

ASHG/ACMG STATEMENT Genetic Testing in Adoption

The American Society of Human Genetics Social Issues Committee and The American College of Medical Genetics Social, Ethical, and Legal Issues Committee

Summary of Recommendations

Reports from geneticists have stated that prospective adoptive parents and adoption agencies are requesting a wider range of genetic tests before, during, or immediately after the adoption process. It is possible that certain children who are determined to have various harmful or undesirable genetic predispositions or characteristics will have a difficult time being adopted or, if adopted, will be treated differently by adoptive parents. Although these reports must be considered anecdotal or preliminary at the present time, it is clear that the pressure for genetic testing in adoption will increase as the range of available genetic tests increases.

The American Society of Human Genetics (ASHG) and the American College of Medical Genetics (ACMG) recommend the following:

1. All genetic testing of newborns and children in the adoption process should be consistent with the tests performed on all children of a similar age for the purposes of diagnosis or of identifying appropriate prevention strategies.

2. Because the primary justification for genetic testing of any child is a timely medical benefit to the child, genetic testing of newborns and children in the adoption process should be limited to testing for conditions that manifest themselves during childhood or for which preventive measures or therapies may be undertaken during childhood.

3. In the adoption process, newborns and children should not be tested for the purpose of detecting genetic variations of or predispositions to physical, mental, or behavioral traits within the normal range.

These recommendations are designed primarily as an educational resource for medical geneticists and other health care providers, to help them provide quality medical genetic services. Adherence to these recommenda-

tions does not necessarily assure a successful medical outcome. These recommendations should not be considered inclusive of all proper procedures and tests or exclusive of other procedures and tests that are reasonably directed to obtaining the same results. In determining the propriety of any specific procedure or test, the geneticist should apply his or her own professional judgment to the specific clinical circumstances presented by the individual patient or specimen. It may be prudent, however, to document in the patient's record the rationale for any significant deviation from these recommendations. (This statement does not address the issue of the use of genetic information about the adoptive parents to determine their suitability for adoption.)

Background

In 1991, the ASHG issued the "Report on Genetics and Adoption, Points to Consider" (American Society of Human Genetics 1991). The report indicated the importance of obtaining a genetic history of a child entering foster care or the adoption process. It stated that the "compilation of an appropriate genetic history and the inclusion of genetic data in the adoptee's medical files should be a routine part of the adoption process." When medically appropriate, genetic data may be shared among the adoptive parents, biological parents, and adoptees.

In 1995, the ASHG and the ACMG issued the report "Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents" (American Society of Human Genetics Board of Directors and American College of Medical Genetics Board of Directors 1995). Among other things, the report stated that "timely medical benefit to the child should be the primary justification for genetic testing in children and adolescents." In addition, it stated: "If the medical or psychosocial benefits of a genetic test will not accrue until adulthood, as in the case of carrier status or adult-onset diseases, genetic testing generally should be deferred."

The ASHG/ACMG statement is consistent with statements of other medical groups and organizations, including the American Medical Association (Code of

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Ethics §2.138), the American Academy of Neurology (Practice Parameter: Genetic Testing Alert), the American College of Obstetrics and Gynecology (Committee Opinion: Ethical Guidance for Patient Testing), and the American Society of Clinical Oncologists (Genetic Testing for Cancer Susceptibility).

The National Human Genome Research Institute's Task Force on Genetic Testing (the NHGRI Task Force), created by the National Institutes of Health-Department of Energy Working Group on Ethical, Legal, and Social Implications of Human Genome Research, has expressly agreed with the ASHG/ACMG's position that timely benefit to the child should be the primary justification for testing. The NHGRI Task Force has recommended, in addition, that, "genetic testing of children for adult onset diseases should not be undertaken unless direct medical benefit will accrue to the child and this benefit would be lost by waiting until the child has reached adulthood" (National Human Genome Research Institute 1997).

Rationale

The issue of genetic testing of newborns and children in adoption involves the interests of a number of parties: (1) the child, (2) the adoptive parents, (3) the birth parents, (4) the adoption agency, and (5) the public at large. Of these interests, the primary concern should be for the well-being of the child. Such an approach is consistent with the standard applied generally to adoption proceedings and advanced in the 1995 ASHG/ACMG report (American Society of Human Genetics Board of Directors and American College of Medical Genetics Board of Directors 1995).

Child's Interests

The best interest of the child is paramount in adoption proceedings and forms the basis of the current legal standard (Kawashima 1981-82; Howe 1983). The best interest of the child encompasses concern for the child's physical and psychological health, privacy interests, and social development. All these concerns may be affected by genetic information.

A significant characteristic common to all adoptions is the desire or need to incorporate the adopted child into the family. The adopted child becomes a full member of the family and acquires status equal to that of a child biologically related to the adoptive parents (Kawashima 1981-82; Murray 1996, pp. 41-69). As a result, the same standard or approach recommended for biologically related children should also be applied to adopted children (Wertz et al. 1994).

In terms of genetic testing, the need to treat adopted children in a manner similar to that in which biologically

related children are treated has been recognized and advanced by the American Academy of Pediatrics (AAP) in its statement on initial medical evaluations of adopted children. The following potential problems have been noted (American Academy of Pediatrics' Committee on Early Childhood, Adoption and Dependent Care 1991).

1. Some parents expect the guarantee of a "perfect child." They may push for unnecessary tests and expect unrealistic predictions from the pediatrician. Just as a birth family cannot be certain that its natural child will be healthy, the adoptive family cannot be guaranteed that a child will not have future health problems.
2. By focusing on an extensive medical evaluation of a child, the pediatrician must be careful not to create a "vulnerable" child through an exaggerated assessment of historical risk. Most adopted children are healthy, even if they come from high-risk backgrounds. Certainly, the risks must be defined and then carefully explained to the family, so that problems can be anticipated and dealt with expediently. This is the same anticipatory guidance the pediatrician uses for all patients.
3. It is not the pediatrician's role to judge the advisability of a proposed adoption, but it is appropriate and necessary that the prospective parents and any involved agency be apprised clearly and honestly of any special health needs detected now or anticipated for the future. Thus, the pediatrician should resist unreasonable demands while empathizing with the adoptive parents' anxieties and concerns.

The welfare of children affected by genetic conditions should be the first concern in the practice of medical genetics (Pelias 1999a). In assessing which genetic tests are appropriate for all children, including adopted children, the nature of the tests is an important consideration. Among the types of tests currently available are (1) tests for diseases that can be prevented or the health consequences of which can be reduced through early treatment; (2) tests for serious childhood diseases; (3) tests for conditions that do not manifest themselves until adulthood and for which no treatment or preventive action is available in childhood; (4) tests indicating a predisposition to a common adult-onset disorder for which some general preventive measures may be taken in childhood; (5) tests for behavioral traits; (6) tests for carrier state and other conditions that may impact the child's future reproductive decisions; (7) tests that parents request without any direct relation to treatment or reproductive options for the child; and (8) tests performed solely for the benefit of another family member. Additional classifications or smaller subsets of available tests are possible (Wertz et al. 1994; Hoffmann and Wulfsberg 1995), and some of the categories may overlap when the same test is performed for more than one

reason, but the eight types of tests described provide a good starting point for discussion of the appropriateness of genetic testing.

Of the eight categories of tests, only the first two categories should be viewed with unqualified approval. The immediate availability of medical benefits for a child who has or may soon develop a genetic condition provides the strongest reason for genetic testing (Pelias 1999a, 1999b). An often-cited example of the first type of test is newborn screening for phenylketonuria (PKU) (Clayton 1992, 1998; Andrews and Elster 1998). Such tests serve the interests of the child directly, are medically indicated, and comply with the standards set forth in the 1995 ASHG/ACMG report (American Society of Human Genetics Board of Directors and American College of Medical Genetics Board of Directors 1995) and the statements of other medical groups and organizations. The test for PKU is used to screen newborns for a genetic condition that, left untreated, will result in severe mental and motor retardation. Where the condition is identified through testing, effective dietary therapy is available (Clayton 1992, 1998). Such screening is also frequently required by law (Clayton 1992). All states either mandate or offer testing for PKU (The National Academies News 1993).

The second type of test, which screens for serious childhood conditions, should also be supported when there is some health-related indication of the need to test. Such indications include symptoms and family history. An example would be a child with a birth sibling who was already diagnosed with cystic fibrosis (CF). Interests of other parties, including the right of the adoptive parents to choose not to adopt a child with a catastrophic disease, are discussed in the sections that follow.

Although only these first two categories of tests are clearly justified, the remaining categories must also be addressed, because "the entry of such tests into the marketplace is raising the specter of their widespread use" (Hoffmann and Wulfsberg 1995). In this regard, technology has increased the number of genetic conditions identifiable through testing, and entities with commercial interests in genetic tests are exerting pressure to expand state screening programs and increase the number of genetic tests available to the public (The National Academies News 1993; Andrews 1997; Buchanan 1998). In addition, some suggest that genetic testing of children in situations in which no immediate medical benefit is expected should not be summarily dismissed as inappropriate, because testing may be otherwise beneficial to the child depending on the purpose of the test, the use to which the test results will be put, the level of maturity of the child, and other individually determined factors (Cohen 1998; Pelias 1999b). Such testing requires greater consideration and caution, however, even

if allowed under some circumstances (Cohen 1998; Pelias 1999b).

The third type of test, which screens for conditions that do not manifest until adulthood and for which no treatment or preventive action is available in childhood, includes tests for Huntington disease (HD) and Alzheimer disease. Presymptomatic tests for such serious, untreatable, late-onset disorders are personal in nature and should only be conducted on a voluntary basis (Morris et al. 1988). Moreover, where no treatment exists for the condition even if revealed, the test is unnecessary, at least from a medical standpoint. Currently, diagnosis for genetic diseases far outstrips treatment technology (Buchanan 1998). As a result, the decision about whether to test for most late-onset or untreatable genetic conditions is better left to the individual at a time when he or she is mature enough to consider all the ramifications of testing (Holland 1997; Rothstein 1997). Importantly, many adults with family histories of genetic predispositions for certain diseases choose not to be tested. For example, only 15% of those having a parent affected with HD choose to learn their own risk for the disease (Greely 1999). Thus, tests that fall within the third category generally do not comport with the best interest of the child.

The fourth type of test involves screening for predisposition to common adult-onset disorders for which some general preventive measures may be taken in childhood. The benefits of such tests, however, may not outweigh the costs sufficiently to warrant their support. Tests that screen for an increased risk of skin cancer or heart disease fall within the fourth type of test. Some of the primary criticisms of these types of tests are that they may label children prematurely and they may result in the implementation of a course of medication that could last >50 years and cause side effects and have no guarantee of a change in life expectancy (AAP 1992; Harrell et al. 1998). Because of the potential for stigmatization where individualized testing is conducted, a more population-oriented approach should be taken. Numerous studies show that a majority of the population would benefit from a more healthful lifestyle, including reducing fat, increasing exercise, and limiting sun exposure. To the extent that selective screening is necessary, family histories can be used (AAP 1992, 1998; Harrell et al. 1998). Because such testing for genetic predispositions in newborns and children often lacks predictive value and is rarely justified (Hoffmann and Wulfsberg 1995), no special exception should be made for children in the adoption process.

The fifth type of test attempts to screen for behavioral traits, such as learning disabilities and personality traits. One of the major problems with this type of test is that biological or genetic markers have not been identified for most childhood behavioral disorders. Other prob-

lems include the unpredictable variability in the timing or severity of the disorder or how it will affect the child's functioning. Even where a genetic marker is identified, the stigmatization of the child and the potential for uncritical reliance on pharmacological solutions are possible. Tests for genetic mutations that cause severe mental retardation, such as fragile X syndrome, would not be included in this category and would be considered as a test of the second category.

The sixth type of test is directed at a child's future reproductive decisions and includes carrier tests for autosomal recessive or X-linked disorders, such as CF and Duchenne muscular dystrophy, and presymptomatic tests for adult-onset disorders, such as HD (Wertz et al. 1994). Tests that may affect a child's reproductive choices later in life are unnecessary at the newborn stage or in the adoption process and serve no immediate medical need of the child (Wertz et al. 1994; Holland 1997). These tests should be postponed until the child is mature enough to decide whether to be tested (Morris et al. 1988).

The seventh type of test offers no present medical benefit or future reproductive benefit but is conducted solely at the request of the adopting parents. Carrier tests for autosomal recessive or X-linked disorders and presymptomatic tests for adult-onset disorders can also fall within this category of tests when the child is nowhere near reproductive age (Wertz et al. 1994). As in the case of the sixth category of tests, tests that fall within the seventh category do not serve an immediate interest of the child, are not medically indicated, and do not comply with the stated positions of ASHG, ACMG, and other medical groups and organizations that have examined and addressed the wisdom of genetic testing of newborns and children.

The eighth type of test analyzes the DNA of several members of a biologically related family to determine the likelihood of a single individual within that family having a certain gene mutation (Wertz et al. 1994). In the context of adoption, this category of test lacks justification. DNA linkage analysis is relevant only to biologically related individuals. Consequently, such tests serve no benefit to the child or the adoptive family because they are not biologically related.

The ASHG and ACMG have already recommended that the principal objective of genetic testing should be promoting the child's well-being (American Society of Human Genetics Board of Directors and American College of Medical Genetics Board of Directors 1995). This objective applies to adopted newborns and children as well as to biologically related newborns and children. If adopted newborns or children are to be integrated effectively into adoptive families, they should receive treatment similar to that of the biologically related children. No child brings a guarantee of perfection (AAP 1991).

Requiring more of adopted newborns and children than of biologically related newborns and children turns adopted newborns and children into commodities (Wertz et al. 1994; Rothstein 1997). Caution needs to be exercised to avoid crafting an approach that is too broad in encouraging the collection of genetic information in the adoption process. Different judgments may be required depending on where a test falls on the spectrum of tests for identifying genetic disorders and conditions (Buchanan 1998; Clayton 1998; Pelias 1999b).

Genetic testing of adopted children, as well as of biological children, involves more than science and medicine (Pelias 1999a, 1999b). Testing can have significant negative psychological, social, and financial implications for the adopted child (Andrews and Elster 1998). Among the negative implications associated with testing are the potential for stigmatization and discrimination, alterations in self-image and future prospects, and shifts in relationships within and outside the family (Freundlich 1998; Pelias 1999a, 1999b).

The stigmatizing effect of genetic information has broad implications. Where a genetic predisposition is uncovered, adoptive parents may choose not to adopt the child. As a result, testing may reduce the chances that the child will be adopted (Rothstein 1994-95; Andrews and Elster 1998; Freundlich 1998). Alternatively, even if the parents choose to adopt, they may treat the child differently because of some feeling that their child's future is preordained (Andrews 1997; Andrews and Elster 1998; Clayton 1998; Freundlich 1998). Expectations of the child's role in the family may be lowered (Wertz et al. 1994). Disclosure of the adoptive child's genetic information outside the family may also adversely affect the child's ability to obtain insurance or employment.

The issue of testing is further complicated by the ambiguity associated with predictive testing. Genetic tests usually do not predict when or to what degree a genetic disease or condition will manifest itself (Holland 1997). More importantly, the mere presence of a gene coding for a genetic disease or condition does not mean that a child will invariably develop the disease or condition. Such test results supply only "probabilities, not certainties" (Freundlich 1998). At best, predictive genetic tests can only provide a range of risk. To subject a child to the potential for stigmatization, discrimination, and poor self-image based on ambiguous information is especially problematic (Clayton 1992; Holland 1997; Freundlich 1998). When the disadvantages of testing are weighed against the advantages of testing, the balance favors not testing, except in cases where genetic conditions manifest themselves during childhood or where effective, preventive measures may be undertaken during childhood.

The arguments against testing are even stronger if the

purpose of testing is to detect genetic variations of normal physical conditions. Such testing is not associated with disease or disability. To allow adopting parents to test an adoptive child for relative genetic advantages in physical or mental endowments reduces the child to a commodity and creates an “underclass” of potential adoptees. This result is contrary to the promotion of the child’s best interest, which is at the heart of all adoptions, and to the medical and legal standards promulgated to protect a child’s genetic information. Moreover, as noted, preadoption genetic testing raises significant ethical concerns, including matters of autonomy, beneficence, equity, knowledge, and nonmaleficence (Freundlich 1998).

In summary, genetic testing of adopted children is unquestionably appropriate if it is consistent with preventive and diagnostic tests performed on all children of a similar age. Genetic testing that has no timely medical benefit to the child should be approached with great caution. Genetic testing that detects genetic variations within the normal range should be avoided.

Adoptive Parents’ Interests

Although the best interest of the child has been and continues to be the legal benchmark of the adoption process, modern adoption laws also seek to protect the interests of the adoptive parents and the birth parents (Howe 1983). Parents contend rightly that the common law affords them broad discretion to make medical decisions on behalf of their minor children (Pelias and Blanton 1996; Andrews 1997; Pelias 1999a, 1999b). Preventive and therapeutic medical decisions should, however, be distinguished from predictive genetic testing. As noted, the results of such testing may cause the adoptive parents to treat the child differently and may give rise to the potential for stigmatization, discrimination, and poor self-image (Andrews 1997). These profound downsides to testing have led some to recommend that the exercise of parental rights be circumscribed if no immediate medical purpose is served or that testing be postponed at least until the child can participate in the decision (Morris et al. 1988; Andrews 1997).

Other reasons given for adoptive parents’ right to seek genetic testing of a child include decisional, emotional, and financial considerations. One argument offered in favor of testing is that the adoptive parents need full disclosure of a child’s medical background before adoption so that they may make an informed decision on whether to adopt. An extension of this argument posits that, by allowing adoptive parents to have the child tested before the adoption takes place, adoption annulments may be avoided if parents find themselves unable to cope with a genetic condition that manifests itself subsequently. Another argument in favor of testing is

that certain adoptive parents lack the emotional or financial means to care for a child with special needs (Rothstein 1997). Adoptive parents also contend that predictive genetic information is needed to monitor the child’s health and seek appropriate treatment (Blair 1992; Lorandos 1996).

Once again, however, allowing adoptive parents to gain access to a child’s predisposition to a genetic condition that may never develop treats the adopted child differently from other children of a similar age and places a burden of perfection on the adopted child (AAP 1991). Children do not come with guarantees. If adopted children are required to present evidence that they are free of genetic diseases, what tests will not be allowed? Clearly, adoptive parents should be apprised of known illnesses, but predictive genetic testing goes well beyond this standard and is neither advisable nor necessary (Morris et al. 1988; Rothstein 1997).

Yet another argument in favor of testing is that adoptive parents need genetic information for estate or financial planning purposes. Because a child with a predisposition for a late-onset, untreatable condition may require special care in the future, the parents may wish to allocate a larger portion of their estate to the child or make other financial arrangements for the child’s care (Clayton 1992; Holland 1997). Waiting until the child is mature enough to make a decision about testing allows the parents to provide for the child financially and respects the child’s right to determine whether he or she wants to know of any genetic predisposition. Alternatively, where the parents do not want to wait until their child is mature enough to make a decision about testing or the parents fear that they will die before their child reaches maturity or manifests a genetic condition, the parents can establish a trust that contains a specific provision for the distribution of the trust proceeds in the event that the child develops a medical condition requiring special care (Holland 1997).

Birth Parents’ Interests

The primary interest of the birth parents who are unable to raise a particular child is the desire to place the child in a safe, secure, and loving environment. In addition, parents have an interest in privacy regarding their identity. This latter interest is reflected in the long history of keeping adoption records sealed (Blair 1992). The birth parents’ privacy interest is of even greater concern when additional sensitive information, including genetic information, is involved (Lorandos 1996). No state currently requires genetic testing of birth parents (Andrews and Elster 1998).

Privacy is of significant interest to the child and to the birth parents. Requiring either the child or the birth parents to undergo testing as a condition of adoption

thwarts this interest. As noted, the child may choose to be tested when he or she is mature enough to consider all the ramifications of testing. With the development of direct DNA tests for genetic predispositions, less historical genetic information from birth parents will be necessary. Consequently, postponing predictive genetic testing until the child is ready to learn his or her status furthers the birth parents' and the child's interest in privacy.

Adoption Agency's Interests

The adoption agency has an interest in placing the children in its custody and in ensuring that those children remain placed with the adoptive parents. The agency has an interest in ensuring the privacy of the child, the birth parents, and the adoptive parents, as well as an interest in shielding itself from potential liability. The protection of all these interests is necessary to the continuation of the adoption process. As a result, adoption agencies need clear guidance on the type of information they are required to disclose and the type of information they are required to hold in confidence.

Because of the potential for liability, adoption agencies may feel compelled to require genetic testing of the child or the birth parents (Lombardo 1996). Actions have been brought against adoption agencies for wrongful adoption based on the agencies' alleged negligence or fraud in placing children without adequately disclosing their health or genetic history (Blair 1996). Courts have recognized a cause of action for wrongful adoption in ≥ 10 states (Leshne 1999).

In addition to being sued for failing to disclose a child's known health or genetic history, an adoption agency and others involved in the placement process may be sued for failing to test the child for a genetic condition. Although adoption agencies are not required to and ordinarily do not conduct genetic tests, they are required to make reasonable inquiry into the child's medical history. More than half the states impose an affirmative duty on adoption agencies to disclose medical information of which they are aware (Leshne 1999). As a result, complete ignorance is not the standard.

Even if liability were not imposed, an adoption agency sued for wrongful adoption is subjected to the time and cost of defending itself. The mere threat of litigation may cause some agencies to require testing without a clear understanding of their duties. As the availability of tests increases, this pressure to test based on a fear of litigation can be expected to increase. Adoption agencies are not guarantors of the health of the children that they place. They can only guarantee that the information in their possession is disclosed (Leshne 1999). With more-wide-spread, less-expensive testing in the future, some agen-

cies may seek to expand the information in their possession by requiring testing for genetic predispositions.

We recommend that adoption agencies perform genetic testing of children only to the extent consistent with this document. We further recommend that in interpreting family health information as well as appropriate genetic tests, professionals trained in genetics be available for consultation with adoption agencies and prospective adoptive parents.

Public's Interests

The public has an interest in facilitating and encouraging adoptions and in ensuring a good fit between the adopting parents and the child. In attempting to protect the interests of the child, public policy should not so restrict access to medical information in adoption that prospective parents decline to adopt in America and instead pursue adoptions overseas. Thus, professional guidelines and public policies must strike a delicate balance to ensure the reasonable interests of all parties. These goals may best be achieved by limiting genetic testing of newborns and children in the adoption process to tests that are consistent with tests performed on other children of a similar age and designed to uncover only childhood-onset diseases or those disorders for which preventive measures or therapies may be undertaken in childhood.

Conclusion

The interests of numerous parties must be balanced in determining when to allow genetic testing of newborns and children in adoption. Chief among these is the best interest of the child. Although the ASHG and the ACMG recognize the need to retain important genetic information in the adoption process, we also recognize the need to protect adopted newborns and children from being subjected to potential stigmatization and discrimination in instances in which genetic testing serves no timely medical benefit. As a result, the ASHG and the ACMG support genetic testing in the adoption process if it is (1) consistent with preventive and diagnostic tests performed on all children of a similar age, (2) generally limited to testing for medical conditions that manifest themselves during childhood or for which preventive measures or therapies may be undertaken during childhood, and (3) not used to detect genetic variations within the normal range.

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