An Occasional Paper

A CAUTIONARY TALE ON GENETIC TESTING: The Case of Foster and Pre-Adoptive Children

by
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May 2002

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A Transcript of Proceedings, Colloquium on The Ethics of Genetic Testing in Adoption 10 March, 2000, edited by Janet Farrell Smith, is published by the McCormack Institute. To request copies of this Transcript, call or write the McCormack Institute of Public Affairs, University of Massachusetts Boston, MA 02125-3393, tel 617-287-5550, fax 617-287-5544. Or request from Professor Farrell Smith at 617-287-6547 or janet.smith@umb.edu.

Many thanks to the McCormack Institute Center for Social Policy for support in producing this Occasional Paper. I express my deep appreciation to Donna Haig Friedman, Director, Center for Social Policy, for help in initiating my research project, including the Colloquium on the Ethics of Adoption, March 9-10, 2000. Thanks to Phyllis Freeman for writing suggestions. My assistant, Anamika Majumder, provided skillful help on computing matters and word processing, thanks to the Office of Graduate Dean. Pre-med student Catherine Chen graciously volunteered her research assistance in medicine and bioethics.

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EXECUTIVE SUMMARY

Ethical and policy questions take center stage in the increasing use of genetic testing information for health care and social purposes. This analysis focuses on children, particularly adoptive and foster care children. Setting the stage for increased genetic testing, we find the rapid growth of technology to test cheaply and efficiently, scientific discovery of genetic markers for more and more common conditions, and the marketing of these tests to primary care and pediatric physicians as well as specialists in genetics. Since availability of technology has historically led to its use, we need to examine these implications for social policy and child welfare before patterns become entrenched.

Great caution is urged in genetic testing of children in general and adoptive and foster children in particular because of the potential social disadvantages to children. A health care access condition must be met before proceeding with genetic testing. Assurance that health care resources be provided to meet the child's medical needs revealed by genetic testing ought to be factored into decision making.

Current guidelines of major U.S. professional societies recommend genetic testing of a child only when an immediate medical benefit exists to treat a condition manifesting in childhood. This analysis summarizes the disadvantages and advantages of genetic testing for the population of foster and pre-adoptive children, claiming that this group, as a kind of test case, poses lessons for children as a whole and even some adults. Genetic testing information may include the following social risks:

- privacy violations
- genetic discrimination
- social stigma within families, communities, society
- future loss of insurability and employability
- creation of an enlarging pool of unadoptable children whose genetic testing information discourages prospective adopters from permanent adoption.

On the other hand, there are benefits to genetic testing which may also include:

- medical diagnosis, prevention and cure of certain conditions: in the future, medical use of genetic tests in pharmacogenomics, or tailoring medications to fit genetic predispositions.
- prospective adoptive parents' right to know the conditions of the child they adopt
- information on the child facilitating responsible decision making for placement on the part of prospective adopters and case workers
- special needs children placing exceptional demands, of which prospective adopters or foster parents need to be informed
- adoption agencies' legal necessities, such as complying with statutory duty to disclose, and forestalling wrongful adoption suits.

Social consequences of genetic testing must be carefully examined before any testing of a child is done. Two conditions ought to be satisfied, namely [a] an existing medical treatment for a childhood onset condition, and [b] reasonable expectation of health-care access to the child's needed treatment, access that genetic testing will not undermine. Social purposes alone are not sufficient reasons to test, due to risk of harms to the child and her future. Challenges and differing positions are explored in order to present a balanced overview of ethical dilemmas and social policy implications of 21st century genetics.

INTRODUCTION

What values will guide policy and practice for children in the new genetic era of the 21st century? How does the situation of foster and adoptive children illuminate the intersection of health policy and social policy? The research presented here takes foster and adoptive children as a test case for potential conflict between healthcare benefits and social uses of genetic information, arguing the position that genetic testing of children in general and adoptive and foster children in particular should be approached with great caution. The potential social disadvantages to children on the unrestricted and unreflective use of genetic testing must be weighed against putative medical advances. The primary objective of this analysis is to provide foresight on these issues, before certain social uses of genetic information become entrenched. Hindsight arrives too late to reverse the impact of trends that may profoundly affect the lives and development of children who are the future citizens of our society. A second related objective is to give a balanced presentation of challenges and alternatives to the thesis put forth. A third objective is to present an ethical analysis of cross-disciplinary and cross-professional problems and insight. For example, who ought to weigh the medical and social harms and benefits to make an informed consent on behalf of the child when the child has no permanent legal parents? Each profession -- law, medicine, social services, family and healthcare policy -- needs to be informed about the other, especially when considering the impact of the new genetics on the status of children.

One might ask, Why is this issue important now, if it is not common practice or widespread? The answer is that we as a society need to articulate the value structure that should guide testing of children, before incidents of genetic testing increase. Foresight, not hindsight, should guide practice and policy, especially with vulnerable groups of children. It is important to create ethical and policy guidelines based on values that feature children's interests. Within the domain of children's best interests we find privacy, equal opportunities for all children, informed consent for medical testing and diagnostics and treatment in the child's best interest. Of course, one purpose of this analysis is to educate the public about the social impact of testing on children as well as ethical issues in information gathered and made available to the prospective adopters.

DISTINGUISHING MEDICAL AND SOCIAL USES OF GENETIC INFORMATION

The distinction between the medical and the social applications of genetic testing information is heightened for foster and adoptive children in an instructive way. From a medical viewpoint, there are very few conditions detectable by genetic testing where direct medical prevention or cures can be applied. Many of these conditions are included in mandatory newborn screening policies, now required in most of the 50 states. The most dramatic are metabolic disorders for which special diets can be applied at birth to prevent developmental delays and other serious medical conditions. Other conditions include rare childhood genetic diseases such as Canavan's Disease, which has an enzymatic medication.

From a social viewpoint, the potential range of genetic testing is broader. First, those in charge of children's education and health are invested in predicting future tendencies. Genetic tendencies or susceptibilities may be thought to facilitate the management of childrearing and future planning. For adoptive children, the desire to compensate for missing medical and family histories adds to incentives to perform genetic testing. Family medical histories may have medical implications, as in monitoring for susceptibility to heart disease. Or they may have social applications, as in cautioning a child with a family history of heart disease in athletic activity. In addition, for children being placed for adoption, prospective parental demand for information, perhaps due to hesitancy in taking care of a child not biologically related, may put pressure on adoption and social service agencies to obtain and reveal maximal information about children in the pre-adoptive stage. Because of these factors, social service observers predict increased social pressures to administer genetic tests to this group of children.

On the other hand, there are social risks to genetic testing on children. The genetic information may be used in a way to stigmatize or reduce equal life opportunities in education, employment and even produce a generalized loss of access to private health care insurance, since insurers share large data bases of medical information on clients. These risks are magnified since foster and adoptive children lack permanent legal parents, the traditional gatekeepers and protectors of children's rights, interests and opportunities.

Genetic information has the power to help or to hinder opportunities for children. Children with permanent legal parents who also have access to quality health care programs may be protected from the social ill effects of stigma and discrimination through misuse of genetic testing information. Children in permanent, economically stable families may benefit from genetic testing, diagnostics and medical procedures. Children who lack permanent parents and family support, who lack stable health care plans of high quality, may be severely disadvantaged in attaining equal opportunities if genetic testing information is entered on their medical and social charts. Due to obstacles in the pathways of opportunity described in this paper, the entry of genetic information to the picture may exacerbate existing inequalities in other areas.

Since children represent the impact of health care policy at the outset of the life-course, their position in the implementation of genetic diagnostics and medicine is especially significant. What happens to children who lack permanent legal parents, in other words, may signal future risk patterns for children generally, and even for some adults. These for children illuminate in general the trade-offs between putative health care benefits and risks of social harm in discrimination and loss of equal opportunity.

SOCIAL JUSTICE AND STRUCTURAL INEQUALITIES IN CHILDREN'S STATUS

Social justice questions on fair equality of opportunity and equal freedom arise for children in general and for foster and adoptive children in particular.[1] The facts show that poverty,[2] inadequate access to health care,[3] lack of equal housing,[4] and sub-standard educational benefits are suffered disproportionately by children in the U.S. The questions explored here illuminate these structural social factors regarding the socially vulnerable group of foster and adoptive children. Studies also show that children of color are disproportionately represented in foster care, in poverty statistics, and in lack of access to health care and equal educational opportunity.[5] As welfare reform exacerbates these problems, and as foster care statistics continue to rise around the country, the problem of equal opportunity for children without permanent legal parents will expand, highlighting this vulnerable sector within an already structurally disadvantaged group of children.

Will a new genetic era bring eugenic assumptions, covertly or overtly, into social policy? Historians of eugenics and genetic policy experts observe the prevalence of

eugenic assumptions in social policy in the first half of the 20th century. They worry whether contemporary genetic social practices will raise eugenics in another form.[6] Eugenics has special relevance to adoption. Historians of adoption have recorded the eugenic assumptions of U.S. of the early 1900s where certain children were deemed unadoptable due to bad heredity or "feeblemindedness," i.e. suspicion of mental health problems and general lack of a "normal" profile. Many experts in adoption policy worry that this past situation will be re-created in contemporary concern over genetic defects or mental health problems in adoptees. Such presumptions could work against children finding parents and stigmatize adoptive families in general.

One major concomitant of genetic disadvantage and social stigma is deepened inequalities. This is especially the case with children, whose major life-task is growth and development of capacities to function as productive adult citizens and workers. One very helpful social justice framework for dealing with children can be found in Amartya Sen's stress on development of capabilities or capacities as a pre-condition to utilizing social opportunities. Sen and others argue that it is not sufficient to distribute goods and services equitably, under a conception of distributive justice, or to ensure formal equality of opportunity in law. In Sen's view we must ensure that persons receive what they need to develop their capabilities to act in the economy and social-political sphere. Without these enabling conditions, as development of capabilities, we are more likely to find powerlessness rather than power, a series of failures to develop rather than a series of steps culminating in full agency.

Social policies using genetic technologies need to be weighed against prinicples of social justice and equal opportunity in order to see their impact on children's development. Growth proceeds by laying down one foundational building block, which serves as the grounding for the next. For example, consider how private health care insurability relates to employment. We can see a domino effect of one action in childhood leading to diminished opportunity in successive life stages. Social stigma often attends children without parents, including adopted and foster children.[7] Compounding this stigma, genetic testing information indicating a risk of a certain disease, may be entered on the medical chart of a young child. Later, the child may be denied health insurance or given very high premiums at the age of 18, when she has to

pay her own health insurance and she applies for a job. Yet, since most health care benefits are tied to employment, and most employers share health care costs, employers who see a high-cost worker are less likely to hire or promote such a person. Genetic testing information which signals a "pre-existing condition" is still a legally valid reason to raise health rates or to deny health insurance.

Hence, genetic testing in childhood, which may seem socially indicated at one stage, may backfire at a later stage by diminishing opportunities, e.g. genetic testing information signaling a red flag to employers when the child enters the job market. Employability is tied to both health care access and housing. So a child who matures into a high risk category in health insurability carries a distinct disadvantage. She does not face a level playing field in the effort to attain adult functioning.

Legal prohibitions on discrimination due to genetic conditions have been enacted into both federal and state law. Genetic privacy legislation now passed in 30 states, attempts to eliminate these problems. In Massachusetts, for example, such action should now be prohibited by legislation passed in July 2000.[8] However, the Massachusetts law does not cover life insurance. Its scope regarding children, whose medical records follow them from cradle to grave, is not yet clear.[9] The protections sanctioned in these laws depend strongly on individual patients' rights to privacy and informed consent. However, in the case of many foster children and those awaiting adoption, these "gatekeeper" conditions are insecure at best and nonexistent at worst. A legal guardian [proxy or surrogate decision maker in place of parents] makes medical decisions on behalf of children without permanent legal parents. Sometimes the consent process is skipped entirely with these children.

U.S. PROFESSIONAL SOCIETIES' POLICY GUIDELINES ON GENETIC TESTING CHILDREN

The predominant message of both genetic policy task forces and U.S. professional genetic associations sounds a note of caution on testing children. Exceptions are made for cases where an effective medical treatment could be applied in the immediate period of childhood. For example, a task force was commissioned by the Institute of Medicine in conjunction with the National Institute for Human Genome Research, the government research entity which has now successfully mapped the human genetic code. Because of the risk for social or psychological harm, this Committee recommends that

> in the clinical setting children generally be tested only for disorders for which a curative or preventive treatment exist and should be instituted at that early stage. Childhood screening is not appropriate for carrier status, untreatable childhood diseases, and late-onset diseases that cannot be prevented or forestalled by early treatment.[10]

Should these criteria apply to children awaiting adoption? For example, should genetic testing be expanded when social service agencies or prospective parents feel they need information in order to make appropriate placement? Legal expert Lori Andrews argues that no state requires a "duty to investigate" that would entail genetic testing of children being placed for adoption. She gives a careful analysis of legal precedent and state laws to support her conclusion. Ethical reasoning arguing against expanded genetic testing for children awaiting adoption, in a "pre-adoptive" stage, has been articulated by child welfare specialist Madelyn Freundlich.[11] The position argued herein agrees with their position and gives expanded reasoning on the ethical and policy levels. Both Freundlich and Andrews consider the above position consistent with agencies' responsibility to divulge current information under a statutory "duty to disclose" existing medical status, records and family history of any child awaiting adoption to prospective parents. In other words, adults considering the adoption of a child have a right to past and current medical information about that child. Agencies responsible for the adoption have a duty to reveal existing information. Yet these duties need not entail a pro-active duty to investigate, gathering additional information, in ways that might potentially harm the interests of both the child and the birth parents in terms of privacy rights or insurability issues.[12]

Leading U.S. medical professional societies concur with this general position. The American Society for Human Genetics [ASHG] and the American College of Medical Genetics [ACOG] have been an influential voice in the U.S. cautioning against testing a child for genetic conditions unless an existing [not experimental] medical treatment can be applied in the child's minority. In 1991 and again in 2000, they affirmed this standard for adoptive children, adding in 2000, that the standard for biological and adoptive children should be the same.[13] The ASHG/ACOG position forestalls pressure from society or from prospective adopters' request to test children for non-medical reasons, for example, as a method of screening out undesirable conditions to satisfy adoption matching requirements. If social service agencies and adoption agencies were to test children before adoption on a wide scale, this would involve expanding the domain of children's testable conditions for a social, not medical reason. It would expose a wider range of information about the child to public view before any decision is made to adopt. However, if the standard for biological and adoptive children is the same, then the primary criterion for testing would be some medical care applicable during childhood, not social purposes. Foster and adoptive children would not be subject to greater testing just because they did not have parents.

Differing views have been voiced. Some practicing physicians and pediatricians in the United States argue there must be very strong reasons not to comply with parental request for tests on children. They see it as reasonable to defer to parent wishes, where medical benefit may be marginal or in gray areas regarding criteria of U.S. professional guidelines.[14] In these cases some physicians argue, they must have a very strong justification not to give the parents information on their child, i.e. to refuse to go ahead and test at the parents' wishes. This dilemma raises the ethical question: Is the pediatrician's primary duty to the child? To parental decision-makers? What imperative takes priority when the child has no permanent parents and stands in limbo between parents, awaiting adoption, or in foster care? Social service professionals face similar quandaries: Which takes priority? The future interests of the child or the interests of prospective adopters?

Gathering medical and family histories during the time a child is released for adoption is of key importance in providing quality health care, both during childhood and

later, when an adoptee reaches reproductive age, and maturity. The prevailing view among adoption experts, medical advisors, and social service agencies stresses the importance of gathering full medical information for foster and adoptive children including hereditary conditions in family histories. Those who observe that all persons have some genetic susceptibilities argue that therefore all citizens are potential targets of genetic discrimination, inferring that the risk of "genetic discrimination" is falsely posed. In rebuttal, critics such as George Annas see dangers in the social consequences of such discrimination regardless of the scientific status of "genetic" or "non-genetic."[15]

MEDICAL BEST INTEREST AND HEALTH CARE BEST INTERESTS OF THE CHILD

A key distinction for genetic policy made by this author lies between a child's medical best interest and health care best interest. A child's medical best interest may be defined as that set of medical procedures which maximizes the child's welfare. The main criteria for assessing medical best interest are scientific, diagnostic and current standards of care. However, what stands in a child's medical best interest may not be available on the child's current health care plan. Access depends on whether or not a child's parents or guardians have the money to provide that set of procedures. Therefore, the medical best interest states an ideal, not necessarily an existing reality in a particular patient or population.

Health-care best interest may be defined as those actions that maximize a child's access to obtaining the best quality health care, in both the short and long-term. Economic and social factors, as well as long-term psychological consequences of genetic testing, could undermine a child's ability to obtain care. Therefore, access is the key term in health care interest, whereas medical best interest is defined scientifically and does not factor in social or economic access. Both medical best interest and health-care best interest should be factored into decision-making about children's medical treatment, especially considering when to undertake genetic testing. Ideally, medical and health-care best interests coincide, as when a genetic test leads to an immediately beneficial medical treatment, accessible to the child on her health care plan, which simultaneously enhances the child's access to health care. Yet in some cases, the two interests may diverge. This is especially so for children whose long term future is clouded by poverty,

substandard educational opportunities, and lack of permanent parents. In these cases, for example, genetic testing information, even if it revealed some medically meaningful data, might, by being recorded in the child's permanent medical chart, undermine the child's economic health insurability. Such testing would therefore undermine the child's health care best interest.

The distinction between the child's interest in medical treatment and the child's interest in health care access has not been made in medical professional societies' guidelines. Nor has it received much attention in ethical or policy analysis. For example, several guidelines permit genetic testing when an existing medical treatment or prevention can be applied in childhood-onset conditions. Presumably they refer to the relevant medical treatment apart from the question of whether or not the child has access to it. Of course, it is always possible to raise monies through charities or advocacy in order to gain access for a given child who lacks access for a given treatment. However, from a social policy standpoint addressing system-wide impact, such actions are not realistic options. They are not realistic for the vast majority of children in poverty, whose parents cannot afford health care, and especially for children awaiting adoption or residing in foster care. These children, especially if they remain unadopted, lack the protection of permanent legal parents, who remain the major providers of health care access.

On a general policy level, what may serve the child's medical best interests may not be available on the existing government-provided health care plan, or on other plans, given the inequities in current health care. Actual health care delivery to a foster children or those awaiting adoption in the "pre-adoptive" stage may not be equivalent to the standard of care extant in the privately insured health care system. A child's permanent legal parents carrying private health care insurance are more likely to have access to the best medical treatment, whereas a child awaiting adoption or in foster care may not have access to state-of-the-art monitoring technology such as CAT scans or MRIs.

So, having revealed a condition, genetic testing information recorded in the child's permanent medical record might actually end up undermining the child's ability to receive the health care to treat that very condition. Information-gathering about something that merits treatment under the child's medical best interest may not enable

increased health care access, but its direct opposite, diminished access. This unfortunate paradox ought to be publicized to those who make policy and specific plans for children. Social service professionals in child placement, adoption agencies in both the private and public sectors, attorneys and legal professionals arranging independent adoptions, need to be aware of the long term social consequences. Medical primary care givers, genetic specialists, and pediatricians, need to be informed.

In sum, policy evaluations often assume that what stands in a child's medical best interest also stands in their health-care best interest, i.e. their interest in securing access to health care delivery on a continuous, life-long basis. In a universal health care system, without deep inequalities, neither of these distinctions might assume great ethical or policy importance. However, because of the insecure basis of current U.S. health care delivery for children, and the numbers of uninsured children, it follows that genetic testing which ostensibly stands to benefit the child's medical best interest, may not further, but may actively undermine, the child's current or long-term interest in health care access.

Another distinction needs to be kept in mind. The term "adoptive child" used, for example, in policy and professional societies' guidelines is ambiguous, referring to [a] the "pre-adoptive" child in temporary or foster care awaiting adoption but lacking permanent legal parents with the rights and responsibilities for that child's medical care or [b] the child who has gone through a finalized adoption, including what is termed the "post-placement" stage, where the social worker monitors the child and family for a healthy adjustment. Distinct ethical, policy and social contexts apply in each stage, especially regarding the potential harms and benefits of genetic testing in the pre-adoptive stage. Under [a], the pre-adoptive stage, assignment of decision making power, i.e. the person responsible for informed consent for medical procedures, including genetic testing, could be socially and legally indeterminate. Under [b], the post-adoptive stage, the permanent legal parent has the right and responsibility to serve the child's best interest. Children in the pre-adoptive stage are especially vulnerable, whereas children in the post-adoptive stage are more likely to be similar to their biological peers by having permanent legal parents. However, both groups [a] and [b] might lack family medical histories, which might be an added incentive to administer genetic tests.

A CAUTIONARY APPROACH TO GENETIC TESTING

The thesis presented here is that professionals in social services and medicine should take a cautionary approach in genetic testing: Err on the side of caution concerning genetic testing of foster and adoptive children, as well as children generally. There should in general be a presumption against genetic testing while respecting disclosure to prospective adoptive parents under the statutory requirements of "duty to disclose." In other words, one can, and ought to, disclose the medical information gathered on an initial medical exam to prospective parents and placement case workers. But this does not require, from a legal or ethical viewpoint, an affirmative "duty to investigate" by gathering genetic testing data that goes beyond the existing medical record. In other words, the burden of proof should lie on proceeding with testing. Acceptable reason to test should reveal information helpful to the child's current medical needs for treatment. Furthermore, any testing should meet the additional criterion advanced here the child's health care interest: Any testing should support, not diminish, the child's current and future potential for health care access.

My basic position agrees with the standards in the guidelines of the major government policy task forces and professional medical societies,[16] affirmed for both biological and adoptive children, that no testing of children be done unless there is an existing medical treatment for a disease manifesting in childhood. Genetic testing for pre-symptomatic conditions [asymptomatic testing], carrier conditions [carrier testing] or adult onset conditions [predictive testing] remains ethically unacceptable for children. It is neither necessary nor helpful from a medical viewpoint. For example, the following illustrate situations where it is ethically unacceptable to administer genetic tests: testing a child for Cystic Fibrosis when no symptoms are present, or carrier testing for Cystic Fibrosis to see if the child will pass the condition to future offspring, or testing for a condition which manifests in adulthood, such as Huntington's Disease. None of these provide diagnostic or treatment information necessary from a medical viewpoint during the child's minority.

CHALLENGES TO A CAUTIONARY APPROACH

The first challenge to the above thesis argues for expanded genetic testing based on the prospective parents' right to know information about the child's status before permanent adoption. Some critics of the "consensus position", as Dr. Lainie Ross calls it, refer to the existing system of "matching" children and prospective parents in state-sponsored child placement.[17] As long as adoptive matching is a placement procedure, she argues, genetic information should be gathered and disclosed to prospective adopters. Genetic testing information amplifies information needed for matching appropriate children to appropriate parents.

Second, some critics argue for a principle of family autonomy justifying parental right over genetic testing of children. This position argues against medical or social standards or regulation directed solely towards children. To emphasize a child's privacy or future autonomy interests over parental ones, it can be argued, weakens the institution of the family. Under a principle of family or parental autonomy, arguments can be given that genetic knowledge of a child's future adult medical conditions do strongly influence ethically justified parental care of children. For example, on this view, it is ethically permissible for parents to use such information in family planning or other decisions. Parents need such information in order to anticipate educational or support resources, e.g. information that a child may later suffer a debilitating disease.

Third, while professional guidelines may agree on the ideal standards, we frequently find gray zones. Even when medical and legal experts place high priority on the child's privacy interests, they may disagree about which cases ought to be subsumed under those standards. For example, there is no curative treatment for Duchenne Muscular Dystrophy, a degenerative condition developing in childhood. The most medicine can offer is merely palliative or supportive care that eases symptoms. Some experts would allow testing a very young child for Duchenne Muscular Dystrophy in order to inform prospective adoptive parents to be better prepared both emotionally and financially to deal with the condition. Others would refuse it on the grounds the child's privacy interests are paramount and no parent is prepared for such a devastating condition and thus neither pre-adoptive children nor biological children ought to be tested for it.[18] Furthermore, genetic policy experts have underscored the striking difference between

public expectations and actual scientific results. The Duchenne case illustrates a generalized phenomenon: The "therapeutic gap" between the number of testable genetic conditions, and ability to treat or cure them, has not closed.

Fourth, some experts justify expanded genetic testing for pre-adoptive of foster children by appealing to the interests of special needs children in adoptive child placement. These cases require a different framework from normal children. They ought to work from the model of HIV+ status or substance abuse cases, where agencies are required to disclose this information on HIV, or previous alcohol or drug exposure to prospective adoptive parents. Given full information, prospective parents can decide whether or not they can handle the financial and emotional challenges of such children. Disclosing such information will, in the view of some experts, facilitate responsible decision making on whether the parents can handle a particular child, and contribute to reducing the rate of "disrupted" or "dissolved" adoptions, where the parents return the child to the state after discovering a condition they cannot handle. Finally, the provisions of more rather than less information to prospective adoptive parents can reduce the prospect of wrongful adoption suits.[19]

CURRENT STATUS OF GENETIC TESTING

What is the prevalence of genetic testing of foster and adoptive children? At the start of the 21st century, incidents of genetic testing of children in general and of foster and pre-adoptive children in particular have come to the attention of professionals in social service and medicine. These, however, are expected to rise, since the production, marketing and distribution of genetic tests has skyrocketed in the past two years. Tests are increasingly available to pediatricians and primary care physicians, so their use may expand from rare genetic disease to diagnostic susceptibility testing for common diseases by primary care providers. Since genetic testing is also becoming known to the public, prospective adopters may increasingly express a demand for such testing.

For example, one independent adoption attorney recommended that a pregnant woman, intending to release her future child for adoption, test the fetus for Huntington's Disease, an adult onset disease. In another case, an agency wanted to give genetic tests to a boy in foster care whose family history included developmental delays, but who

showed no problems. His case social worker protested, and the boy was adopted. Later this case worker found the boy happily ensconced in his new adopted family, at the top of his class.[20]

In one recent case a West Coast state social service department, in order to facilitate adoptive placement, considered testing two foster siblings for Cystic Fibrosis (CF). Although they had a family history of CF, the children did not manifest symptoms of the disease, which appears soon after birth, if it appears at all. In other words, the children did not now, nor would they ever, have the disease, but they may have inherited the gene as carriers to pass on to their heirs. In this case, social workers were persuaded by colleagues in the state genetic department that there was no compelling medical need to test. Nor were they required by law to investigate to uncover further information other than that existing already in the children's charts. The author found in interviews that increasing numbers of prospective adopters consulted medical geneticists for a physical or genetic testing examination that was done privately, independently of adoption agency screening procedures. In some of these cases, the genetic information from the consultation was not entered on the child's permanent medical record, so it had little impact on the child, positive or negative, other than affecting the immediate adoption decision by those prospective parents.

LIMITS OF THE LAW

The law does not offer definitive answers to the question of whether or not to administer genetic testing. Most professional policy guidelines recommend against testing children unless there is an immediate medical treatment for a manifest childhood disease. These, however, are not legally binding. For example, if a social service agency wanted to test a foster child for Cystic Fibrosis, even though there was little chance of it manifesting in childhood, there would be little legal sanction against such testing.

Even if the law gives no direct answers on testing questions, legal and economic incentives to test or over-test may function in the background, affecting the children's interests in indirect ways. "Wrongful adoption" suits, based on fraud and neglect, have been successfully brought against adoption agencies that withheld medical information on a child adopted by a parent who subsequently found difficulties in raising the child.

Specific cases have demonstrated the agencies can be negligent in disclosing existing medical information. However, adoption agencies, fearful of capricious but still costly legal suits brought by dissatisfied adoptive parents, may be overly cautious about liability, with the consequence that they tend toward testing of children. Thus, social results of liability pressures may bring over-testing, initiating chain of social consequences. Repeated testing instances may signal problems to health care insurers even if actual test results indicate no difficulties. They may discourage prospective adopters, raising questions about a child from the mere fact of extensive testing.

BRIEF HISTORY OF U.S. GENETIC TESTING AND SCREENING POLICY

Genetic testing and screening policy on children in the U.S. now breaks down into two groups. Newborn infants are subject to state-mandated screening is in almost all of the 50 states. Experts judge that the balance of benefits outweighs the risks, since revealed conditions, such as PKU allow immediate treatment to prevent harms. Special diets and enzymes administered immediately to newborns can prevent mental retardation. So the rationale for mandatory PKU screening presents a paradigm case, giving an ethical and policy justification for mandatory genetic testing.

In older children, however, there is currently no federal or state policy requiring genetic screening or testing of children. For this age group, governmental and professional attitudes have been more cautious. Caution remains the policy position of most professional organizations. As explained above, the American Society of Human Genetics [ASHG] and the Institute of Medicine recommend, for example, that "Because of this potential for psychological and financial harm, a growing number of commentators and advisory bodies are recommending that genetic testing not be undertaken on minor children unless there is an immediate medical benefit."

However, it is important to keep in mind the balance of public interests and private rights in current policy reasoning, especially as this applies to populations under state care. If state interest in gathering personal private information is deemed compelling, as it is in the military, which obtains a genetic profile of every member, then state agencies acting in the public interest may override the individual right to privacy to gather genetic information. A parallel reasoning for foster and pre-adoptive children

might emerge. The fact that the state has custody of them, functions as their guardian, in place of legal biological parents, implies that the state therefore has an obligation to manage this population their best interest as well as the maintenance of public health and safety. Although social opinion recently quashed the prospect of genetic screening for markers such as an extra Y chromosome, allegedly associated with criminal behavior, the technological possibility for such testing remains. It is not impossible that some experts might recommend genetic testing or screening of foster care children in care of the state, e.g. as predictors of socially problematic costs or behavior. However, as argued below, environmental factors, such as lower social and economic opportunities for foster children emerging into adulthood, are primary factors in undermining equal rights and opportunities. So the question of privacy rights for those under state care remains an important consideration.

Race and ethnicity are especially controversial classifications which are bound to affect foster and adoptive children. The fact that African American children are over-represented in foster care sounds a note of caution. Since genetic testing and screening policies began, the issues of race and ethnicity have raised serious questions of stigma and discrimination. These have not had a favorable history in the U.S. An example is the former discriminatory US Air Force policy of not allowing African Americans carrying the Sickle Cell Anemia's gene to pilot, under the mistaken impression that they would blank out in flight and the mistaken conflation of carrier status and the actual presence of a disease. Government sponsored mass screening for Sickle Cell Anemia in the 1970's brought charges that stigma to the Black community added a component of biological or genetic prejudice to existing racial disparities.[21] The screening was quickly stopped and has become an infamous example of stigmatizing genetic policies.

The statistically higher prevalence of Tay Sachs in the Jewish Ashkenai community, the prevalence of Sickle Cell Anemia in those West African descent, of Thalessemia in those of Eastern Mediterranean or Asian descent, of Cystic Fibrosis in those of Northern European background, all raise the question of how to balance appropriate diagnosis and treatment with the possibility of group stigma. To neglect cultural attitudes that condition the delivery of health care is to underserve certain populations, as Berkeley sociologist Troy Duster has observed in a special report on

ethnicity and genetic disease.[22] The issue needs to be raised and addressed for foster and adoptive children, especially since these are often children of distinct ethnicity, whether from domestic or international origin.

ADVANTAGES OF GENETIC TESTING FOR FOSTER AND ADOPTIVE CHILDREN

Medical Best Interest of the Child: In some cases there is a dramatically effective medical treatment that needs to be applied immediately to prevent harm to the child. Genetic testing reveals which children will be helped. The classic instance illustrating medical best interests supporting genetic testing is PKU, or phenylketonuria, which requires a special diet avoiding proteins in order to prevent mental retardation. All newborns are screened for PKU by state law in most of the 50 U.S. states. In some cases genetic testing has predictive value with no immediate medical intervention. Dispute arises over medical benefit in Duchenne Muscular Dystrophy, where, as noted, no cure exists and only palliative care can be given. Other examples of medical benefit might be found in testing for the P53 mutation associated with childhood cancers. If a family history exists, and genetic test reveals the mutation in a particular child, physicians may monitor aggressively for tumors in the brain or lymph systems. However, the fact of false negatives shows that genetic testing is not always completely reliable.

Child Placement: According to some social service professionals, a clear medical profile and family history information in a medical record facilitates appropriate placement of children in permanent adoptive or foster homes. The case for expanded genetic testing has been made by child welfare experts who point to the model of special needs children, children with disabilities, or specialized diseases which would severely burden prospective parents. Adoptive or foster parents need to be fully informed of the heightened responsibilities incurred by providing health care for these children.[23]

Prospective Adoptive Parental Interests and Informed Consent: Adoptive parents have a right to know as much about the child they adopt as they possibly can. This principle can be argued from a general parental right to know, from equity principles drawing on the analogy between prenatal and pre-adoptive genetic testing, and finally, from a principle of parental responsibility. The best interest of the child is effectively served by placement with parents who are informed of conditions they are financially and

emotionally prepared to handle. To facilitate responsible parenting, full genetic information is required. It is also required to fulfill the conditions of informed consent by prospective adoptive or foster parents to take on the responsibility of a particular child. Parental right to know, with as full as possible information, can be inferred from both responsibility and informed consent.

Advances in Genetic Medicine: Genetic profiling may produce major advantages to children whose genetic profiles have been carefully assembled. These benefits, discussed in detail below, include the possibility of in tailoring medications to those individuals in whom they are most efficacious. Genetic medicine will also identifying susceptibilities by genetic testing and then administer preventive strategies to prevent diseases from arising in the first place or lessen the risks.

DISADVANTAGES OF GENETIC TESTING FOR FOSTER AND ADOPTIVE CHILDREN

Currently, many policy experts, professionals in medicine, law and bioethics, as well as the general public, are cautious about the consequences of genetic testing for the following reasons. The risk of genetic discrimination constitutes the first reason of concern to health care experts, to the public, and to some advocacy groups. Health care insurance can be lost entirely or premiums increased due to what insurers deem a "pre-existing condition". Loss of insurance in one case can mean loss of insurability generally because private health care insurers share massive databases covering national populations. Records are also accessed by employers who assess costs of health care, since as noted above, the majority cost of private health care insurance is borne by employers. Federal legislation in 30 states currently prevents genetic discrimination in health insurance and employment on the basis of genetic testing data.

New privacy laws have devised heightened protections. However, whether current legislation will adequately enforce these protections is an open question. Medical records are stored electronically and easily available to many parties, a technological reality which challenges the time-honored ethical principle of patient-physician confidentiality. It is also unclear how protections will apply to children generally or to children without legal parents, since much legislation assumes patients are adults. Because of patients'

cradle-to- grave electronic medical records, information recorded in childhood, seemingly innocuous then, may have very different effects later during adulthood. Constrained opportunities due to genetic testing information may end up undermining persons' economic security, social status within families, within communities.

From an ethical principle of avoiding unnecessary harm, the prospect of genetic discrimination puts genetic testing of children in a cautionary light. The medical ethical injunction 'Do No Harm' signals a need to scrutinize social, psychological and economic effects of gathering genetic information. From the vantage point of justice, under a principle of fair equality of opportunity, if genetic testing information undermines equal future life opportunities for a child, then it is unjustified, unless some immediate medical procedure serves the child's interest.

The risk of stigma, both within families and in communities, signals a form of prejudice or disregard that goes beyond legal categories of discrimination. For example, if children within a family who test positive for a disease may be "preselected" for vulnerability or negatively stigmatized by family members.[24] On the other hand, if a family is strongly identified with and even politically active around a given familial disease, and one sibling tests negative, a child may feel marginalized or like a "outlier" in relation to family unity. Instances of survival guilt are also common in persons who receive negative test results, e.g. in families that carry strong histories for breast and ovarian cancer with the BRCA1 mutation. A women who tests negative must rationalize her status vis-a-vis an affected sister. So, a negative genetic test result does not necessarily guarantee human well-being or contentment.

Within communities, individuals who are known to be carriers have been stigmatized. For example, a retired army colonel who was known to carry a reproductive genetic disease was forced to leave the town he lived in. The problem is exacerbated in Sickle Cell Anemia, which could draw stigma upon the African American community. Or as Tay Sachs would be treated in the Jewish community.

Mental health conditions are especially vulnerable to stigma in current society. This stigma may increase with the prospect of genetic testing. However, there is currently no genetic test, for example, for a "schizophrenia gene." No such single genetic alteration has been identified. Scientists consider schizophrenia to be multi-factorial, not

a mono-genic disease. However, if scientists discover even mildly predictive genetic markers, then many experts anticipate a large potential for stigma associated with such testing, e.g. in prospective parents who are particularly worried about mental health conditions in children they adopt.[25] In addition, genetic testing may be used in the future to track children into educational niches, as in special needs or learning disability classrooms. Adopted and foster children, historically subjected to eugenic scrutiny, may be considered eligible for such testing.[26] Each of these types of stigma could result social tracking or increasing a population of un-adoptable children that some experts are worried might become one social consequence of genetic testing.

Privacy Interests: Privacy interests apply to all children and also to those foster care or adoptive process. They also apply to the birth parents and birth families of these children, and to the prospective adoptive parents, and eventual adoptive families. Although children do not enjoy full legal rights, they do enjoy interests, which, according to child advocates, should be protected during their minority and for the future, to preserve their options in adulthood. Informational privacy can be defined as others not having access to one's personal information without one's consent, or the consent of a proxy, surrogate decision maker. This decision making role, for a minor child, is usually served by the legal parent. However, "gatekeeper" protections such as consent become ambiguous for children in limbo between birthparents and adoptive parents, or children in the foster system. Privacy interests need to be connected with health care systems in realistic ways. In the ideal, children's privacy interests are explicitly defined and strongly asserted in the model legal code, "The Genetic Privacy Act," authored by Annas, Glantz and Roche, health law professors at Boston University.[27]

Informed Consent Based on the Child's Best Interest: Each medical diagnostic or treatment procedure must receive the informed consent of the patient. This principle, firmly embedded in U.S. law and ethical foundations of medicine, is based on the autonomy of the individual. For children, an adult proxy makes a surrogate decision based on the child's best interest. The legal parents have the prima facie right to be decision maker for their children. As some clinical geneticists and pediatricians have observed, the decision maker and the target to whom genetic information is disclosed are

both ambiguous in the case of foster and pre-adoptive children. Is this decision maker the state? The social service worker? The adoption agency?

Child's "Open Future" and Future Autonomy Rights: A child's future right to decide for themselves at majority could be violated if testing for a non-essential medical purpose is conducted on the child. An example would be carrier testing or testing for an adult-onset condition that lacks any relevant prevention or treatment in childhood. Philosophers Joel Feinberg and William Ruddick have proposed that every child ought to have an "open future" where the child's options for opportunities or to decide for themselves, under a principle of liberty or autonomy, are preserved as far as possible.[28] Testing to serve a current need has a permanent effect on the child's future: The information is placed in the child's chart forever. Moreover, not all knowledge of the future is beneficial, even if it predicts truly. Experience in genetic testing for Huntington's Disease, which arises in a person's later life, has shown the psychological ill effects of a "genetic prophecy" that can hang over a person's life, clouding hope and the enjoyment of living life in the present.[29] In effect, taking action precludes options in the child's open future and possibly robs the child of autonomy to decide in the future what risks and benefits to undertake for themselves. Of course, when immediate medical benefit exists, a surrogate ought to make a decision for the child based on a reasonable assessment of what best preserves the child's survival and health interest.

Creation of a Pool of Un-Adoptable Children or a 'Biologic Underclass': One major worry lies in the possible social consequence of genetic testing, namely, enlarging a pool of unadoptable children.[30] This concern is expressed by child welfare professionals who already face the difficulties of placing foster children as well as by legal and policy experts. Historically, stigma has attached to adoptive children. To many people, a child not a product of "one's own" bloodline takes on a secondary or suspect status.[31] One source of adoptive children has been out of wedlock births which has historically brought the stigma of "illegitimacy."

Suppose genetic testing of foster and adoptive children becomes widespread. Then, this whole population of children may come to be viewed as "in need of screening." Professional and public perception may regard these children as presumptively inferior, as happened at the height of the 1920's eugenic movement. Even

if all genetic test results are positive for a given child, the social presumption against normalcy risks harm and diminished opportunity to all such children. It creates a hierarchy of acceptable to undesirable children which adds another layer of stigma to this group of children. The social irony is enhanced by the fact that many of these children suffer only from the condition of needing parents. Yet the rise of genetic testing and screening may function in public perception to discourage prospective adopters. Finally, those whose genetic profiles reveal "problems" may revolve in foster care as a socially rejected class.

TRADE-OFFS ON GENETIC TESTING ON FOSTER AND ADOPTIVE CHILDREN

The following dilemma arises in public policy given rapidly advancing genetic technologies. Either alternative, testing or failing to test, may bring harms to children in the future, so genetic testing itself may be a double edged sword. On the one hand, testing may put a child at social risk, due to potential for genetic discrimination. On the other hand, failing to test may put a child at a disadvantage in receiving particularized health care treatments as genetic medicine advances into the field of pharmacogenomics. Medical experts and pharmaceutical industry researchers predict that, within five to ten years, genetic medicine will utilize genetic profiles to tailor medications to the individual patient. When pharmacogenomics becomes the standard of care, we may find that the failure to gather genetic profiles of foster and adoptive children will become a health care disadvantage.[32]

Also, future applications of genetic medicine will make advances beyond the narrow model of testing for monogenic disease, associated with one gene marker. The situation will become more complex. For example, if hormonal treatment for irregular menses is indicated, a teenage girl might benefit from knowing whether she carries a BRCA1 marker for early onset breast or ovarian cancer, since hormones exacerbate the risk of breast cancer.[33] Hence, as genetic profiles become part of routine standard of care, failure to test certain sub-populations could also disadvantage children.

Here we have a clear illustration of how foster and adoptive children serve to magnify and sharply delineate public policy issues. Consider the following double bind. Because of heightened risk to future equal opportunity [due to risk of discrimination and

stigma], it stands in the child's best interest to avoid acquiring genetic information. However, because of changing technologies revising the medical standard of care and subsequent vulnerability to unequal health care access, it stands in the foster and adoptive child's best interest to gain genetic information. Thus, equally with others, they can benefit from genetic medicine early in their life span. However, each point of this bind is also fraught with difficulties. The gatekeepers to give informed consent, to weigh the risks of harms and benefits, are often ambiguous or absent. On the other side, questionable access to health care for foster and adoptive children calls into question whether expert genetic profiling and diagnostics will be applied. So, the bind is compounded by the prospect of the child facing risks on each point.

Medical experts predict a new focus on children and even infants. Preventive treatments delivered early in the human life-span may be more effective in changing the developmental trajectory of the patient and consequently more advantageous in avoiding chronic conditions or illness. Genetic profiles will reveal these susceptibilities, the earlier the better, and the child will be preventively treated. The upshot is a risk of deepened inequalities in health care under what promises to become a technologically transformed standard of care. If health care delivery for foster and adoptive children falls below what becomes the standard of care, due to lack of genetic testing profiles, then we may see a divide between those who have permanent parents, with means, and those who do not, those who have private and those with public health care. The foster and adoptive group of children may then enter adulthood with comparative health care disadvantages. Ultimately, the fact that either policy, testing or not testing, might turn out to harm this group of children, or subject them to unequal opportunities, points out the depth and complexity of possible trade-offs between health care and social policy.

CONCLUSION

The best response to these complex dilemmas is continuous vigilance and scrutiny by public policy, by parents, by agencies, legislators and professionals dealing with child welfare. Current professional guidelines for testing children, such as the ASHG/ACOG guidelines affirmed here, limit acceptable testing to conditions for which an immediate benefit exists in childhood. All children will be protected, including foster and adoptive

children, if these are followed. In addition, a "health care access condition," one of the original contributions proposed by this paper, must be added to the calculation of the child's best interests in each case. It is not enough to test on the supposition that a medical procedure exists: A child must be capable of realistic access to the existing medical procedure and that access not undermined by gathering genetic information. In addition, foster and pre-adoptive, already adopted children, should enjoy the same medical and ethical standards for testing, so as to avoid a double standard for adopted or foster children without permanent parents.

Overall, public policy needs to examine the social consequences of applying new medical and genetic technologies, especially regarding children, who may become the prime patients in the future. Unequal access to social opportunities falls especially hard on children in U.S. society. The prospect of widespread and un-reflective genetic testing or screening threatens to reinforce these cycles of poverty, adding layers of differential access and unequal opportunity existing patterns. For children, equal opportunity in the present means permanency, stable family life, as well as parental protection and access to health care. Equal opportunity in their future means entering adulthood with equal prospects for employment, housing, health care, and economic security. These challenges fall especially hard on pre-adoptive and foster children. The increasing numbers of children who stay in foster care have been exposed as a profound national problem. Many foster children exiting the system at 18, the age of majority, are thrust out into society with little support, have trouble finding jobs and housing, a pattern that reinforces cycles of poverty and unequal opportunities.

Some experts are worried about a "biologic underclass" arising in the genetic era that adds unequal health care access and genetic stigma to already existing inequalities. Children are located at the key developmental stage for grounding adult functioning and equal opportunity through three factors: family, education and health care. Foster and pre-adoptive children comprise an especially vulnerable class of children precisely because they lack legal parents and stable families to lay the ground for these future options.

A cautionary tale to guide policy formation is offered here. As technology advances, genetic testing, diagnosis and treatment will perform different roles. Not all

medical or social consequences can be predicted, so the normative standards discussed here will be re-evaluated as new procedures become the standard of care, for example, in the predicted rise of pharmacogenomics. Under new paradigms of health care, the lack of genetic testing profiles may leave certain groups of children without equal health care. We need to ask, at each stage of this rapidly evolving technology, what will protect children without permanent parents, in terms of their health care and overall development, both in the short and long term. We need to ask what promotes equity for their future life chances. We need to find ways to support these children in finding stable, nurturing, families. Their life prospects in society are lessons to society and are instructive for us all.

NOTES

[1] For models of justice, see John Rawls, Theory of Justice. (Cambridge, MA: Harvard University Press, 1972), Amartya Sen, Amartya, Inequality Reexamined (Cambridge, MA: Harvard University Press, 1992), Susan Okin, Justice, Gender and the Family (New York, NY: Free Press, 1987), Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler, From Choice to Chance: Genetics and Justice (New York: Cambridge University Press, 2000), Norman Daniels, Just Health Care (New York: Cambridge University Press, 1985). On genetic discrimination and privacy, see Mark A. Rothstein, ed., Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (New Haven, CT: Yale University Press, 1997). For justice in genetics specific to women and children, see Mary Mahowald, Genes, Women, Equality (New York: Oxford University Press, 2000).

[2] About 14 million children live below the poverty line. For documentation, see Renny Golden, Disposable Children: America's Child Welfare System (New York: Wadsworth Publishing Company, 1996) p.55. Children are twice as likely as adults to live in poverty. See Jim Weill, "The Convention on the Rights of the Child and the Well-Being of America's Children" in Georgia Journal of Fighting Poverty, Vol. 5, (1998) p.257.

[3] More than 10 million children lack health insurance. For documentation See U.S. Census Bureau, Health Insurance Coverage: 1998, http://www.census.gov. See also Jim Weill, "The Convention on the Rights of the Child and the Well-Being of America's Children" in Georgia Journal of Fighting Poverty, Vol.5 (1998) p.259.

[4] Housing constitutes a major problem, with severe shortages for families and children in poverty. See Donna Haig Friedman, Parenting in Public: Family Shelter and Public Assistance (New York: Columbia University Press, 2000), pp.114-116. For documentation of the fact that many homeless families face increased scrutiny for removal of children to foster care. Many families in poverty who find what might be called "minimally adequate" housing are forced to pay more than half their income in rents. These factors are exacerbated by welfare reform. Some surveys put children at 25% of those in the homeless population. For documentation of each of these points, see Arloc Sherman, Cheryl Amey, Barbara Duffield, Nancy Ebb and Deborah Weinstein, Welfare to What: Early Findings on Family Hardship and Well-Being, (New York: Diane Publishing Company, 1999), available at http://www.childrensdefense.org. See also Megan Sandel, Joshua Sharfstein and Randy Shaw, There's No Place Like Home: How America's Housing Crisis Threatens Our Children (New York: Diane Publishing Company, 1999).

[5] Guggenheim notes: "Close to half the children who live in poverty conditions are African American; only about 16% are white." See Renny Golden, Disposable Children: America's Child Welfare System, (1997), p. 68. For additional sources and analysis of

how these factors relate to the relative lack of societal supports for U.S. families, see Martin Guggenheim, "Review of Bartholet, Nobody's Children" in Harvard Law Review, Vol.113 (May 2000), p.1739.

[6] Diane Paul, "Is Genetics Disguised Eugenics?" in Robert F. Weir, et al. eds., Genes and Self-Knowledge: Historical and Philosophical Reflections on Human Genetics (Iowa City, IA: University of Iowa Press, 1994). Diane Paul, "Eugenics Anxieties, Social Realities and Political Choices" in Social Research, Vol.59 (1992), [3F]: pp. 363-383. On history of Eugenics, see Diane Paul, Controlling Human Heredity (New York: Humanities Press, 1992). See also Ruth Hubbard and Elijah Wald, Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators, and Law Enforcers (Boston, MA: Beacon Press, 1997).

[7] The classic analysis of stigma is Erving Goffman, Stigma: Notes on Management of Spoiled Identity, (Englewoods Cliffs, NJ: Prentice Hall, 1964). For stigma in adoption, see analysis in Elizabeth Bartholet, Family Bonds, (Boston, MA: Houghton Mifflin, 1994).

[8] The Health Insurance Portability and Accountability Act of 1996 [HIPAA] Public Law 104-191. *Federal Register,* 1999. Massachusetts Legislation, 2000. Chapter 254 of the Acts of 2000. An Act Relative to Insurance and Genetic Testing and Privacy Protection.

[9] For case descriptions, see Kimberly Quaid, David H. Smith, Roger B. Dworkin, Gregory P. Gramelspacher, Judith A. Granbois and Gail H. Vance, Early Warning: Cases and Ethical Guidance For PreSymptomatic Testing in Genetic Diseases (Bloomington and Indianapolis, IN: Indiana University Press, 1998).

[10] Lori Andrews, Jane Fullarton, Neil A. Holtzman, and Arno G. Motulsky, eds., Assessing Genetic Risks: Implications for Health and Social Policy, (Committee on Assessing Genetic Risks, Division of Health Sciences Policy, Institute of Medicine. Commissioned by National Center for Human Genome Research at National Institutes of Health, Washington) (Washington DC: National Academy Press. 1994) p. 11.

[11] Madelyn F. Freundlich, "The Case Against Preadoption Genetic Testing" in Child Welfare Vol.77(6) (Nov-Dec 1998) pp.663-79. See also Madelyn F.Freundlich and L. Peterson Wrongful Adoption: Law, Policy, & Practice (Washington, DC: Child Welfare League of America 1998). pp.11-26.

[12] Lori Andrews, an expert in genetics and health law, grounds her argument in legal precedent. See Lori Andrews, "Gen-Etiquette: Genetic Information, Family Relationships, and Adoption," in Mark A. Rothstein, ed., Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (New Haven, CT: Yale University Press, 1997).

[13] "Genetic Testing In Adoption: Joint Statement of the American Society of Human Genetics and the American College of Medical Genetics," in American Journal of

Human Genetics Vol.66 (2000) pp.761-7. See also "Points to Consider: Ethical, Legal and Psychosocial Implications of Genetic Testing in Children and Adolescents" American Journal of Human Genetics Vol.57 (1995), pp.1233-36.

[14] The British Society for Clinical Genetics gives guidelines which specify testing for conditions which arise in childhood, a standards which may give more leeway to parental autonomy and need to know the status of children in criteria for genetic testing. See Angus Clarke, "The Genetic Testing of Children: Report of a Working Party of the Clinical Genetics Society" in Journal of Medical Genetics Vol.31(10) (Oct 1994), pp.785-97. See http://www.bshg.org.uk. However, the British Society guidelines do urge caution on genetic testing and strongly emphasize a thorough evaluation of psychological and social risks. Genetic discrimination in risk of higher premiums or loss of health care insurability, currently an issue in the U.S., needs to be compared with the British Society's assumption of a system of universal health care coverage in the United Kingdom.

[15] This practice of taking family histories, which enters the hereditary [now regarded as genetic] information part of the medical record, adds another scientific policy controversy to the present set of issues. Those who oppose a special category for genetic testing information or specific legislation for "genetic discrimination" criticize what they call "genetic exceptionalism" or the view that genetic information can be distinguished from other types of medical information on a patient. The sharp policy and scientific controversy over "genetic exceptionalism" engages the scientific theory that every disease includes some genetic mechanism, or can be described partially in genetic terms, even if its causation is not hereditary. For a view affirming the special status of genetic information, see George Annas, "Privacy Rules for DNA Databanks: Protecting Coded Future Diaries," in Journal of American Medical Association Vol.270 (1993) pp.2346-50. For a critique see, Thomas Murray, "Genetic Exceptionalism and Future Diaries: Is Genetic Information Different from Other Medical Information?" in Mark A. Rothstein, ed., Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (New Haven, CT: Yale University Press, 1997). For analysis of privacy in health care policy, see Phyllis Freeman and A. Robbins, "The Health Data Privacy Debate: Can We Achieve Comprehension Before Closure?", An Occasional Paper, John W. McCormack Institute of Public Affairs (Boston: University of Massachusetts, 1998).

[16] Committee for the National Institute of Human Genome Research and the Institute of Medicine, headed by Lori Andrews. Also the *American Society for Human Genetics and the American College of Medical Genetics*. Op. cit. See footnote 14 on professional guidelines.

[17] See Presentation on Ethics of Pre-Adoptive Genetic Testing in Panel, with Lanie Ross M.D., Madelyn Freundlich, J.D., Janet Farrell Smith, Ph.D., in Transcript of Proceedings, Colloquium on The Ethics of Genetic Testing in Adoption 10 March, 2000 (Boston, MA:

University of Massachusetts Boston, sponsored by the Center for Social Policy, McCormack Institute) pp.84-94.

[18] Presentation by Leonard Glantz, Dean and Professor of Health Law, Boston University School of Public Health "Right to Privacy in Genetic Testing of Children," in Transcript of Proceedings, Colloquium on the Ethics of Genetic Testing in Adoption 10 March, 2000 (Boston, MA: University of Massachusetts Boston, sponsored by the Center for Social Policy, McCormack Institute) pp. 36-50.

[19] Two legal experts have differed sharply on these issues, Cf. the exchange between Madelyn Freundlich, J.D., MSW, and Leonard Glantz, J.D., in Transcript of Proceedings, Colloquium on The Ethics of Genetic Testing in Adoption 10 March, 2000 (Boston, MA: University of Massachusetts Boston, sponsored by the Center for Social Policy, McCormack Institute) pp. 36-50.

[20] See also Ruth Hubbard and Elijah Wald, Op. cit. Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists, Physicians, Employers, Insurance Companies, Educators, and Law Enforcers (Boston, MA: Beacon Press, 1997). Also, Barbara Katz Rothman, The Book of Life. A Personal and Ethical Guide to Race, Normality, and the Implications of the Human Genome Project (Boston, MA: Beacon Press, 1996) and Keith Wailoo, Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health, (Chapel Hill and London, NC: The University of North Carolina Press, 2001).

[21] Four hundred thousand children lost health insurance because of welfare reform. See Families USA Foundation, Losing Health Insurance: The Unintended Consequences of Welfare Reform. May 1999. Also available at http://www.familiesusa.org. See also Jocelyn Guyer, Matthew Broaddus & Michelle Cochran, Missed Opportunities: Declining Medicaid Enrollment Undermines the Nation's Progress in Insuring Low-Income Children. http://www.cbpp.org/10-20-99health.html.

[22] Troy Duster, Principal Investigator, "Pathways and Barriers to Genetic Testing and Screening: Molecular Genetics Meets the High Risk Family", in Final Report, Institute for the Study of Social Change (Berkley, CA: University of California, 2000).

[23] Julia B. Rauch and N.Rike, Adoption Worker's Guide to Genetic Services (Chelsea, MI: The National Resource Center for Special Needs Adoption). [n.d]

[24] On stigma, see Goffman, Op. cit. On the phenomenon of "preselecting" a child for illness, creating a syndrome of weakness and vulnerability, even where in fact none may occur, see the discussion by experts in genetic counseling, Kimberly Quaid, David H. Smith, Roger B. Dworkin, Gregory P. Gramelspacher, Judith A. Granbois and Gail H. Vance, Early Warning. Cases and Ethical Guidance For PreSymptomatic Testing in Genetic Diseases (Bloomington and Indianapolis , IN: Indiana University Press, 1998).

[25] Presentation on "Adoption and Mental Health," in Transcript of Proceedings, Colloquium on The Ethics of Genetic Testing in Adoption 10 March, 2000 (Boston, MA:

University of Massachusetts Boston, sponsored by the Center for Social Policy, McCormack Institute) pp. 20-29. See also, Anita Allen, "Genetic Privacy," in Mark A. Rothstein, ed., Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (New Haven, CT: Yale University Press, 1997).

[26] See Laura Rothstein, "Genetic Information in Schools," in Mark A. Rothstein, ed., Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (New Haven, CT: Yale University Press, 1997).

[27] George Annas, Leonard H. Glantz and Patricia Roche, The Genetic Privacy Act and Commentary (Boston, MA: Health Law Department, Boston University School of Public Health, Feb 28 1995).

[28] See Joel Feinberg, "The Child's Right to an Open Future," in William Aiken and Hugh LaFollette, eds., Whose Child? Children's Rights, Parental Authority and State Power (Totowa, NJ: Littlefield Adams, 1980) and William Ruddick, "Parents and Life Prospects" in Onora O'Neill, Ruddick William, Having Children: Philosophical and Legal Reflections on Parenthood. (New York: Oxford University Press, 1979).

[29] See analysis by Alice Wexler, who herself came from a family history of Huntington's Disease, and refused to reveal whether or not she underwent genetic testing for it, Mapping Fate. A Memoir of Family, Risk, And Genetic Research, (New York: Random House, 1995) . Also, Zsolt Harsanyi, Genetic Prophecy: Beyond the Double Helix, (New York: Rawson,Wade, Publishers, Inc., 1994).

[30] See comment by Susan O'Hara, "The Use of Genetic Testing in the Health Insurance Industry: The Creation of a Biologic Underclass," in SouthWest University Law Review Vol.22 (1993) p.1211.

[31] Janet Farrell Smith, "A 'Child of One's Own': Property, Progeny and Adoption", in Sally Haslanger and Charlotte Witt, eds., The View From Home: Philosophical Issues in Adoption, (Boulder, CO: Westview Press, 2002).

[32] On research and ethics in pharmacogenomics, see Nicholas Wade, "Tailoring Drugs to Fit the Genes" in New York Times, 20 April 1999, p.D9. Amalia Issa, "Ethical Considerations in Pharmacogenomics Research," Topics in Pharmacological Science [TIPS]. Vol. 21, 2000.

[33] See commentary by Katherine Sims M.D., Director of the Neurogenetics Clinic at Massachusetts General Hospital, in Transcript of Proceedings, Colloquium on The Ethics of Genetic Testing in Adoption 10 March, 2000 (Boston, MA: University of Massachusetts Boston, sponsored by the Center for Social Policy, McCormack Institute) pp. 70-80.