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Genetic Testing in Children and Adolescents, Points to Consider: Ethical Legal and Psychosocial Implications of (ACMG/ASHG)

Am. J. Hum. Genet. 57:1233-1241, 1995

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This report focuses on genetic testing in response to a family history of genetic disease or to parents' request for genetic testing. For purposes of this report, testing is distinguished from screening, with the latter referring to population-based programs that are more likely to be initiated by a provider or institution, e.g., in the newborn period or in the school setting. The word "children" refers to individuals <18 years of age, but special considerations for adolescents are discussed within this report. This report applies equally to adopted children and children awaiting placement for adoption. This report acknowledges that genetics services are provided by geneticists, genetic counselors, neurologists, oncologists, and primary-care physicians and nurses, all of whom are included as providers.

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ASHG/ACMG REPORT

Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents

The American Society of Human Genetics Board of Directors and The American College of Medical Genetics Board of Directors

Rapid developments in genetic knowledge and technologies increase the ability to test asymptomatic children for late-onset diseases, disease susceptibilities, and carrier status. These developments raise ethical and legal issues that focus on the interests of children and their parents. Although parents are presumed to promote the well-being of their children, a request for a genetic test may have negative implications for children, and the health-care provider must be prepared to acknowledge and discuss such issues with families.

This report is grounded in several social concepts: First, the primary goal of genetic testing should be to promote the well-being of the child. Second, the recognition that children are part of a network of family relationships supports an approach to potential conflicts that is not adversarial but, rather, emphasizes a deliberative process that seeks to promote the child's well-being within this context. Third, as children grow through successive stages of cognitive and moral development, parents and professionals should be attentive to the child's increasing interest and ability to participate in decisions about his or her own welfare.

Counseling and communication with the child and family about genetic testing should include the following components: (1) assessment of the significance of the potential benefits and harms of the test, (2) determination of the decision-making capacity of the child, and (3) advocacy on behalf of the interests of the child. The following points should be considered:

I. POINTS TO CONSIDER

A. The Impact of Potential Benefits and Harms on Decisions about Testing

1. *Timely medical benefit to the child should be the primary justification for genetic testing in children and adolescents.* Under this condition, genetic testing is similar to other medical diagnostic evaluations. Medical benefits include preventive measures and therapies, as well as diagnostic information about symptomatic children. If the medical benefits are uncertain or will be deferred to a later time, this justification for testing is less compelling.
2. *Substantial psychosocial benefits to the competent adolescent also may be a justification for genetic testing.* The benefits and harms of many genetic tests are psychosocial rather than physical. Relevant issues include anxiety, self-image, uncertainty, and the impact on decisions relating to reproduction, education, career, insurance, and lifestyle.
3. *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.* Exceptions to

this principle might occur when the adolescent meets conditions of competence, voluntariness, and adequate understanding of information. Further consultation with other genetic services providers, pediatricians, psychologists, and ethics committees may be appropriate to evaluate these conditions.

4. *If the balance of benefits and harms is uncertain, the provider should respect the decision of competent adolescents and their families.* These decisions should be based on the unique circumstances of each family. The provider should enter into a thorough discussion about the potential benefits and harms and should assess the family's understanding of these issues.
5. *Testing should be discouraged when the provider determines that potential harms of genetic testing in children and adolescents outweigh the potential benefits.* A health-care provider has no obligation to provide a medical service for a child or adolescent that is not in the best interest of the child or adolescent.

B. The Family's Involvement in Decision Making

1. *Education and counseling for parents and the child, commensurate on maturity, should precede genetic testing. Follow-up genetic counseling and psychological counseling also should be readily available. Providers of genetic testing should be prepared to educate, counsel, and refer, as appropriate.*
2. *The provider should obtain the permission of the parents and, as appropriate, the assent of the child or consent of the adolescent. Decisions about competence should not depend arbitrarily on the child's age but should be based on an evaluation of the child's cognitive and moral development. The provider should also attempt to establish that the child's decision is voluntary.*
3. *The provider is obligated to advocate on behalf of the child when he or she considers a genetic test to be - or not to be - in the best interest of the child. Continued discussion about the potential benefits and harms - and about the interests of the child - may be helpful in reaching a consensus.*
4. *A request by a competent adolescent for the results of a genetic test should be given priority over parents' requests to conceal information. When possible, these issues should be explored prior to testing. When a younger child is tested and the parents request that the provider not reveal results, the provider should engage the parents in an ongoing discussion about the benefits and harms of the nondisclosure, the child's interest in the information, and when and in what manner the results should be disclosed.*

C. Considerations for Future Research

As genetic testing for children and adolescents becomes increasingly feasible, research should focus on the effectiveness of proposed preventive and therapeutic interventions and on the psychosocial impact of tests. Such data are necessary to define the empirical benefits and harms of testing before judgments about the advisability of testing are formulated.

II. DISCUSSION

Benefits and Harms of Genetic Testing in Children

Parents sometimes request that their children be tested for adult-onset problems, so that they can address psychosocial issues. Such nonmedical uses by parents are one of the most controversial issues in testing children (Working Party of the Clinical Genetics Society 1994). While some providers argue that parents should be able to obtain such information (Pelias 1991), other providers suggest that access to such information should be restricted or prohibited if the children will realize little or no immediate medical benefit (Harper and Clarke 1990). Some geneticists already limit testing for adult-onset diseases to individuals who are >18 years of age, e.g., in some protocols for Huntington disease (Bloch and Hayden 1990) and breast cancer (Biesecker et al. 1993). One justification has been that, since such testing requires informed consent, and since children are not competent to give consent, therefore children should not be tested. However, this argument is so broad that it would preclude all pediatric care.

As with any other medical intervention, when children do not have the capacity to provide voluntary, informed consent, the decisive consideration in genetic testing in children should be the welfare of the child. Decisions about genetic testing in children should be based on an assessment of the possible benefits and harms that may be associated with the tests (see Table 1). The putative benefits and harms include medical, psychosocial, and reproductive issues that have implications for the child, the immediate family, and more distant relatives.

Table 1
Potential Benefits and Harms of Genetic Testing of Children

Category	Benefits	Harms
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Medical issues	Early and effective preventive or therapeutic interventions	Ineffective or harmful preventive or therapeutic interventions Increased surveillance Avoiding unnecessary surveillance Refinement of prognosis Clarification of diagnosis
Psychosocial issues	Reduction of uncertainty Reduction of anxiety Opportunity for psychological adjustment Ability to make realistic plans for education, employment, insurance, and personal relationships Alerting other family members to genetic risk	Alteration of self image Distortion of parents' perception of child Increased anxiety and guilt Altered expectations by self or others for education, employment, and personal relationships Identifying other family members with late-onset diseases Discrimination in employment and in obtaining insurance Detection of misattributed paternity or adoption
Reproductive issues	Avoiding birth of child with genetic disease Preparing for birth of child with genetic disease Informed family-planning decisions by parents	Coerced decisions

Medical issues.

Medical issues include the possibilities of treatment and prevention, decisions about surveillance, and the resolution of questions about prognosis and diagnosis.

1. *Treatment and prevention. Tests that offer children the potential for therapeutic benefit are most likely to be supported by the public and by medical professionals. For example, testing for familial hypertrophic cardiomyopathy, a disease associated with increased risk for sudden death, allows drug therapy to prevent arrhythmias (Maron et al. 1987). Individuals identified as having genetic diseases or disease susceptibility may also benefit from preventive advice about lifestyle changes. For example, children with familial hyperlipidemia may benefit from dietary restrictions (Cortner et al. 1993).*

Although some medical benefits from diagnosis in childhood are established, others remain unconfirmed- and may even be associated with the possibility of harm. One possible harm to a child determined to have a deleterious gene is increased medical tests and treatment regimens that may not have proved benefits. For example, presymptomatic diagnosis of cystic fibrosis has not yet demonstrated any medical benefit and may be associated with increased costs, unnecessary treatments, and familial distress (Farrell and Mischler 1992). Thus, the potential for benefit of unestablished treatment and/or prevention regimens is a questionable justification for testing. Empirical verification of the benefits and harms of prevention and treatment should precede recommendations for routine testing (Wilfond and Nolan 1993; Marteau 1994).

2. *Surveillance. Genetic testing can identify patients with an increased susceptibility to disease. The identification of genes associated with cancer might prompt surveillance to detect presymptomatic cancer. For some disorders, such as retinoblastoma, monitoring is associated with effective treatment (Gallie et al. 1991), although the medical benefit of surveillance is less certain in other syndromes with cancer predispositions (Li et al. 1992; Garber and Diller 1994). The benefits of tests depend on the accuracy of additional diagnostic tools and protocols and diminish when early detection fails to improve the patient's prognosis.*
3. *Reduction of surveillance. When genetic testing excludes a child from risk for a disease, the child may benefit from discontinued medical surveillance. Thus, a child with a prior risk for Von Hippel-Lindau disease may avoid further surveillance procedures when test results are normal (Glenn et al. 1992).*
4. *Refinement of prognosis. Genetic testing can be helpful in refining prognosis, either when it leads to a precise diagnosis or when the genotype is well correlated with phenotype. The severity of phenotypic expression in diseases associated with trinucleotide repeats is often correlated with the number of*

repeats (Sutherland and Richards 1993).

5. *Clarification of diagnosis.* Genetic testing may provide clarification of an uncertain diagnosis if diagnostic data from other sources are inconclusive, or if interpretations of diagnostic data are limited by the sensitivity of other evaluations. DNA studies are now especially useful in confirming a diagnosis of fragile X, because conventional cytogenetic studies may yield equivocal results (Tarleton and Saul 1993), or in confirming a diagnosis of neurofibromatosis in patients whose physical exams are inconclusive (Hofman and Boehm 1992).

Testing children may also benefit other family members when it is necessary to improve the reliability of linkage analysis and mutation analysis desired by other family members. However, participants in such studies should understand that unexpected information about paternity or adoption could be revealed.

Psychosocial issues.

Psychosocial issues associated with medical problems or preexisting issues may be either exacerbated or alleviated by testing. The provider should discuss these issues with children and parents. The presence of severe anxiety or other psychopathology should be an indication for further psychological intervention-and not necessarily an indication for genetic testing.

1. *Reduction of uncertainty.* A significant psychological benefit of genetic testing is resolution of uncertainty. Data from adults at risk for Huntington disease confirmed a reduction of anxiety, both in persons determined by linkage analysis not to be at risk and in those found to be at increased risk, while the least reduction of anxiety occurred in those who had indeterminate test results (Wiggins et al. 1992). Even for individuals identified as having a life-shortening disease, testing may lead to appropriate adjustment and preparation.

Both parents and children may be anxious about their uncertain future. Genetic testing, even if confirming the presence of disease, may remove the uncertainty and allow parents the opportunity to confront the issues directly. When test results are favorable, psychological benefits may accrue to both parents and children.

2. *Alteration of self-image.* Children with genetic diseases may suffer a loss of self-esteem during a critical period when children's self-identity is developing (Koocher 1986). Children's understanding of illness and disease is often limited and may foster self-blame for their disease (Perrin and Gerrity 1981). If a child's genetic information is disclosed outside the family, the ensuing loss of privacy may exacerbate poor self-esteem. Alternatively, in some instances, an affected child may view the disease state as being normal and may even develop positive attitudes of identification with the affected family member (Petersen and Boyd, in press).

Those individuals whose tests reveal that they are not at genetic risk may develop "survivor guilt," based on the knowledge that one or more of their siblings will develop-and perhaps die from-a serious genetic disease (Wexler 1985). For a child who is at risk of carrying recessive genes, the status of "not knowing" may allow the child to assume that he or she is a carrier and to share some of the burden (Fangs and Johnson 1993). For some children, whose assumption of carrier status provides an important source of self-identity, the knowledge of being a noncarrier could generate a shift in such identity. Further, the fact that siblings may make unfounded assumptions about their genetic status emphasizes the need for thorough age-appropriate genetic counseling, regardless of a decision to provide a genetic test during childhood.

3. *Impact on family relationships.* Presymptomatic diagnosis in children also has the potential to alter the relationships that exist between parents and their offspring and among siblings (Fangs and Johnson 1993). A child known to have a deleterious gene may be overindulged, rejected, or treated as a scapegoat (Gardiner 1969). The "vulnerable child" syndrome occurs when the perception of serious illness causes parents to become overprotective and to restrict a child's participation in childhood activities (Green and Solnit 1964), responses that can occur even when test results reveal a normal genotype. Unaffected siblings may also experience altered relationships with their parents, particularly in the case of children who feel disenfranchised if they see that an affected sibling is receiving a disproportionate amount of care and attention (Carandang et al. 1979).

Testing a child for an adult-onset disease may inadvertently provide predictive information to other family members, who may not be interested in this information. However, identifying a child with a genetic disease or a gene predisposing to disease could benefit relatives who may wish to consider testing for themselves. Although the provider might presume an obligation to inform other family members at risk, some patients may prefer not to inform other family members. Current recommendations (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983) and practices (Wertz and Fletcher 1988) suggest that the patient's wishes for confidentiality should be respected as long as the failure to disclose genetic information is not likely to result in immediate serious physical harm to the relative.

4. *Impact on life planning.* Information about future health can have implications for planning one's life. The possibility of serious disease or early death may influence an individual's educational goals,

occupational choices, and specific career plans. This information also may influence choice of domicile, perhaps to live closer to family, to other support systems, or to adequate medical facilities. Genetic test results may have financial implications for retirement planning and for obtaining life, disability, and health insurance (McEwen et al. 1993).

Individuals at risk for developing a disease or for transmitting a deleterious gene to their children may be stigmatized and subject to inappropriate discrimination (Billings et al. 1992). Expectations of others for education, social relationships, and/or employment may be significantly altered when a child is found to carry a gene associated with a late-onset disease or susceptibility. Such individuals may not be encouraged to reach their full potential, or they may have difficulty obtaining education or employment if their risk for early death or disability is revealed. Presymptomatic diagnosis may preclude insurance coverage (Ostrer et al. 1993) or may thwart long-term goals such as advanced education or home ownership (Billings et al. 1992; Alper and Natowicz 1993). Finally, this information could be used to assess the suitability of both parents and children in questions of adoption (Wertz et al. 1994). At present, the extent of protection under the Americans with Disabilities Act of 1990 is unclear and untested (Natowicz et al. 1992).

Reproductive issues.

Reproductive issues continue to be a major source of concern when genetic testing is contemplated. Genetic information often influences the reproductive choices of individuals at risk for transmitting a genetic disorder, although genetics-service providers strive to offer nondirective counseling. Individuals who want to avoid having a child with a certain genetic disorder have several options, including adoption, artificial insemination by donor, in vitro fertilization with preimplantation diagnosis, prenatal diagnosis, and termination of pregnancy. Prenatal diagnosis, when feasible, offers benefits independent of abortion, including improved perinatal management and the opportunity to prepare psychologically for the birth of an affected child or by changing employment, obtaining insurance, or moving closer to social support services or medical facilities.

Reproductive benefits may be of minimal value to children--and even to sexually active adolescents who are not likely to make family--planning decisions primarily on the basis of their genetic status. Additionally, children may not receive genetic information in an understandable or usable form--or at the appropriate time for the benefit to accrue. However, the knowledge of presymptomatic disease in a young child could have some impact on the reproductive decisions of parents, who may use this information for prenatal diagnosis in future pregnancies or to make decisions about the number or spacing of future children.

Promoting the Interests of Children and Their Families

Parents generally have the authority to make medical decisions for their children. This authority may be limited if a decision is likely to cause a child serious harm without the prospect of compensating benefit. What further complicates these issues in genetic testing is the uncertainty about the putative benefits and harms. Additionally, as children grow, their ability to participate in decisions increases, and, at times, their choices may be at odds with the wishes of their parents. These issues emphasize the provider's obligations to explore both the interests of children and the interests of their parents.

Presumption of parental authority.

Presumption of parental authority is a fundamental principle for families and professionals who are discussing genetic testing for children.

1. *Roots of parental authority.* Prior to the 20th century, the law viewed children as chattel, or property, of their fathers (Melton 1983). Although children were certainly valued, parents had full authority to make decisions about raising their offspring. Although children today are viewed as individuals rather than as property, the law still recognizes parental authority over decisions relating to a child's education, nourishment, medical care, and general well-being (Pelias 1991).

The most compelling justification for parental authority focuses on the well-being of the child and acknowledges that parents are usually in the best position to make such a determination and have the greatest interest in making decisions to promote the well-being of the child (Melton 1983). A second justification for parental authority rests on the interests of parents in their own self-determination, including the authority to make decisions on behalf of their children (Holder 1988). This justification derives in part from the moral principle of autonomy, a concept that supports the personal choices of individuals, without interference from third parties such as health-care providers or the government. This principle is the basis of the doctrine of informed consent, the precept that competent adults must receive appropriate information and give consent for diagnostic tests or therapeutic interventions. Because most children lack the capacity to make appropriate decisions, this role generally falls to the parents or guardians, who, by extension of their own autonomy, are entitled to make decisions on behalf of their children (Buchanan and Brock 1989).

2. *Limits of parental authority.* In spite of the presumption of parental prerogative, parental authority can be limited if there are objective reasons to believe that a decision or action has significant potential for an adverse impact on the health or well-being of the child (Wadlington 1983). Such limitations are best exemplified by child-abuse and -neglect laws, which prohibit parents from acts of omission or commission that could or do result in serious harm to the child.

The law also requires parents to provide certain medical benefits for their children, even if those benefits are contrary to the beliefs of the parents. Newborn screening for phenylketonuria (PKU) may be justified because of the child's interest in dietary treatment to avoid mental retardation (Laberge and Knoppers 1990). Similarly, immunizations may be required both in the interest of the child and in the interest of the public health. Further, specific life-saving treatments, such as blood transfusions and treatment for bacterial meningitis, may be administered over the objections of a child's parents, because these treatments have a high probability of restoring the child to health (American Academy of Pediatrics Committee on Bioethics 1988).

Parents also may be legally constrained in choosing medical interventions for their children. Parents may not, for example, generally authorize the involuntary sterilization of their minor children, without approval of a court of law (Reilly 1991). Nor are parents at complete liberty to consent to having their children used as research subjects. Although competent adults may consent to participate in nontherapeutic research, federal regulations stipulate that parents may give permission for their child's participation in nontherapeutic research only if the research meets more stringent requirements of benefit and safety (45 CFR 46.408, 1994).

In the clinical setting, providers may refuse to provide requested diagnostic or therapeutic interventions that offer no or few benefits but that incur more than minimal risk or cost. Although respect for personal autonomy reinforces the principle of noninterference by third parties, patients are not at liberty to assert entitlements to services by third parties (Brett and McCullough 1986; Youngner 1988). For example, providers are not obligated to acquiesce to parental requests for antibiotics for viral infections or for a computed-tomography scan for evaluation of a simple headache. The provider does, however, have a responsibility to explain why he or she will not provide the requested intervention and, if feasible, to identify other providers who may be willing to provide the requested services.

3. *Legal trend to recognize the authority of minors.* Although the law protects the autonomy of adults, on the presumption that adults are competent to make their own decisions, the law presumes that minors are not competent in this respect. Many states, however, permit adolescents to consent to medical treatment in the absence of parental consent (Wadlington 1983; Holder 1988). These states recognize a "mature minor rule," which views some adolescents as capable of understanding the consequences of some medical decisions. Mature-minor rules are circumstance specific and generally address situations in which the state has an interest in the adolescent's seeking medical attention that might not be sought if the problem were disclosed to the parents. These circumstances typically include reproductive issues, such as contraception, as well as sexually transmitted diseases. Other sensitive areas, such as treatment for drug and alcohol abuse and psychotherapy, are protected as well. The "emancipated minor" status also acknowledges an adolescent as competent to make decisions, by virtue of adult status under the law. For example, adolescents who are living on their own or who are married, pregnant, or have children are generally permitted to make medical and other decisions usually reserved for adults.

The decision-making capacity of the child.

Although 18 years of age is the general legal standard for decision making, the concepts of the mature minor and the emancipated minor derive, in part, from empirical observations about the gradual development of a child's cognitive skills and moral reasoning. These capacities mature over time and at different rates in different children (Weithorn 1983; Buchanan and Brock 1989). As children progress through successive stages of development, they become capable of greater participation in decisions about their own welfare. The child's maximal participation, commensurate with his or her best capacity, may even contribute to the further development of these very skills. Thus, there are strong psychological and philosophical justifications for a more nuanced understanding that grants some level of decision-making authority to children <18 years of age.

Competence to make decisions depends on three broad capacities: the capacity for understanding and communication, the capacity for reasoning and deliberation, and the capacity to develop and sustain a set of moral values (Buchanan and Brock 1989). By the age of 7 years, children can usually begin to participate in decisions, since they have sufficient cognitive and language skills to understand some information. Thus, in the United States, a 7-year-old is generally entitled to give "assent" to participation in research involving human subjects (45 CFR 46.408, 1994). Although consent requires competence to make an independent choice, assent only requires a rudimentary understanding of risk and benefit--and a decision to participate or not (Grodin 1994).

During adolescence, children begin to develop concepts of mortality, cause and effect, and right and wrong, as well as a sense of connection to the future (Buchanan and Brock 1989). As adolescents' decision-making capacity increases, additional consideration should be given to their wishes, even when these wishes differ from those of their parents or when these wishes are not clearly in the child's best interest. Adolescents may have a genuine interest in information about career and child-bearing choices, although they may still be vulnerable to coercion by family or peers, to stigmatization, or to altered self-image. By the age of 12 or 14 years, some children, though, will have sufficient decision-making capacity to evaluate the specific risks and benefits of tests or treatments (Wadlington 1983; Weithorn 1983).

The provider as a fiduciary for the child.

The provider, as fiduciary for the child, must be conscientious about considering requests for testing, as well as requests for nondisclosure.

1. *Assessing requests for tests. Providers of genetics services emphasize the importance of a nondirective approach in the counseling of patients about reproductive issues. However, health-care providers also have a fiduciary relationship with patients and often make specific recommendations about medical services. Providers caring for children may discourage actions that may be adverse to the interests or the well-being of the child. Although providers generally should respect parents' wishes, the provider ultimately must balance the responsibilities to the health and well-being of the child and to the wishes of the parents. Thus, a provider must sometimes evaluate whether a request by parents is appropriate in view of the relative benefits and harms to a child. In situations where these factors are primarily psychosocial rather than medical, such an assessment may be difficult.*

*Until more information is available regarding the risks and benefits of genetic testing, the provider's guiding principle continues to be *primum non nocere*--first do no harm. Thus, when faced with uncertainty, the provider may be obligated to avoid the possibility of harm, rather than to provide unclear benefits. There may be rebuttable presumption to defer testing unless the risk/benefit ratio is favorable. On the other hand, in specific cases where the benefits and harms of genetic testing are more uncertain, more weight should be given to the wishes of the competent adolescent and the parents. These issues are not always straightforward, and, at the very least, the provider has a responsibility to engage in detailed conversations with the family. Parents may overestimate the power of genetic testing or be unaware of potential risks. It also may be advisable to obtain consultation from other genetic-service providers, pediatricians, psychologists, and ethics committee, to evaluate benefits/harms, decision-making capacity, and voluntariness. Sometimes a dialogue with parents about the nature of testing will lead to a consensus about its value to the child and the family. If a consensus is not attainable, the provider may decline to conduct the test or might suggest other providers, who may be willing to provide the testing.*

The practice of medical genetics provides some examples of tests that may not be in the best interest of the child. For example, parents may request a determination of their young daughter's Tay-Sachs carrier status, for the purpose of encouraging her to be sexually responsible when she is older. The possibility of stigmatization without any clear immediate benefit is a serious concern. On the other hand, different issues may arise when, to help the parents make their own family-planning and socioeconomic decisions, parents request that young children be tested for adult-onset diseases. For example, the parents choice about future children might be dependent on the genetic status of the child, or parents may wish to know about adult-onset diseases prior to deciding how much to save for a college education. In such cases, the balance swings between benefit to the family and benefit to the child. The unique potential of presymptomatic genetic testing to predict a child's future should be approached with great caution.

Adolescents who request tests prompt additional considerations. For example, if an adolescent requests testing for Huntington disease, it may be important to ascertain whether the request originates from the adolescent or from the parent. In the face of uncertain benefits and harms, an adolescent's request for a test necessitates an individual assessment of competence and voluntariness.

2. *Assessing requests for nondisclosure. Parents occasionally may request that a test result not be disclosed to the child. This may pose a conflict between the interest of the parents in making decisions that they believe are for the well-being of the child and the interest of the child in self-determination. As the child matures, justifying such a request may become more difficult, even if the provider agrees that disclosure might not promote the well-being of the child.*

A request for nondisclosure may indicate some ambivalence on the part of the parent regarding the significance of the test results--and thus a potential for harm either from the parent's interpretation of the test results or from the child's eventual discovery of the concealment. The provider should consider deferring testing pending a detailed discussion of these issues.

If genetic testing occurs prior to the request for nondisclosure to the child, the provider may wish to defer a decision about disclosure until after the issues have been explored fully. Factors such as the age of the child, the need for medical interventions, and the need for the child to participate in therapeutic plans must be explored in comprehensive genetic counseling. It is recommended that, on reaching adulthood, the individual should be informed of the existence of the test results and should be given the option to know the results.

Conclusion

Providers who receive requests for genetic testing in children must weigh the interests of children and those of their parents and families. The provider and the family both should consider the medical, psychosocial, and reproductive issues that bear on providing the best care for children. This will require the provider to engage individual families in comprehensive discussions of these issues and to provide them with specific information and recommendations about genetic testing. Because such testing has potential for both great benefit and great harm, and because the availability of tests continues to expand, providers of genetic services will play increasingly important roles in counseling families about the suitability of genetic testing for their children.

ENDORSEMENTS This report was approved and adopted by The American Society of Human Genetics (ASHG) Board of Directors and the American College of Medical Genetics (ACMG) Board of Directors. It has also been endorsed by the following organizations: Alliance of Genetic Support Groups, Council of Regional Networks for Genetic Services, International Society of Nurses in Genetics, National Society of Genetic Counselors, and American Academy of Pediatrics.

Acknowledgments

This report was drafted by a subcommittee of the ASHG Social Issues Committees: Benjamin S. Wilfond, M.D., University of Arizona, Tucson (chair); Mary Z. Peliás, Ph.D., J.D., Louisiana State University, New Orleans (cochair); Bartha Maria Knoppers, Ph.D., J.D., Université de Montréal, Montréal; Philip R. Reilly, M.D., J.D., Boston; and Dorothy C. Wertz, Ph.D., Boston. Additional contributions were made by members of the ASHG and ACMG Social Issues Committee, including Paul Billings, M.D., Veterans Affairs Medical Center, Palo Alto; Lynn Dale Fleisher, Ph.D., J.D., Sidley & Austin, Chicago; Peter Rowley, M.D., University of Rochester, Rochester, NY; Charles Strom, M.D., Ph.D., Illinois Masonic Medical Center, Chicago; and Randi Zinberg, M.S., Mt. Sinai Medical School, New York. The subcommittee is also grateful for comments and contributions from Patricia Boyd, Ph.D., Johns Hopkins University, Baltimore; Ellen Wright Clayton, M.D., J.D., Vanderbilt University, Nashville; Joanna Fanos, Ph.D., National Institutes of Health, Bethesda; Dorene Markel, M.S., M.H.S.A., University of Michigan, Ann Arbor; and Katherine Schneider, M.P.H., Dana Farber Cancer Institute, Boston.

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