

# No Gain, No Pain: Ethics and the Genomic Revolution

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## ABSTRACT

The mapping of the human genome and scientific discoveries regarding genetic contributions to disease hold great promise for the prevention and treatment of an array of conditions. Social workers and other professionals must keep abreast of these developments and the ethical dimensions of such progress. Familiar ethical provisions such as confidentiality, informed consent, self-determination, and social justice take on new meaning in light of innovations in genetic science. This article reviews ethical issues and practice implications emerging from advances in genetics knowledge, and it suggests mechanisms for continuing professional development and involvement in this important area.

The past decade has borne witness to significant advances in scientific understanding of the role that genes play in the development, progression, and outcome of an array of biological and behavioral conditions. Genetic testing has been used in the study of diseases (e.g., cystic fibrosis, cancer), traits (e.g., homosexuality, aggression), and conditions (e.g., addiction, trauma response). Although hardly exhaustive, this list demonstrates the myriad ways in which genetic research intersects with many of the issues encountered in social work practice. The evolving knowledge of genetics has significance for social workers as they incorporate findings into their treatment protocols, assist clients in comprehending the impact of genetic tests and results, and respond to potentially pernicious uses of genetic data. If social workers are to respond competently to evolving scientific discoveries, they must understand the ethical dimensions of such progress.

The dilemmas posed by genetic advances do not all fall into the realm of futuristic “what if” scenarios, such as human cloning. However, the familiar ethical provisions of confidentiality, informed consent, and self-determination take on new meanings when applied to genetic testing and its results. Contemporary concerns involve the potential uses of genetic information, including its use to disadvantage already marginalized populations, such as persons with disabilities, the poor, or persons of color. This article reviews emerging ethical issues related to advances in genetic research, and it suggests strategies to address these ethical challenges.

## Understanding the Advances

A fundamental understanding of genetics is essential to appreciate the scope and impact of genetic tests and thera-

pies. The human genome is comprised of approximately 20,000 genes (National Human Genome Research Institute [NHGRI], 2006a). Each gene contains a double strand of deoxyribonucleic acid (DNA), and most genes code for the production of proteins, which are the building blocks of organs and tissues in the human body. The unique sequence of proteins allows each species to reproduce the properties that make it distinct, which, in effect, enables humans to produce humans while cats produce cats (Griffiths, Miller, Suzuki, Lewontin, & Gelbart, 2000). The human species is thought to share approximately 99.9% of the same DNA, and the remaining 0.1% difference is evidenced by variations in characteristics such as blood type, eye color, and right- or left-handedness.

In April 2003, the sequencing, or mapping, of the human genome was finalized to the current limits of science, resulting in what has been likened to “all the pages of a manual needed to make the human body” (NHGRI, 2006c, p. 1). The achievement of this scientific milestone allows researchers to locate the specific genes believed to be linked with an assortment of negative health conditions. Randomly or because of environmental stimuli, some genes mutate and begin to produce abnormal protein sequences that can ultimately lead to disease. Most diseases are thought to have a genetic component, and NHGRI has defined the following three categories (NHGRI, 2006b):

1. Single gene disorders are caused by a mutation in a single gene. Sickle cell disease, cystic fibrosis, and Tay-Sachs disease are examples of single gene disorders.
2. Chromosome disorders are caused by an excess or deficiency of the genes that are located on chromosomes or by structural changes within chromosomes. Down syndrome, for example, is caused by an extra copy of chromosome 21, but no individual gene on the chromosome is abnormal.
3. Multifactorial inheritance disorders are caused by a combination of small variations in genes, often in concert with environmental factors. Heart disease and most cancers are examples of these disorders. (p. 6)

The multifactorial disorders, which result from the interactions of genes and the environment, are of particular relevance for social work practice. In addition to heart disease and most types of cancer, researchers are investigating genetic links among behavioral disorders such as alcoholism, obesity, and mental illnesses (NHGRI, 2006b). Some researchers have posited that an individual’s response to adverse life events may be moderated by genetic factors (Moffitt, Caspi, & Rutter, 2005). For example, Caspi and his colleagues (2002) found that the outcomes of childhood maltreatment were influenced by the gene that encoded for high levels of

the neurotransmitter-metabolizing enzyme monoamine oxidase-A (MAO-A). Maltreated children with high levels of MAO-A were less likely to have antisocial outcomes (e.g., conduct disorder, commission of a violent offense) in later life than maltreated children with low levels of MAO-A. It is noteworthy that the sample for this study was based on a general population birth cohort and that participants were assessed periodically from ages 3 to 26, thus making the study particularly useful for evaluating gene and environment interactions.

In a second study using the same longitudinal sample, Caspi et al. (2003) investigated whether differences in the 5-HTT gene influenced an individual’s response to stressful life events such as substantial changes in finances, health, or relationships. Results indicated that the “gene interacts with life events to predict depression symptoms, an increase in symptoms, depression diagnoses, new-onset diagnoses, suicidality, and an informant’s report of depressed behavior” (p. 387). The results of both studies have been replicated by other researchers (Moffitt et al., 2005).

Although these examples demonstrate that the role of genes in behavior and health is situated in a social and experiential context, critics have noted the complexity in unraveling the connections (Elder & Shanahan, 2006). Adverse life events are mediated by an assortment of factors that are both genetic and environmental. The larger point to be made is that the longstanding question of nature *or* nurture is a false dichotomy (Ridley, 2003). Although evolving scientific knowledge continues to explicate the interactions between genes and environment, the existing evidence is sufficient to challenge any notion that either nature or nurture alone acts as the causal agent of behavior.

Our developing knowledge of genetics is expected to dramatically change the way medicine is both practiced and experienced. Guttmacher and Collins (2005) wrote as follows:

In a relatively few years, when the role of specific genetic factors in disease is more fully understood and a human genome can be sequenced for less than the cost of a colonoscopy (for example), an individual’s sequence will likely become part of the standard medical record, especially since, unlike the colon, an individual’s genome sequence is relatively static . . . . Similarly, it will become the standard of care to sequence cancer patients’ tumors and to use that information to refine prognosis and guide therapy. (p. 1400)

In much the same way that an individual’s family history is currently used to determine the risk of disease, genetic sequencing may soon be used to predict problems and improve the efficacy of drugs in preventing and

treating disease. Understanding how diseases operate at the molecular level will allow targeted drug treatment as well as provide understanding about why certain drugs benefit some individuals or populations more than others (Guttmacher & Collins, 2005). The anticipated results of genomic advances are more tailored methods of prevention and more targeted forms of treatment.

These radical and rapidly evolving scientific advancements hold great promise in alleviating suffering. They also hold the potential for misuse that might imperil fundamental ethical principles and populations of concern. While unraveling the secret of the human genome, the genetics community has attempted to establish some degree of balance between scientific advances and hazards. Although an unprecedented amount of resources has been devoted to addressing the ethical, legal, and social implications of genomics (Guttmacher & Collins, 2005), several important issues continue to be contentious. In particular, four issues warrant the specific attention of the social work community: self-determination, privacy rights, applications to informed consent, and threats to social and economic justice.

### ***Implications for Self-Determination***

Genetic testing is often undertaken in an effort to provide a patient with the knowledge of future risk. For example, a woman with a strong family history of breast cancer may be interested in genetic testing to determine her level of risk. Knowing the risk of disease may empower some patients as well as enable them to engage in increased monitoring and prevention activities. However, the results of a genetic test may also raise new concerns and leave important questions unanswered.

In most cases, genetic testing is unable to provide a conclusive answer, and it instead yields information regarding the relative risk for a particular disease. Thus, people might learn that they have a 40% risk of inheriting a particular form of cancer. As Finkler, Skrzynia, and Evans (2003) pointed out, these results have created new uncertainties beyond whether an illness might develop, including questions of disease severity, age of disease onset, and the impact or value of preventive measures. Given the current limits of genetic science, the risk assessment provided by genetic testing raises a host of new questions that are unanswerable. As patients struggle to make sense of relative risk, some may find that genetic testing creates a level of uncertainty that rivals the uncertainty experienced prior to testing.

Furthermore, the results of genetic testing may also conflict with an individual's self-identity. Individuals who have maintained a salutary lifestyle, and thus believe themselves to be healthy, may be faced with reconciling this self-concept with a newfound understanding

of heightened genetic risk for disease. As Jonsen (1996) pointed out, individuals who learn they are at high risk, despite being presently (and, perhaps, permanently) asymptomatic, may nevertheless begin to perceive themselves as sick. Such a devaluation of an individual's health rating is not without possible repercussions. For example, Idler and Benyamini (1997) found that low self-ratings of health consistently predicted higher mortality, whereas positive ratings predicted survival. Thus, although the risk assessment provided by genetic testing may be empowering, the potential consequences of this new reality should be carefully considered in advance.

**Age and disease considerations.** The use of genetic testing to evaluate risk is complicated when the genetic condition uncovered is not amenable to intervention or when the patient is a minor. For instance, some gene-related conditions, such as breast cancer, can be treated successfully if discovered early and monitored closely whereas other inherited conditions, such as Huntington's disease, are irreversible and have no treatment options beyond palliative care. The decision to undergo genetic testing requires a substantially different rationale in each of these circumstances. Those considering genetic testing for conditions such as Huntington's disease must also consider the question that may emerge: "Do I want to know whether I will contract a disease for which there is no cure?" An individual's response to this question may become less ambiguous when viewed in the context of reproduction—those at risk of Huntington's disease may be inclined to undergo testing before making a decision to become parents.

Perhaps even more difficult is the decision faced by the parents of children already thought to be at risk of an incurable genetic disorder. To illustrate the ethical challenges involved in testing for conditions that are incurable, we give particular attention to this issue as it relates to children.

There is consensus that genetic testing in minors is acceptable in situations in which testing would allow for the early treatment or alleviation of a disease (Borry, Stultiens, Nys, Cassiman, & Dierickx, 2006). However, the appropriateness of genetic testing in children for conditions in which medical intervention offers no benefit is far more ambiguous. Often, the projected onset of the disease is a crucial factor in determining the usefulness of genetic testing. If the expected onset of an incurable disease is in the adult years, testing protocol typically involves waiting until the child becomes an adult, at which point the adult patient can determine whether to undergo genetic testing. However, child-onset diseases that are incurable pose a more difficult quandary (Borry et al.). Some policy statements on the issue have argued that testing for incurable child-onset diseases may be acceptable in situations in which the age of onset is indefinite whereas

others contend that without options for beneficial medical intervention, childhood testing is always inappropriate. In situations that lack clear consensus, the medical community, family, and, perhaps, the child (given a certain level of maturity) must carefully consider the potential risks and benefits before engaging in testing.

The question of testing for incurable diseases in children presents important issues regarding parent rights. For example, the previous discussion described how genetic testing guidelines for adult-onset diseases suggest waiting until the child reaches adulthood. However, in some countries, competent children as young as 15 have been permitted to undergo genetic testing without parental approval (Borry et al., 2006). Alternatively, what if the parent of a 10-year-old child desired genetic testing for an adult-onset disease (assuming the parent intended to keep the results secret until the child reached the appropriate age)? If this type of testing is prohibited, then this position presumes that parents are not entitled to the *future* health information of their children, which could deprive parents of information needed to adequately plan for their children's later needs. Put another way, though parents are entrusted with the health of their children and generally given access to a child's *current* health information, they may be denied knowledge of what their child's health will be in the future.

**Parents' rights—The new eugenics?** Client actions in light of the results of genetic testing add further complexities to the notion of self-determination. Parents concerned about the possibility of giving birth to a child with a genetic disease may elect to participate in prenatal genetic testing. Genetic counselors are charged with helping families comprehend and respond to the results, though parents ultimately decide whether to proceed with the pregnancy. However, recently questions have emerged that challenge the limits of parental autonomy as well as the value-neutral position traditionally espoused by genetic counselors.

A well-known example in this regard involved identification of the gene associated with achondroplasia, a genetically transferred condition that results in dwarfism. Following breakthroughs in the identification of the gene associated with this disorder, a couple who had achondroplasia pursued prenatal genetic testing with the intention of aborting "normal" fetuses in an effort to have a child who also had achondroplasia (Green, 1997). This example initially appeared in the literature as something of an anecdote, though recent evidence suggests that this scenario is more common than once thought. In a survey of *in vitro* fertilization clinics, Baruch, Kaufman, and Hudson (2008) found that 3% of clinics reported having helped parents select for an embryo with a known disability or disease. Whether parents with dwarfism select

embryos positive for achondroplasia or whether deaf parents use prenatal testing so that they may have *only* deaf children, the important message is that these examples demonstrate the unintended consequences of self-determination as it intersects with genetic testing (Green). Should parents have the absolute right to abort healthy fetuses in favor of those with disabilities or disorders? Does the choice of selecting disability constitute a form of harm? Or, does the majority's preference for normally developing fetuses reflect a fundamental and troubling bias against persons with disabilities?

Such questions are dependent upon personal and societal conceptions of disability and disease. For parents in the deaf community, the birth of a deaf child would not necessarily be perceived as unhealthy or abnormal. Quite the contrary, some deaf and achondroplastic parents hope and pray for children who will share their identity (Sanghavi, 2006). The widespread use of prenatal genetic testing in the general population has thus alarmed some in the disability community. A primary concern is that prenatal genetic testing reduces individuals to their disability as though there were "nothing else to know or imagine about who the child might become" (Asch, 1999, p. 1652). Whereas prenatal genetic testing may confirm that a child is at high risk for cystic fibrosis, such testing cannot assess whether the child will like music, be proficient in math, or become a good cook. Thus, those in the disability community might argue that the appropriate societal response to genetic disease would be the eradication of corresponding stigmas and barriers, not the eradication of disability through prenatal genetic testing.

### **Implications for Privacy Rights**

Because genetic data reveals family links, new challenges arise in interpreting privacy for any given individual. For example, if a woman wishes to undergo genetic testing to determine her risk of breast cancer in light of her grandmother's early death from the disease, the finding may also reveal her mother's risk, regardless of whether her mother chose to undergo the testing. Imagine a scenario involving a social worker whose client group consists of two sisters, one of whom has a 17-year-old daughter. The sister without the daughter desires a genetic test and the other refuses. Assume that the daughter, for her own health benefit, wants to know the outcome of her aunt's test. If the aunt has reason to be concerned about her niece's future health, she is then faced with the ethical question of whether she should share the outcome of her test with her niece, even if doing so is against her sister's wishes. Sharing the information with the niece may make it difficult for the sister who refused testing to keep her own risk unknown. However, the aunt's refusal to share the results may deprive the niece of information related

to her health. Clearly, cases such as these raise questions regarding to which information on familial risk an individual member should be privy, and they raise the ethical and clinical dilemma of how to manage a client's right *not* to know (Finkler, 2003).

Contemporary genetic counseling practice offers some guidance about how divergent interests within a particular client system might be addressed. Immediate strategies used by genetic counselors include focusing on a family's commonalities and making concerted efforts to involve all key stakeholders (Lafans, McCarthy Veach, & LeRoy, 2003). However, because the genetic counselor's time with families is limited, social workers and other professionals will need to pick up where genetic counseling leaves off—an area of responsibility that requires new practice skills and knowledge. These additional services may include helping family members better understand the available options and the possible consequences of each choice as well as ensuring that communication occurs in an open and nonthreatening environment.

The definition of *family* and the scope of the medical professional's responsibility to warn family members of risk are altered as genetic knowledge advances. *Duty to warn* is a concept familiar to social workers, though it has primarily been used in the context of the threat of violence. However, advances in deciphering the genetic code related to disease may necessitate a new conceptualization of duty to warn. This point was aptly illustrated by Clayton (2003) in a description of a New Jersey court case. In this case, a man died of colon cancer in the 1960s, and when the man's daughter contracted the same disease 25 years later, she filed a lawsuit against the estate of her father's surgeon. In the suit, the daughter claimed that the surgeon had an obligation to warn her that she had a 50% chance of developing the same form of colon cancer because it can be an inheritable condition. Even though the woman was a child at the time of her father's death, an intermediate appellate court ruled that the surgeon had a duty to warn. Duty to warn, at least according to the New Jersey court, superseded the commitment of confidentiality. Extending the preceding scenario only slightly, consider that a client may disclose to a social worker that she has a disease with a strong genetic link. Perhaps this client does not intend to make her condition known. Does it become the social worker's responsibility to warn the client's children that they are at a particular risk of developing the disease?

Patient privacy is further threatened by potential misuses of genetic data. This concern is exemplified in the case of a railroad employee diagnosed with carpal tunnel syndrome after 27 years with the company (Shim, 2001). After the man underwent successful surgery, his company requested samples of his blood, with the unstated intent of submitting it for genetic testing. A spokesman for the company confirmed that the testing was to determine

whether the condition was the result of job-related overuse or the product of a genetic mutation. Conceivably, if the testing had determined that the man was predisposed for the condition, the company might have used the information to deny liability for his treatment. Once the practice became known, the U.S. Equal Employment Opportunity Commission filed suit, citing a violation of workplace antidiscrimination laws, and the company discontinued testing and negotiated a settlement with the employee (Shim, 2002).

### **Informed Consent**

The exercise of self-determination and protection of privacy are inextricably linked to the provision of informed consent. Individuals who are interested in participating in a particular treatment or research study are informed of the intent, risks, and rewards related to the endeavor. By providing their consent, individuals acknowledge their awareness of the potential risks and rewards inherent in their participation. The process of informed consent generally culminates with the prospective participants signing a document that acknowledges their acquiescence. Medical treatments commonly use informed consent when patients undergo a potentially beneficial, though risky, treatment, and virtually all research conducted with human participants requires informed consent. The three cornerstones of informed consent are voluntariness, understandability, and competence; all three are challenged in the era of genomics.

**Voluntariness.** Shortly after birth, every U.S. infant is expected to have blood drawn to test for a variety of diseases and conditions (Kaye, 2006). Newborn screenings began in the 1960s, when scientists discovered practical methods to test for phenylketonuria (PKU). If left untreated, PKU can lead to mental retardation; however, a special diet can avert the negative effects of the genetic condition. As science has progressed, additional tests have been added to routine newborn screenings, but these vary from state to state.

Newborn screenings also vary in other important regards. Only three states require formal permission from parents for the screening tests (Clayton, 2005), and while most allow parents to opt out of the screenings, it is unclear how often parents are clearly presented with an opportunity to do so. Furthermore, in a small number of states, the newborn screenings are mandatory. The legality of required screenings was recently challenged by a Nebraska couple who refused to submit their child for testing, based on their religious tenets (Bratton, 2007); however, the Nebraska Supreme Court ultimately upheld the law.

Whether parents *should* submit their child for newborn screening and whether they should be *required* to do so are perhaps different questions. The position against mandated screening is based on the high standard usu-

ally set for state intervention in parental autonomy as well as on the relatively low likelihood that a child will have any of the conditions in question (Newsom, 2006). However, states commonly intervene in other nonthreatening circumstances, such as required education for children. In addition, voluntariness might be interpreted in terms of the newborn in question. Given the choice, might an unscreened child who developed mental retardation because of PKU prefer to have been screened? In this scenario, it seems reasonable that states mandate screening in situations in which the individual at risk cannot exercise choice and when the condition is preventable or amenable to treatment.

**Understandability.** Understandability is an integral component of the informed consent process, yet it can be difficult to achieve, based on a variety of factors. King and her colleagues (2005) evaluated consent forms that spanned 10 years of gene transfer studies. Gene transfer, also known as gene therapy, is a process in which healthy genes are added to an individual with defective genes. The authors investigated how language used in the consent forms either clarified or confused the differences between patient treatment and research. This study also evaluated the manner in which possible benefits of participation in clinical trials were described to potential participants. The study found consent forms were characterized by “vagueness, inconsistency, and overstatement, all of which may promote confusion about what subjects can expect from receiving the experimental intervention” (p. 5). Experimental interventions were often referred to as “treatment,” and benefits were inconsistently described.

The significance of the King et al. (2005) study is heightened by the reality that the participants all suffered from diseases such as cancer and HIV. King and her colleagues found that individuals struggling with these incurable diseases were often misled about the difference between research, which is intended to produce knowledge, and therapeutic treatment, which is intended to produce a cure or alleviate symptoms. Thus, it is important to maintain awareness that clarity and specificity in consent procedures are particularly important when research is conducted with individuals rendered vulnerable by their health status. It is also noteworthy that these troubling findings of misconceptions emerged from research areas with particularly stringent oversight procedures in place and generally regarded as having consent forms of high caliber.

**Competence.** Informed consent has traditionally been understood and practiced at the individual level. However, genomic advances and applications tested in human research may require new conceptualizations and practices of informed consent when research involves understanding genetic variations among ethnic groups (Sharp & Foster, 2000). For example, the International HapMap (IHM) Project

combines the resources of geneticists in the United States, Canada, the United Kingdom, China, Japan, and Nigeria (IHM Project, 2003). The project will investigate 270 DNA samples from citizens of specific regions in each of these areas, looking for common DNA patterns.

Unlike most genetic research, the IHM Project made concerted efforts to involve each of the included communities in the research process. Both community groups and local governments helped develop the project’s informed consent and collection procedures, and community advisory groups continue to serve as liaisons for the ongoing project.

To some extent, such efforts may serve more as political acts of good will than procedures to ensure participant and community protection. The IHM Project has not attempted to conceal the ethnicities and locations of the participants. What are the consequences if results of genetic testing reveal that a particular group is at greater risk of a disease or disorder? In such a case, even members of the participating ethnic group who did *not* consent might experience social, financial, and other repercussions. These very risks are acknowledged in the IHM Project informed consent template, which notably includes a section titled “Are there any risks to my community or group?” (IHM Project, 2006, p. 4). The consent template describes these risks by stating that results of the research “may make some people look down on your group unfairly” (p. 4).

Despite the progressive measures to improve the informed consent process, the IHM Project continues to treat informed consent as an individual-level procedure. However, the results of genetic testing conducted with regionally specific ethnic groups may necessitate the use of group consent procedures. Though attaining group consent is somewhat ambiguous and certainly difficult, every effort should be made to ensure the consent of all those who will be impacted by genetic test results.

### ***Threats to Social and Economic Justice***

The intersection of race and genetics is perhaps best illustrated by considering the health disparities that exist between Whites and minority groups. According to the Centers for Disease Control (CDC, 2006), African American death rates are 30% higher than Whites for heart disease-related deaths and 41% higher than Whites for stroke-related deaths. Furthermore, American Indians are twice as likely as Whites to be diagnosed with diabetes, and several types of cancer are more prevalent among minority groups than in the White population. Are such disparities the result of genetic differences among race and ethnic groups, or are they the result of social and economic factors (Lee, Mountain, & Koenig, 2001)?

Although race is a social construct, the testing of population groups brings race into a biological sphere, and it presents two risks associated with the genetic testing of

marginalized populations. First, genetic testing could diminish or redirect attention from the structural and environmental causes of disease. For example, if African Americans were determined to be at elevated risk of cardiovascular diseases because of their genes, such a finding could overshadow factors such as access to health care, poverty, and neighborhood effects that also play a role in disease. Second, in instances in which genetic testing reveals differences among populations, the notion of distinct racial categories may be reified. How are we to make sense of the assertions that we share 99.9% of our DNA with one another, but that the remaining one tenth of a percent may predispose populations to alcoholism, schizophrenia, or colon cancer? The culminating effect of these risks is that race could be used much as it always has—to benefit certain groups and disadvantage others.

Another example of the potential for genetic testing to threaten justice involves decisions about how to best utilize limited resources, which is a dilemma frequently encountered by social workers. Consider the research by Caspi et al. (2002) previously discussed in this article, in which the outcomes of childhood maltreatment were found to be influenced by the gene responsible for high levels of monoamine oxidase-A (MAO-A). What if an enterprising and underfunded child welfare agency proposed that services be targeted toward individuals whose gene expression produced low levels of MAO-A, based on the argument that children with high MAO-A levels are more resilient? The agency might argue that if a genetic test can indicate those in greatest need, it is improper to provide the same level of services to all children.

Of course, the risk of such an approach to child maltreatment is that MAO-A levels are *predictive*, and not conclusive. As such, some children who might benefit from intensive services would be denied these services because their high MAO-A levels predict they will experience fewer problems later in life. Thus, while genetic testing is typically utilized to identify the risk of potential problems, in this scenario it is turned on its head; it is the “low-risk” children, those with high MAO-A levels, who could be denied services. In contrast to the previously discussed threats of genetic testing whereby discrimination may result from a finding of “bad genes,” this example demonstrates how testing could also be used to discriminate against those with “good genes.”

## Implications for Social Workers

Though claims about the usefulness of genetic information have sometimes been given to hyperbole, descriptors such as “revolutionary” are still abundant (Guttmacher & Collins, 2005, p. 1402). If current assessments of the value of genetic information are even marginally accurate, the

revolution will ultimately impact social workers at every level of practice, and few elements of the profession will remain untouched. The social work community must establish whether it intends to be an active or passive participant in this changing environment.

### **Patient and Public Education**

As genetic information becomes increasingly common in health care, social workers will be in prime positions to assist patients in navigating complex new realities. Testing may be used to inform an individual of the risk of disease, but traditional medical practice will likely not be equipped to help patients respond to the practical and psychosocial implications of this knowledge. Fortunately, social work practice will likely be better positioned to help clients cope with their genetic identities, consider options for disclosure to family and friends, and weigh decisions about the future.

Similarly, social workers may be able to assist clients in identifying conditions that have a genetic link. For example, in taking an in-depth family history, a social worker may learn of the recurrence of a certain condition in the family that is known to have a genetic link. If the client expresses interest in learning more about the issue, the social worker could make the appropriate referrals so that the client can participate in the necessary testing, treatment, or monitoring.

In addition, social workers may provide beneficial services to those engaged in genetic research. Consider the example in which a social work researcher is a key investigator on the team evaluating the role that social isolation and loneliness have on rates of premenopausal breast cancer in Black women (McClintock, Conzen, Gehlert, Masi, & Olopade, 2005). Who better than a social worker can help elucidate these complex environmental phenomena? Social workers are uniquely situated to translate genetic advances to the world while translating the lived experience for researchers involved in genetic research.

### **Advocacy and Informed Consent**

Though improvements have been made in the area of informed consent, some aspects of the procedure continue to need further consideration. These areas not only include newborn screenings but also the legal and ethical evaluations of the mandates for these screenings. However, a short-term goal would be the improvement of the consent process in states that, at least in theory, allow parents to opt out of newborn screenings.

Improvements in the consent process are also needed in the areas of understandability and competence. Researchers must continue efforts to ensure that written consent forms are clear, accessible, and visually appealing (Mackintosh & Molloy, 2003). In addition, based on a

study that found consent forms in cancer research to be an average of 14 pages long (Verastegui, 2006), investigators should add brevity to this list of needs. However, understandability in informed consent is meaningless if competence is absent. Because genetic research poses significant challenges to the traditional functions and methods of informed consent, these challenges will need to be addressed through continued development of group consent and consultation protocols. Group consent procedures are both appropriate and feasible with highly cohesive groups, such as the Amish, though infeasible with groups that are amorphous in nature, such as Irish Americans (Weijer, Goldsand, & Emanuel, 1999). In situations in which group consent is not feasible, other methods must be developed and promoted.

### **Policy**

Current legal protection from genetic discrimination is inconsistent across the United States. Forty-one states have passed legislation that prohibits genetic discrimination by insurance companies, and 32 states have passed legislation prohibiting genetic discrimination by employers (NHGRI, 2007). In addition, some employers, such as IBM, have voluntarily instituted policies promising not to discriminate in hiring or insuring based on genetic testing. Haga and Willard (2005) pointed out that the fact that employers have taken such action reflects the need for greater federal protection. However, despite support from both the genetics community and the public, the federal government has repeatedly failed to pass comprehensive legislation to ensure protection from genetic discrimination.

The Americans with Disabilities Act (ADA) offers limited protection against genetic discrimination by employers, and the Health Insurance Portability and Accountability Act (HIPAA) provides similar protection against genetic discrimination by insurance agencies. However, neither ADA nor HIPAA prevent employers and insurance agencies from gaining access to genetic information, which allows for the possibility of scenarios such as the following described by Rothenberg et al. (1997). Depending on the type of employment in question, employers are permitted to request a physical examination or medical records, which include any genetic information contained in the medical record. Although the employer would be prohibited from discrimination based on genetic information, if discrimination did occur, the burden of proof would be with the employee. Thus, although the protections offered by ADA and HIPAA are beneficial, their limitations highlight the need for comprehensive federal protection.

### **Professional Competence**

As the field of genetics continues to evolve, new ethical,

legal, and social implications will rapidly emerge while novel responses to existing dilemmas will also be put forth. This environment of near-constant change will require social workers to keep abreast of new thought and research in the field of genetics. Numerous resources exist to help professionals develop and maintain professional competence in the area of genomics.

The National Association of Social Workers (NASW, 2003) has adopted standards for the integration of genetics into social work practice. These standards outline the manner in which the profession's expertise, knowledge, and values can best be utilized in a genetic context. Consistent with our argument, the NASW standards hold that best practice will be to help clients maximize the benefit of genetic information while guarding clients against misuse of genetic information. In addition, NASW provides written materials as well as opportunities for members to acquire continuing education on genetics.

A second key resource is the NHGRI, a division of the National Institutes of Health that is responsible for genetic research. NHGRI maintains a comprehensive Web site that includes information on educational resources, current research, policy, and ethical issues related to genetics and genomics. In addition, a host of other entities, the discussion of which is beyond the scope of this article, also maintain Web sites on all aspects of genetics. However, the *caveat* to remain a cautious consumer of information is nowhere more important than in this realm. Ground-breaking discoveries are sometimes reported in sensationalized headlines, only to be quietly retracted when such findings cannot be replicated (Conrad, 2001). Therefore, those interested in reliable gene-related information may benefit from literature searches in disciplines such as anthropology and sociology, which offer more temperate evaluations focused on the larger implications of the findings than would be found in the hard sciences.

### **Conclusion**

The genomic revolution has been described in terms of both promise and peril. Rather than promoting the wholesale acceptance or rejection of genetic advances, we have opted to take a position of cautious optimism. The appropriateness of particular practices, at both the micro and macro levels, may be less critical than fully understanding their possible implications. Thus, when addressing certain procedures, it is not only their acceptability but also the contexts in which these procedures are embedded that must be discussed. As a profession that has been charged with the service and advocacy of marginalized groups, social work must ensure that the genetic revolution moves forward in a way that maximizes benefit and minimizes harm.

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