999-2001, grant no.056009.

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