Childhood, genetics, ethics and the social context

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How much do ethics and genetics have in common? This chapter suggests that current understandings of ethics and of scientific, clinical and counselling work in genetics have common characteristics. More critical awareness of these common threads, and more attention to the social context would deepen understanding in all these disciplines and increase their efficacy. Underlying patterns of thought in social attitudes towards childhood and eugenics will be considered, to show how ethics and genetics reflect and reinforce such attitudes.

The example of Robert illustrates how attention to the social context can easily be lost. Robert had no physical or mental disability. However, his family lived in two small damp rooms and he often had ear infections. When he began to attend school, he was soon in trouble for not obeying his teacher, and for not learning or relating positively to other children, because his hearing had become so poor. Soon he was `kept in' during break times and he grew more lonely and restless. His parents began to `ground' him after school, and he became more sad and angry. The teachers started to talk of hyperactivity, fragile X and Asperger's syndrome, and referral to special school. Robert is one of many examples of how social conditions are reframed into supposed genetic ones.

Policy from the past

Today's health services for those affected by genetic conditions can have great benefits as amply illustrated through this book. However, a darker side of genetics is linked to trends from the past which, although now less consciously and publicly followed, can still be influential.

One typical example of its time, is a Medical Research Council (MRC) Report from 1932. The premise of the Report is that crime `indicates a congenital fault of mental organisation... a failure of the brain to function properly'. Menstruation is posited as a cause of insanity and crime `attributable to irritation of the ovaries or uterus, a disease by which the chaste and modest woman is transformed into a raging fury of lust'. Facial and other anomalies of the `criminal type' were thought to resemble `the Mongoloid or sometimes the Negroid', being morally and physically `peculiar'.

Psychologists quoted in the Report had examined numerous women prisoners, noting their abnormal genitalia, menstrual changes and `orgies' which included attempts to escape from prison. Many case studies of working class adolescents noted ugly and `fierce' features, the `marks of a hopeless moral reprobate'. These `very dangerous' girls, the MRC Report recommended, must be sterilised and permanently confined in colonies `under the guardianship' of psychologists who should be allocated `hunting grounds' in working class areas from which to select their cases.[i]

Are attitudes now very different? The 1990s are only an academic generation from the Report, because the experts quoted, such as Cyril Burt, were teaching in the 1950s when many of today's professors were trained. Similar views pervade present society, on `problem adolescents', on `congenital faults' that are thought to affect morality and behaviour, on the importance of researching and controlling `abnormality', and on biology as destiny without reference to social influences. Overt misogyny and racism are far less respectable today, but prejudice against disability and difference is still pronounced,[ii],[iii] and working class and black young people are greatly over-represented in psychiatric and penal systems.[iv] The following sections consider how current attitudes in genetics, ethics and society reflect or challenge those earlier views on inherited conditions.

Today's attitudes towards childhood and adolescence

Inevitably, genetics is influenced by its social context, including attitudes towards babies and children. Our society is somewhat hostile to children. Of course, there are many loving relationships between adults and children, as there are loving relationships between individual black and white people. But just as there are racist structures in society, there are also ageist ones set against young people. Ageism is almost always discussed in relation to old people. We do not even have a word for `childism', possibly because it is so endemic and accepted that it is rarely noticed.

Here are a few examples of numerous negative responses to young people. Governments that have ratified the United Nations (UN) Convention on the Rights of the Child[v] report regularly on their progress to the UN. The UN was very critical of the British government for its many failures to respect and protect children.[vi] In over 300 pages, ways are documented in which law, policy and practice in the UK have to be changed if standards are to meet those in the Convention.[vii] Problems for young people are increasing[viii] and one common theme is exclusion from mainstream society: increases in school exclusions, homelessness, and unemployment among young people; rising suicide rates among young men; one in three children living in poverty; cuts in benefits for young people; fear of strangers and dangers keeping children away from public places.

A revealing measure of public opinion is the political parties' manifestos, advocating policies which they believe will attract the most votes. The two main British parties emphasise measures to control and punish young people, such as a proposal (June 1996) for an evening curfew for everyone under a certain age, although the vast majority are not criminals. Young people are constantly criticised and derided in the mass media, and tend to be stereotyped as either victims or villains, instead of being seen as the complex and often competent individuals they actually are. Adolescence is usually framed as a `problem' age, as if this is a biological inevitability. It is not certain that teenagers really experience more problems than other age groups, and the problems they have can more clearly be traced to social structures than to their personal qualities or physiology.[ix],[x]

Another exclusion is in social research. Children are hidden inside `the school' or `the family'; adults' views about them are surveyed but we know almost nothing about children's own views and experiences.[xi] In Western societies concerned with cost rather than value, children tend to be seen as expensive dependents, a threat or a nuisance.[xii] Anthropologists find that abortion and active child abuse, which includes unrealistic demands for `the perfect child' and excessive pressures on children to succeed, are endemic in wealthy societies. In contrast, passive inadvertent child neglect and infanticide through poverty is endemic in poorer societies where children are loved in less conditional ways.[xiii] Different treatment of children and attitudes towards them arise from deep assumptions about differences between adults and children. Human beings are divided into two unrealistic extremes, with the left side column (in figure 1) assigned to children and, until recently, to women, and the right side to adults and especially professionals.

Trends in attitudes towards children and teenagers, with the `them-and-us' opposition between adults and younger people, have been summarised because these can influence values and policies in genetic research, practice and counselling. If, however unconsciously, children are seen as a threat or a drain on market economies and on adults' freedoms, children with genetic impairments are likely to be viewed still less favourably. Such attitudes can then generate and licence programmes to prevent the birth of impaired children, and to control teenagers and young adults who carry certain traits and disorders.[xiv] Arguably, to divert billions of dollars and accompanying public concern and hope into genetic research and away from social research and reform, detracts from addressing the real problems of young people.[xv]

Figure 1. Assumed child-adult dichotomies

Genetic research is presented as a means of furthering children's interests in the future through the development of gene therapy. The newsletters of self help associations concerned with genetic disorders celebrate research as liberating children from extremely distressing conditions and their siblings from passing on disorders to their own children. Yet how much are these reports intended to further researchers' interests and to increase their funding, support and prestige? Researchers assume that they serve the families' interests, but when genetic knowledge is used mainly to detect and end affected pregnancies, the benefits to, for example, people who have muscular dystrophy, are less clear. When asked, people usually say that they would rather have some life than none at all. There is a tragic contradiction in the newsletters between reports which celebrate the lives of affected children (when they win medals and awards or go to university) and reports which support research primarily used to prevent their lives. The research may detect a relevant gene long before any `treatment' other than termination in pregnancy is available. Disabled people are concerned that by the time a treatment is developed, so few of them will have survived prenatal screening programmes, and the few that do so are likely to be so stigmatised, that investment in developing `cures' will no longer be considered worthwhile. It is probably more economical and efficient to select unaffected embryos for in vitro fertilisation, rather than to try to tamper with genes after conception. In any case, whilst gene manipulation for disorders such as cystic fibrosis or muscular dystrophy will not necessarily alter the person concerned, with other disorders this may not be so. Is Down's syndrome or fragile X an essential part of the `actual' person? Who would they be without these conditions? Is the ethical and most rewarding approach to these conditions a social rather than a scientific one: to accept affected people as they are and as valued members of society?

Main questions arising from a realistic view of social attitudes towards children in late twentieth century Western society are: How much do current attitudes towards children licence the human genome programme? And how much does the programme, with many other factors, affect attitudes towards children?

Research about childhood

Current social research about childhood has three main areas.

i) Analysis of popular and academic theories of childhood[xvi] shows how philosophy and developmental psychology are misled, for example, by pre-Darwinian notions of evolution,[xvii] by scientists' personal fantasies,[xviii] and by inaccurate assumptions, such as those in figure 1. Scholars are gradually unravelling and refuting such theories.

ii) Large scale studies of children's social and economic status report much disadvantage and exclusion.[xix]

iii) Small scale surveys of individual children's views and experiences demonstrate that they have greater capacities than has generally been assumed.[xx],[xxi]

The extensive research literature on childhood presents an intellectual challenge (inviting us to rethink numerous influential fallacies and to reexamine realities) and also an emotional challenge. Initially, people tend to be angry and anxious when their deepest assumptions about childhood are questioned.

Perhaps inadvertently, ethicists and geneticists tend to assume and thereby to reinforce discredited theories about children's incapacities and limitations.[xxii] This is shown in debates about children's consent to genetic tests, when historical beliefs, instead of being critically examined, are quoted to justify future policies.[xxiii] Ethicists accept refuted theories about children's limitations[xxiv],[xxv] and question their status as human beings and even the value of their lives.[xxvi] In both disciplines, when the human intellect is highly valued inevitably, even if inadvertently, professional and academic thinking implicitly undervalues the lives of young and disabled people of low intelligence.

Troubled by the animal aspects of human nature, ethicists have pursued two simplistic and unsatisfactory alternatives.[xxvii] One is to perceive `real' humanity as mainly consisting in our spiritual and intellectual aspects, the body being regarded as a problem. In this view, young children risk being classed as animals rather than humans, and forfeit their human rights. Childhood is seen as a long apprenticeship in becoming human, and even young adults' morality is still sometimes reduced to biological terms. For example, in 1996, a psychiatrist wrote a leader (which is supposed to summarise the most up-to-date conclusions) on `Teenage sex' in the British Medical Journal. She alleged that unreliable use of contraceptive may be attributed to `cognitive immaturity'. `We know that the frontal lobe of the brain, which deals with control of sexual drives as well as abstract reasoning and planning, is not completely myelinated until 14 or 15 years of age. Major changes in cognitive ability occur between early and late adolescence, most notably the capacity to reason abstractly, predict future consequences, and see things from different perspectives.'[xxviii]

Genetics identifies with such reductionism in the attempts to improve and `perfect' the body, to trace the origins of behaviours such as violence to bodily material rather than to the mind or relationships or the social context, and to assume that people generally would prefer to select for high intelligence. Another response is to emphasise animal aspects of human nature in a negatively `brutish' image of irrational humanity, and to stress the need to control this, such as through contract theory,[xxix] risk management,[xxx] and market forces instead of altruism.[xxxi]

Contracts which are appropriate in business deals between strangers now invade personal relationships. Marriage is no longer acceptance `for better, for worse, in sickness and in health'; it is becoming more like a business contract with a growing number of conditions, including checking out potential partners' genes. The parent-child relationship is perhaps the only remaining human relationship of unconditional acceptance, though this is increasingly provisional and intolerant, from pre-childhood in parents' antenatal choices to the end of childhood as growing numbers of homeless young people illustrate.

Although it is only one of many social movements, arguably genetics plays a key part in this move to redefine human relationships as contracts.[xxxii] In promoting `parental choice', genetics not only makes selection and rejection of potential children possible, it also presents such choice as morally acceptable, even desirable and responsible, though until 30 years ago abortion was illegal in Britain and considered reprehensible.

Frequent reference to parents' guilt about passing on genetic defects represents a change away from former religious and fatalistic views about inheritance and human nature. It further implies that we `ought' to pass on `high' standards of mind and body to our children, and expect high standards from them. Standards of what it counts to be acceptable human being are rising, as more genetic conditions are identified for which prenatal choices can be offered.

The `contract society' which emphasises formally negotiated and conditional relationships brings welcome new benefits and liberties, but also brings losses in trust, tolerance and security. Contracts, being essentially bargains between equally informed and voluntary agents for their mutual reward, especially disadvantage children. Knowledge and power (the elements of informed voluntary consent to contracts) are often unequally distributed between children and adults. To talk, as some ethicists do, of a contract between the fetus and the parent is to misunderstand the essentially equal nature of contracts. The infinite variety and subtleties of parent-child relationships elude definition and slip between the hard grid of the formal contract. The salient qualities in parent-child relationships largely concern being, rather than doing, but to set a contract about the kind of person a son or daughter must be turns the child into a kind of `super-pet'.[xxxiii]

Popular notions of the child as a net drain on resources, and a burden rather than a blessing, are extended in antenatal genetic services when it is stated or implied: `Children are so difficult to bring up (a telling phrase) that any extra defect or disability will make life hard, perhaps impossible, for the parents.' The assumption that life with a disability is too great a burden for a family to bear can implicitly over-estimate the biological effects of disabilities and under-estimate the social measures which help severely impaired people to lead a fulfilling life. It can express overt hostility to disabled people, or covert hostility in presupposing that society will reject them.

Some laws in Europe are moving away from seeing children as their parents' property, towards respecting children, and allowing parents to have rights only in so far as this enables them to fulfil their responsibilities.[xxxiv] However, genetics is moving the other way in its emphasis on parents' choice, their right and ability to select and reject potential children,[xxxv] and their right to know and publicise personal and sensitive information about their child.[xxxvi][xxxvii]

Many geneticists and counsellors believe that they simply respond to society's demands for testing and screening, and that morally they are reactive rather than proactive. Yet by virtue of their relatively high status, derived from their alliance with scientific and innovative medicine, wittingly or not, they strongly influence public opinion, collectively through the mass media[xxxviii],[xxxix] and individually when counselling new clients.[xl] The antenatal period is an impressionable time for future parents, especially during a first pregnancy and for those with little experience of children or of disability. Along with medical advice, clients absorb social and moral advice from professionals they see as experts in a prestigious specialty. A pattern of parental choice and notions of potential children as `perfect', acceptable or substandard products is promoted through antenatal screening. As consumerism overtakes former more fatalistic and religious world views, and colours the way society frames the questions raised by genetics, public policy, morality and science mirror and fortify one another in ways that currently are especially apparent with genetics.

Genetics and eugenics

Eugenics means `pertaining or adapted to the production of fine offspring, the science which treats of this'.[xli] The aims and net effects of genetics and eugenics are similar. For example, currently in Britain, spina bifida is diagnosed in about 1,000 fetuses each year, and about 900 of these pregnancies are terminated. Some adults with the condition argue that their lives are worthwhile and they criticise the current policy.

Because of its history, eugenics is usually dissociated from genetics by geneticists and ethicists. They argue that eugenics involved `state' coercion, whereas genetics takes the opposite approach in respecting and increasing personal choice. Yet when the social reality of the two approaches are considered in some detail, the abstract contrasts become less convincing. Diane Paul illustrates how eugenics has a public `front door' policy.[xlii] This involves an overt public policy, government programmes, and open appeal to people's patriotic obligations. If anyone resists the eugenic programme then there is obvious coercion which enforces compliance. The public and private benefits are much publicised.

In contrast, genetics has a `back door' approach when governments support eugenic practices in law and publicly funded hospitals, such as abortion of impaired fetuses and discouragement of `risky' conceptions. Yet in Britain there has always been some political ambivalence, linked to wariness about eugenics, towards abortion and infertility services, which have never been adequately funded or routinely provided in all districts.[xliii] Counselling services tend to be individual and semi-private (when compared with national nursing specialities). Clients are offered choice, and indirect persuasion through `non-directive counselling' and values propagated through the mass media. The private benefits to the adults concerned are emphasised, and the discussion of the benefits to the state are confined mainly to medical journals.

In an abstract analysis, genetics and eugenics can look very different. However, in an analysis which takes account of the social context, it is immediately clear that the net results are the same: a highly organised national programme to ensure `the production of fine offspring'. The second `personal choice' approach can be seen as more effective than enforced eugenics. Power is less effective when people are aware of it, and is far more potent when people believe that they are choosing and not complying.[xliv],[xlv] This is not to say, that individual and state interests are necessarily at odds, but that abstract analyses which ignore historical links can be misleading.

Antenatal screening and selection are claimed to be humane alternatives to infanticide which has been accepted in all societies. This argument begs questions about choices and choosers. Families on subsistence level have far fewer options about sustaining impaired babies, than parents have in wealthy societies with effective health services. The uncertain history of infanticide tells us nothing about the mothers' views, and whether they were consenting or distraught. Parents' grief at stillbirth and infant death, which 40 years ago went unmentioned in medical textbooks, is now widely understood as an intense experience.[xlvi] Antenatal screening is not experienced by women as wholly beneficial.[xlvii] Concepts of percentile charts and measuring the fetus and child for `normal' growth are very recent. A `norm' meant a carpenter's set square until the late nineteenth century, when eugenicists began to apply to term to people.[xlviii] Although physical differences have always been noted, differences in mental ability appear to have been largely unnoticed before the eighteenth century,[xlix] and these alone would not show in the early months so would not be a case for infanticide. Measuring human physical and mental difference and attempts to correct and prevent difference are recent concerns.[l] The next section considers whether ethics dealing with abstractions or with everyday evidence contributes most to the moral understanding of genetics.

Abstract or evidence-based ethics?

The ethicist Daniel Callahan claims that the `blooming [sic] buzzing confusion' of actual experience `cannot be ordered or morally interpreted without the help of abstractions ... The aim of ethical theory is to provide us with some general, high-level abstractions that will help us to make sense of experience'.[li] Ironically, he quotes William James's notion of the `buzzing confusion' which babies were supposed to exist in. Psychologists have since demonstrated babies' powers to make sense of experience and have concluded: `the buzzing confusion which William James once attributed to the infant's perceptual world lay not in [the infant] but in the our own minds and recording techniques.'[lii] So if babies can manage to make sense without benefit of abstract philosophy, cannot adults also? How essential is abstract philosophy to our understanding?

Callahan asserts: `We have all been better off standing firm, hanging on to our abstractions'.[liii] He illustrates his point with the example of `hard and exceptionless, highly abstract rules against ... racism' which have succeeded in `banning and forbidding' racism. He criticises sophisticated racists who plead for compromise `in the name of context, ambiguity, multiculturalism, sensitivity or whatever other version of moral complexity can be thrown into the breach against the devil of abstractions'. Yet who can believe that racism has been really banned, or that this can happen only through `hard rules' and not also through attention to personal experiences and beliefs?

All theories are imbued with values, and when ethicists or counsellors imagine that they can be `value-free', existing in some curious time and space warp, and suppose that thereby they can think more clearly and technically, they are more vulnerable to influence from subconsciously held values.[liv] Criticising abstract ethics, the philosopher Bernard Williams considers that it `makes people think that, without its very special obligation, there is only inclination; without its utter voluntariness, there is only force; without its ultimate pure justice, there is no justice. Its philosophical errors are only the most abstract expressions of a deeply rooted misconception of life'.[lv] Understanding depends on making the two approaches, which Callahan sets in opposition, work together. Yet Callahan seems to have set up a straw polarity, since he concludes by advocating `a working back and forth between our abstract principles and the actualities of experience.. The problem is not with abstractions as such. It is in knowing which to keep, which to modify and which to abandon'.

Yet this begs the questions: Who are `we'? Who has authority to `change principles'? And how they will do so? The philosopher Mary Midgley gives a helpful analogy.[lvi] Schizophrenia (or any other condition which might be genetic) is like a mountain with tents set all around it. Each tent represents a discipline or way of understanding schizophrenia: psychiatry, history, anthropology, nursing, personal experience, poetry, ethics, religion, genetics, biochemistry, psychotherapy, and so on. Many of the tent dwellers acknowledge that their expertise offers only a partial view and they value learning from others. A few experts, Midgley names biological reductionists, illogically insist that only their tent can achieve the sole authentic view of the entire mountain and encompass or surpass all the other disciplines. Purely technical or abstract reasoning in ethics or genetics risks excluding numerous other relevant considerations. The next part of this paper considers ways of understanding genetics which take greater account of the complex social context.

Reducing social into genetic concepts

The neurobiologist, Steven Rose, criticises the way some geneticists try to reduce social concepts into genetic ones[lvii] In this kind of reductionism, dynamic processes become things, people's fluid transient reactions are seen as fixed entities, their many complex characteristics are separately identified as immutable parts of their character. Individual's reactions to other people and events, which make sense when seen in context, are viewed in isolation as `phenotypes' assumed to derive from their genotype, reducing the person to a mindless set of biological impulses. Inherited impairments are inaccurately called `handicaps' as if they solely determine the person's level of ability and opportunity throughout life. This fatalism ignores the powerful effects of social circumstances, and the ways in which personal and political action can transform impaired people's lives. Some one using a wheel chair may live a very limited handicapped life, or a very fulfilled one.[lviii],[lix]

Steven Rose further considers how personal characteristics are reduced into impersonal concepts which are then seen as fixed (potentially or actually genetic) traits which drive the affected individual. This can encourage us to think in mechanistic ways about human beings. The cliche of a genetic `blue print' can imply that anatomy is destiny, that each person's entire life is mapped out from birth by the genes, like the design which determines exactly how an engine will be built, and that any deviation is incorrect. In contrast, `growth' suggests the unique individual branching out unexpectedly. In such biological determinism, free will, human agency, imagination and impulse are sidelined. Difference can too readily become `abnormality' to be avoided, rather than diversity to be celebrated.

The expectation that ethics and genetics can or should be value-free and non-directive, in itself expresses a set of values. Morality then tends to be seen aesthetically as `choices' and `personal values' which have no strong roots in social consensus or in their impact for good or ill. Reverence for individual choice, without specifying the nature or effects of choices, disguises how powerful people tend to be the choosers and vulnerable ones the losers. When there are discrepancies of power and knowledge, a neutral position is not possible. When scientific and ethical expertise is valued much more highly than personal experience, such as living with the effects of genetic disorders, morality tends to take its meaning from abstract law and principles, philosophical or scientific ones, instead of from living relationships and experience. People then tend to be seen less as creators of their own lives, and more as relatively passive consumers of services, and of life itself when they are offered prenatal choices. Risks which were once accepted or else undertaken in the expectation that resources and support would be found to cope with their effects are now presented as the responsibility of isolated individuals, to be reduced or avoided. Rather than learning partly through their own sensations and bodily experiences, people are encouraged to turn to scientific and moral experts to interpret to them their own subcellular activity.[lx]

When counsellors counsel in genetics, statistical risk and moral decision making, one measure of their effectiveness is change in their clients' behaviours. Professional and economic pressures combine with technological imperatives to act - to control, reduce, prevent, correct - to believe it is better to do something than nothing. This has been contrasted with a `feminine' approach of `holding' together a tension of opposites, a more `wait and see' ethos.[lxi],[lxii] When ethics is linked with business management and risk calculation it is drawn into a similar ethos of control. This tends to put greater onus on any one who rejects decisive health interventions and, for example, decides not to abort a fetus with Down's, to justify their `inaction', although for the woman, to continue with the pregnancy, entails much more action than to end it. Common terms, such as `positive' results when impairment is found, increase the implication that doing `nothing' is negative. A genetic counsellor lecturing to midwives in 1996 said `occasionally we lose a Down's', meaning `occasionally a fetus with Down's is not detected prenatally and is born at term. This reverses centuries of midwifery values when `loss' meant death and not birth.

Some ethicists elevate science to a moral authority, basing their understanding on the science of genetics, instead of viewing it from a more independent critical position that sees science as one (very effective and important) type of knowledge among other types.[lxiii] Abstract ethics can reinforce the very weaknesses and problems in medicine that most worry people: impersonal reductionism, harsh utilitarianism, social control by experts who use confusing jargon, threats to the very freedoms which ethics purports to respect, a predominance of one discipline over all others, as the medicalisation or the ethicalisation of people's lives.

Genetics needs to be complemented and enriched by ethics that takes account of shared moral values including compassion, and respect with care on personal and political levels. Outward looking ethics considers the impact of decisions not only on the individuals concerned but on everyone who might be affected, such as everyone affected by a certain genetic condition and their place in society and the ways they are perceived and treated.

Conclusion

The specialist chapter in this book on law and ethics are very clear and elegant, with most useful and orderly summaries. They are like well organised kitchens where everything is allocated to the correct place. We know far more about a teaspoon when it is classified as cutlery and not mistaken for a tea bag. In contrast, attention to the social context can look messy and trivial. What is the point of taking out a teaspoon to look at it again? When the subject is not a teaspoon but, for example, a child with spina bifida, it is vital to review our own assumptions about children's needs and abilities, adults' responsibilities, the nature of genetic conditions and their actual effects, about what we know and do not know, and what we can learn from this child. People cannot be tidied away like cutlery.

Greater attention to the social context, besides questioning current assumptions about childhood, can complement analysis in ethics and law and increase critical awareness of common threads between ethics and genetics. It can question covert assumptions that we are hostages to our biology rather than competent agents. By deepening understanding between all the related disciplines it can help to increase the richness and relevance of their various contributions to understanding of genetics. It can question trends towards seeing humans as machines, helplessly driven and looking for experts' solutions and technical answers. Social awareness sees how the parts inform and are informed by the whole, in each individual and in society.

Figure 1. Assumed child-adult dichotomies

feeling	thinking
emotion	reason
body	mind
ignorant	knowing
inexperienced	experienced
foolish	wise
volatile	stable
weak	strong
dependant	protective
unreliable	trustworthy
immature	mature
irresponsible	responsible
child	adult

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