



**Testing, Treatment, and Trust: Social Work Professional Development and the Genomics Revolution**

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# Testing, Treatment, and Trust: Social Work Professional Development and the Genomics Revolution

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## Introduction

Knowledge in the area of human genetics and the human genome is increasing at an exponential pace. In the fields of medicine and behavioral health care, genetics and genomics shape our diagnostic processes and interventions strategies. The Human Genome Project has identified a draft sequence for the entire human genome (Human Genome Project, 2001a); genes have been linked with physical conditions (e.g., cancer, Alzheimer's, asthma), mental disorders (e.g., bipolar disorder, schizophrenia), and personality traits and behaviors (e.g., risk taking, shyness), (Clayton, 2001; Faraone, Tsuang, & Tsuang, 1999); and testing is available for several hundred specific genetic disorders (Human Genome Project, 2001b). Genetic information impacts every aspect of human life, having significant implications for both health and mental health, but also for other arenas such as insurance, employment, reproductive decisions, education, access to care, privacy, and human rights (Andrews, 2001; Bishop, 1993; Taylor-Brown & Johnson, 1998). As a result, the genomics revolution impacts nearly every aspect of social work practice, including health care, mental health care, substance abuse services, services to children and families, services to older adults, and policy practice. In order to be effective practitioners social workers must educate themselves on current genetics and genomics findings and their implications for practice.

In this rapidly expanding and technologically sophisticated sphere, what are the roles and responsibilities of social work? What fundamental knowledge must all social workers possess to practice competently in light of genetic advances? This article identifies some of the key roles social workers may take when genetics plays a part in clients' challenges or decisions, at both the micro and macro levels. In light of these roles we argue for

the responsibility of social workers to obtain ongoing professional development in genetics and genomics. This article offers a flexible curriculum developed by the authors, which can be used for both classroom instruction and professional development activities, and describes pilot and planned implementation efforts for this curriculum.

## Social Work Roles and the Genomics Revolution

Though some aspects of genetics testing, counseling, and intervention are the province of specially trained practitioners, all social workers must be well versed in concepts and current findings in the field of genetics. This is essential for a number of reasons, both in the clinical and the policy/advocacy arenas. Social work is grounded in a holistic biopsychosocial approach (Compton & Galaway, 1989). An understanding of genetics and genomics is thus essential in enhancing social workers' understanding of their clients' biopsychosocial situation.

Social workers may play a number of roles in client situations where there are genetic issues. These include: identification and referral source; educator and facilitator of decisions; multi-disciplinary team member; provider of long-term psychosocial supports and services; advocate; and policy shaper. In practice with clients, a social worker may realize that the client's issue could have a genetic component, possibly not yet considered. The social worker must be able to identify individuals who may benefit from genetic testing or consultation, and be able to refer the client to the appropriate agency for these services. This requires knowledge of both genetic conditions as well as community resources for providing genetic services. As part of the discussion around referral, the social worker must also be able to provide the client with basic education regarding genetics and why genetic services may be of benefit to him/her.

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In addition, the social worker should be able to discuss the implications (physical, psychological, financial, etc.) of genetic testing or consultation and facilitate the client's decision-making process regarding accessing the genetic service.

For those clients receiving genetic services, social workers must be able to work in collaboration with other healthcare providers, functioning as full partners in their clients' multidisciplinary teams. This requires a solid understanding of genetic concepts, testing and intervention, and an ability to use and understand genetic terminology. For many clients receiving genetic services, short-term information, treatment, and support are provided by genetic counselors and members of the treatment team. After that specialized treatment is concluded the client may be left with a number of psychosocial sequelae, including emotional stress, financial burden, long-term planning for progressive disorders, etc. Social workers are needed to provide the long term psychosocial supports and services clients and families need to cope with the knowledge gained from genetic testing, the genetic disorder itself, the long-term psychosocial impact of living with a genetic disorder, and the implications of the genetic disorder for family members (Shild & Black, 1984).

At the systems level, social workers are needed to advocate for clients, helping them navigate systems and access needed services. This could include helping clients with confusing processes and procedures to access care, assisting clients in overcoming barriers such as lack of transportation to service agencies, and helping clients identify sources to pay for services (e.g., advocating with insurance companies to reimburse for genetic testing). In addition, social workers must be active policy shapers, involved with protecting clients' rights around genetic issues. There are significant policy issues in the area of confidentiality of genetic information, discrimination in insurance and employment based on genetic information, and disparities in access to genetic testing and services, with heightened risk for vulnerable populations

such as minorities and individuals of lower socioeconomic status (Andrews, 2001).

As an example of these roles, a social worker may be asked to provide services to a 47-year-old woman whose mother has recently died of breast cancer. The client is concerned about the possibility of carrying the BRCA-1 gene, which has been linked with breast cancer. Together the social worker and client work through the decision about testing for the gene, exploring the potential advantages and risks of testing and its results. The client decides to be tested, and the social worker helps her identify a provider and determine how she will pay for the testing. The client then finds she does carry this gene. Now the social worker provides ongoing support and problem-solving assistance as the client develops the coping and self-care skills necessary to live with this information, as she navigates insurance and employment issues, and as she considers whom in her family she should tell about these results, particularly her 25-year-old daughter and her 50-year-old sister. Realizing there are no supports in the community for women like this client, the social worker advocates with the genetics testing agency to establish a support group for women carrying the BRCA-1 gene. Finally, as a result of working with this client the social worker becomes active in a state-wide task force looking at legal issues around genetic testing, DNA databases and confidentiality. Throughout all of these activities the social worker needs a solid understanding of genetics in order to provide the support, counseling, problem-solving, and advocacy skills the client, her family, and the community need.

The National Association of Social Workers (NASW), in an effort to emphasize the importance of addressing genetics in social work, recently developed Standards for Integrating Genetics into Social Work Practice (NASW, 2003). This document identifies genetics as an expanding part of social work practice and emphasizes the need for clarity and education about this area. The standards are written to "enhance social workers' awareness of the skills, knowledge, values, methods, and sen-

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<sup>1</sup> *Genetics refers to the study of single genes and their actions, while genomics involves the interaction of all the genes in an organism.*

sitivity needed to work effectively with clients, families, health care providers, and the community, and increase their understanding of the impact that the field of genetics has upon them" (p.2). They provide a framework for professional development activities in the field. The areas addressed in the standards are:

- Ethics and Values, requiring social workers to function in accordance with the NASW Code of Ethics in the integration of genetics into their practice;
- Genetics Knowledge, requiring social workers to have and continue to develop knowledge and understanding about genetics;
- Practice Skills, requiring social workers to use appropriate practice theories, skills, and interventions that reflect the workers' understanding of genetic factors;
- Collaborative Practice Model, stating social workers shall work with their client with genetic concerns in partnership that includes mutual respect, shared information, and effective communication;
- Interdisciplinary Practice, stating social workers shall participate in multidisciplinary genetics service teams;
- Self-Awareness, requiring social workers' ongoing development of understanding of personal, cultural, and spiritual values and beliefs around genetics and genetic therapies;
- Cross-Cultural Knowledge, requiring the ongoing development of specialized knowledge about client groups' history, traditions, values, and family systems as they pertain to genetics;
- Research, stating that social workers shall contribute to and be aware of the development of research-based and practice-relevant knowledge around genetics;
- Advocacy, requiring social workers to safeguard the privacy and confidentiality of their clients' genetic information, and advocate to ensure fair social policies and access to quality genetic services.

### **Social Work Professional Development in Genetics**

If social workers are to meet the standards outlined above, and are to be competent practitioners when addressing genetic issues, professional development is essential. Because of the rapid pace of discovery in the field of genetics, the majority of social work practitioners completed their education prior to the development of innovations in testing and treatment, and thus has little professional training in genetics. It falls upon continuing social work education to provide this content. In addition, even when genetic content is fully integrated into the social work curriculum, the rapid pace of discovery means new information will be continually generated, and ongoing professional development will be necessary.

A number of useful resources have been initiated over the past few years to develop social workers' competence in genetics. Discussed in detail in the standards (NASW 2003), these include the National Coalition of Health Professionals in Genetic Education, which developed core competencies for social work practice and genetics in 1996 (Jenkins, 2001), and the Human Genome Education Model project (1997-2001), which provided workshops and training programs in genetics. Funded by the National Institutes of Health and led by social workers, this initiative was aimed at human services practitioners (including social workers), and provided a range of national trainings (Lapham, Kozma, Weiss, Benkendorf, & Wilson, 2000). In addition, NASW has developed both a practice update (Taylor-Brown & Johnson, 1998) and a policy statement (NASW, 2000) on genetics. However, these resources are only a beginning. Social workers will need a range of informational resources on genetics, continually updated and in a variety of media to meet their ongoing professional development needs in the area of genetics. These resources will be needed for both academic curricula and continuing education venues. What we describe here is one such resource: a flexible social work and genetics curriculum that can be used for both classroom instruction and professional contin-

uing education purposes.

### **The Curriculum**

#### **Partners in this Journey: What Social Workers Need to Know About the Genomics Revolution**

This curriculum (Strom-Gottfried & Scheyett, 2003) is a systematic program, designed to translate the available literature, including web- and media-based resources, into easily adoptable modules for inclusion in courses throughout the master's curriculum as well as into continuing education programs that can be delivered to practicing social workers. The curriculum is designed for maximum flexibility; modules can be taught individually (though in sequence, since foundation genetic knowledge is a necessary prerequisite for additional content), in clusters, or as a whole. In addition, modules can be infused into existing course content at the master's level, and are especially useful in courses such as human behavior in the social environment, discrimination and inequality, social policy, research, and social work methods.

The curriculum consists of ten modules, with each module estimated to take one hour to 90 minutes. All modules follow the same format, beginning with Learning Objectives, highlighting Key Content Areas, providing Suggested Activities, and including Readings and Resources. The module topics, with learning objectives for each, are provided below. Example modules (Modules 1 and 2) are provided in the Appendix.

#### **Module Outlines**

##### **Module 1: Introduction: History and the Basic Science of Genetics**

###### *Learning Objectives*

At the end of this module, students should be able to:

- Discuss the reasons why social workers need to understand and participate in the genomics revolution
- Discuss the essential historical facts leading to the Human Genome Project
- Articulate the basic concepts of classical and molecular genetics
- Have beginning skill in taking a genetic history as part of a biopsychosocial assessment.

##### **Module 2: Understanding the Roles of the Interdisciplinary Team**

###### *Learning Objectives*

At the end of this module, students should be able to:

- Identify the disciplines involved in genetic testing, counseling and research
- Describe the roles that each member plays in the team
- Identify strategies and resources for enhancing team effectiveness across disciplines.

##### **Module 3: Ethics Essentials**

###### *Learning Objectives*

At the end of this module, students should be able to:

- Describe the unique nature of ethical issues emerging genetic advances
- Describe at least one ethical challenge posed by the genetic revolution for each of the following areas: conflicts of interest, competence, self-determination, informed consent, confidentiality and patient privacy
- Describe the ethical issues raised by the notion of perfectibility
- Articulate a process for exploring and resolving ethical dilemmas
- Illustrate the link between ethical issues and those raised in other modules, such as those on psychosocial implications and traditionally marginalized populations.

##### **Module 4: Implications for Traditionally Marginalized Populations**

###### *Learning Objectives*

At the end of this module, students should be able to:

- Describe historical and contemporary disparities in health care research and access and the ways that these influence the response to genetic advances
- Describe the impact of genetic testing on traditionally marginalized groups such as women, persons of color and those with disabilities
- Describe potential misuses of genetic information as they affect traditionally marginalized populations.

**Module 5: Medical Genetics**

*Learning Objectives*

At the end of this module, students should be able to:

- Explain the basics of genetic testing and identify a number of disorders for which there are genetic tests
- Explain gene therapy and its applications in layperson terms
- Articulate the concepts behind pharmacogenomics
- Discuss reproductive issues as they apply to gene testing and gene therapy
- Discuss roles social workers can and should play in medical genetics.

**Module 6: Psychosocial Implications of Genetic Testing**

*Learning Objectives*

At the end of this module, students should be able to:

- Describe the psychological and social implications of genetic testing and genetic information for carriers, the asymptomatic ill, and on the family as a whole
- Define key terms in psychosocial aspects of genetic testing.

**Module 7: Gene Therapy**

*Learning Objectives*

At the end of this module, students should be able to:

- Describe the promises and limitations of gene therapy
- Describe the ethical implications of gene therapy.

**Module 8: Behavioral Genetics**

*Learning Objectives*

At the end of this module, students should be able to:

- Explain the multifactorial polygenic model for behavioral disorders
- Discuss the evidence for a genetic component to schizophrenia, mood disorders, anxiety disorders, substance use disorders, and ADHD
- Identify the personality traits for which there

seems to be a genetic component

- Apply foundation behavioral genetic knowledge to social work practice.

**Module 9: Research Issues in Social Work**

*Learning Objectives*

At the end of this module, students should be able to:

- Identify the central areas for social work research in light of the genomics revolution
- Articulate ways in which social work practitioners can be involved in research on issues raised by the genomics revolution.

**Module 10: Public Policy and Advocacy Issues**

*Learning Objectives*

At the end of this module, students should be able to:

- Discuss the major policy issues for social workers in the genomics revolution, including genetic discrimination, ownership and control, economic issues, and family impact
- Identify the three policy models for genomics issues—medical model, public health, model, and fundamental rights model.

**Implementation and Evaluation of Curriculum**

To date the authors have used the curriculum in both continuing education settings and the classroom, infusing the workshops and content of graduate level coursework at their institution. Content from Module 3 (Ethics Essentials) has been infused into ethics workshops and discussions facilitated by one of the authors, and content from Module 8 (Behavioral Genetics) has also been infused into an anti-stigma workshop developed by another of the authors. Additional continuing education workshops using the curriculum's content are planned for the future. Materials from the curriculum have also been made available to practitioners through the UNC School of Social Work's Research to Teaching web site, which provides slide shows and training notes on current faculty projects and publications ([ssw.unc.edu/rti](http://ssw.unc.edu/rti)).

Content from all of the curriculum modules has been incorporated into a multi-disciplinary graduate level seminar (including social work,

nursing, and public health), *Genomics in Society*, open to students and practitioners in the university community. The seminar was very well received, and evaluation results are summarized in Table 1 below. Comments from students were very positive; representative comments included "The course gave me much insight into the ethical, social, and legal issues involved with genomics" and "Excellent course – took controversial and complicated topics and provided means to apply to careers ... tremendous information." In addition, content from Modules 8 (Behavioral Genetics) and 10 (Advocacy Issues) has been used in one author's MSW health and mental health policy course, and content from Module 1 (Introduction: History and the Basic Science of Genetics) incorporated into an author's MSW adult health and mental health disorders course. Evaluation results for these courses are also shown in Table 1. As can be seen, both courses were highly rated; rating of course discussion related to social work values was particularly strong, and this content included frequent focus on the ethical issues in genomics.

### Ongoing Content Dissemination and Social Work Professional Development

Ensuring that all social workers have access to relevant genetics information requires a dissemination strategy aimed at three groups: social work educators, social work practitioners, and social work students. The implications of the genomics revolution are vast for social work education; social work faculty will be required to increase their understanding of genetics and genomics and incorporate content across the social work curriculum. For the purposes of this paper, however, we focus our discussion here on strategies to reach practitioners; strategies for dissemination to social work educators and students are described elsewhere (Strom-Gottfried & Scheyett, 2003).

When considering dissemination strategies for social work practitioners, two factors must be considered: relevance and accessibility. Content must be presented in a way that clearly links genetics to the daily practice of social workers and should provide sufficient time for discussion and exchange of ideas. Ideally, genetics content should be provided in a series of face-to-face continuing educational workshops, with ample time for exploration of issues. This is challenging, however, given the time and financial resource limitation many social work practitioners face. Professionals providing continuing education may wish to consider alternative delivery strategies, such as providing foundation content (i.e., Modules 1-3) in face-to-face workshop format, with opportunity for questions and discussion, and encouragement for providers to network and continue discussion after the training has concluded. Workshops for the remaining modules could be provided periodically, but also made available on through internet-based training, with discussion boards, listservs, or other interactive elements for content discussion. Additional strategies to disseminate genetics content to social work practitioners could include specific tracks at regional and national conferences of social workers, linkage between social workers and other practitioners (e.g., in medicine, nursing, public health) working in the

**Table 1: Evaluations for Courses with Genomics Content** (1=lowest rating, 5=highest rating)

Course (N=)	Overall course rating		Course stimulates critical thinking		Course related to social work values	
	Mean	St.Dev	Mean	St. Dev	Mean	St. Dev.
Genomics in Society (N=5)	5.00	0.00	5.00	0.00	N/A	N/A
Adult Health and Mental Health Disorders (N=12)	4.83	0.40	4.92	0.29	4.92	0.29
Health and Mental Health Policy, Spring 2003 (N=44)	4.70	0.53	4.51	0.68	4.86	0.40
Health and Mental Health Policy, Spring 2004 (N=46)	4.68	0.58	4.46	0.83	4.83	0.38

area of genetics, and development of genetics resources on web sites for social work practitioners.

A challenge for professional development in the area of genetics is dissemination of content to social work practitioners who may not yet realize its relevance to their work, and will not enroll in workshops specific to genetics in social work. For this population it is important to develop strategies to infuse genetics content into other continuing education workshops, and thus heighten awareness of the importance of the topic. Infusion strategies could include the use of genetics examples in social work ethics workshops, inclusion of genetics resources in case management trainings, discussion of genetically-based perinatal loss in trainings on bereavement, and use of examples of families caring for an individual with a chronic genetic disorder in workshops on caregiving and families.

Perhaps the greatest challenge to social work educators and trainers is the need for ongoing revision of curriculum materials. Given the rapid growth of knowledge in this field, frequent updating of materials may be needed. Educators and trainers should review the relevant health and social work literature, particularly publications from the National Association of Social Workers. In addition the *Journal of Genetic Counseling* and similar journals are excellent resources. Finally, in addition to journals there are a number of important web sites with current information on new findings.

These include:

- <http://www.doegenomes.org/>  
The Human Genome Project web site, with a range of current publications on medical and ethical issues.
- <http://www.cdc.gov>  
The Centers for Disease (CDC) control publish a number of relevant articles on genetics, genomics, and practice and ethical ramifications.
- <http://scbe.stanford.edu/pges/>  
The Stanford University Center for Biomedical Ethics. The center addresses a range of social, ethical, legal, and political implications of advances in human genetics from multiple per-

spectives.

- [http://genomics.duke.edu/home/top\\_flash.cgi](http://genomics.duke.edu/home/top_flash.cgi)  
Website for The Institute for Genome Sciences and Policy (Genomics Institute) at Duke University.

### **Conclusion**

The earliest call for social work involvement in genetics dates back to Schild's seminal work in 1977. Social workers are needed in the field of genetics, and social workers with knowledge of genetics and genomics are needed across all fields of practice. The skills and values in social work practice are of tremendous relevance to genetics issues. Social workers' skill sets include the ability to work with both individual and family systems, to partner with clients in navigating complex ethical and legal issues, and to advocate and effect change at macro system and policy levels, all grounded in the principle of social justice. Given this potentially good "fit" between social work skills and service needs, the question becomes "Why are social workers not taking the lead in psychosocial genetic issues and services?"

From our preliminary curriculum evaluations it is clear that when presented with genetics information social workers are eager, capable, and enthusiastic learners. From our work it is also clear that vast quantities of information on genetics and genomics are available from the scholarly literature, web sites, and government reports. We posit, therefore, that the greatest barrier to increased social worker understanding of and action in genetics-relevant fields is lack of awareness. If social workers become more aware of opportunities to practice in genetics arenas and (perhaps more importantly) of the relevance of genetics and genomics information to their practice across settings, then their interest in understanding and gaining skill in addressing psychosocial genetic issues will increase.

Given this, recommended next steps for social work professional development in genetics and genomics should include both awareness enhancement and content provision. In addition to ongoing development and evaluation of continuing educa-



tion and university curriculum content, strategies to help social workers understand the relevance of genetic and genomic information in their practice should be developed, implemented, and evaluated.

Social marketing concepts may be useful in this process. Only when social workers see that genetics is relevant across fields of practice will we be able to fully integrate genetics content into the

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**Appendix**

**Module 1: Introduction: History and the Basic Science of Genetics**

*Learning Objectives*

At the end of this module, students should be able to:

- Discuss the reasons why social workers need to understand and participate in the genomics revolution
- Discuss the essential historical facts leading to the Human Genome Project
- Articulate the basic concepts of classical and molecular genetics
- Have beginning skill in taking a genetic history as part of a biopsychosocial assessment

*Key Content Areas*

1. Reasons for social work involvement and understanding of genomics

- Role in the biopsychosocial understanding of clients and their families
- Referring clients for genetic testing or evaluation
- Medical issues
- Psychosocial issues around decision to be tested
- Role as full participant in medical interdisciplinary team
- Collaboration with genetic counselors
- Long term support after testing or disorder
- Advocacy
- Individual clients/families and ethical/legal issues
- Policy action around discrimination and access

2. History

- Mendel and classical genetics
- 1945: the Department of Energy and concern about energy effects
- 1986: the Human Genome Project
- 2000: draft of human genome sequence

3. Basic Concepts

Terms:

- Genome
- Chromosome
- Gene
- Nucleotide
- Mutation
- Proteins
- Proteome
- Genotype vs phenotype

Classical genetics:

- Looking at patterns of heredity
- Autosomal dominant and recessive
- X-linked

What we learn from family studies, twin studies, adoption studies:

- Nature vs. nurture
- Multifactorial probability of developing a disorder/trait

Molecular genetics:

- Gene sequencing: how do they do that?
- Genetic testing: which disorders? How accurate are they?
- Key discoveries (Human Genome Project: What We Have Learned So Far <http://www.ornl.gov/hgmis/publicat/primer2001/4.html>)
  - The human genome contains 3164.7 million chemical nucleotide bases (A, C, T, and G).
  - The average gene consists of 3000 bases, but sizes vary greatly
  - The total number of genes is estimated at 30,000 to 40,000
  - The order of almost all (99.9%) nucleotide bases is exactly the same in all people.
  - The functions are unknown for more than 50% of discovered genes.
  - About 2% of the genome encodes instructions for the synthesis of proteins.
  - Scientists have identified about 1.4 million locations where single-base DNA differences occur in humans.
  - The ratio of germline (sperm or egg cell) mutations is 2:1 in males vs females.

#### 4. Taking a Genetic History

##### Content:

- Covering at least 3 generations
- Countries of origin
- Ages and causes of death
- Medical information, including birth defects, psychiatric disorders, genetic disorders

##### Process:

- Confidentiality
- Sensitive questioning
- Unclear historian or lost history: probing and collateral sources

#### Suggested Activities

Activity for Section 1 - Reasons for social work involvement and understanding of genomics

Goal: Help students understand the multiple and complex roles social workers can play with clients and families where genetics plays a part.

Action: In discussion groups, have students discuss the role of the social worker and potential challenges the social worker might face for the following case. Allow students to discuss the first paragraph, then provide them with the information in the second paragraph, then the third, etc.

Case: You are a social worker in a community health clinic. Martha is a 42-year-old Caucasian female, who comes complaining of mood swings and trembling. Until these symptoms she has had good health, had no mental health problems, and uses no substances.

During your assessment process, Martha informs you that her mother died of Huntington's disease 20 years ago. This is an autosomal recessive disorder, characterized by psychological changes, involuntary movements, and eventual total inability to move and death. There is no treatment or cure.

Martha goes for evaluation and is found to have early stage Huntington's disease. She comes back to see you, tell you of her finding, and talk to you about her severe suicidal ideation.

Martha's daughter Susan comes to see you.

Susan is 24 years old and pregnant. She wants to talk with you about her concerns regarding having and transmitting Huntington's, and to weigh the pros and cons of being tested.

#### Activity for Section 3 - Basic Concepts

Goal: Help students understand the vast number of genetic disorders, and distinguish between directly inherited genetic disorders and disorders which are a result of genetic vulnerability and environmental risks.

Action: Break students into small groups. Ask each group to list as many disorders as they can which run in families. Compile a master list, then as a large group, identify whether the disorder is directly inherited, or a result of genetic vulnerability. Look at the comparative proportions and discuss.

#### Activity for Section 4 - Taking a Genetic History

Goal: Allow students time to practice taking a genetic history.

Action: Break students into pairs and ask all pairs to come up with a fabricated three-generation genetic history for a client. Then ask each member of a pair to leave their current partner and create a new pair with someone else. Have one person in the pair role play their fabricated client, and the other play a social worker obtaining a genetic history. After 15-20 minutes, have the pair switch roles. Return to large group and discuss—What worked well? Where was it hard or confusing to ask questions? How did it feel to be the client? What other thoughts/questions do you have about taking a genetic history?

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**Module 2: Understanding the Roles of the Interdisciplinary Team**

*Learning Objectives*

At the end of this module, students should be able to:

- Identify the disciplines involved in genetic testing, counseling and research
- Describe the roles that each member plays in the team
- Identify strategies and resources for enhancing team effectiveness across disciplines.

**Key Content Areas**

Members of the team:

- Primary Care Physician
  - Description of discipline
  - Role on the team
  - Specialized knowledge for this role
- Nurse
  - Description of discipline
  - Role on the team
  - Specialized knowledge for this role

- Genetic Counselor
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
  - "Single disorder" (non-Master's) Counselor
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
  - Clinical Geneticist
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
  - Social worker
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
  - Psychologist
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
  - Public Health Professional
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
  - Laboratory Staff
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
  - Clergy
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
  - Ethicists
    - Description of discipline
    - Role on the team
    - Specialized knowledge for this role
- Issues for effective interdisciplinary practice
- Differences in reimbursability
  - Differences in educational preparation and focus
    - Specialists vs. generalists
    - Need establishment of basic proficiencies in medicine, nursing, social work and public health
  - Evolving knowledge base and role relationships
  - The role of volunteer organizations

- Structures and strategies to strengthen team effectiveness
  - Communication
  - Coordination

#### *Suggested Activities*

Map with the class the path of a patient through the process of genetic information, testing, education and intervention. Ask each student to imagine being pregnant (or having a pregnant spouse) and track the journey of genetic exploration from that point. What role will each of the professionals play? How will these differ if genetic susceptibilities are identified? Where are points of possible tension or difficulty? As a patient, what skills, knowledge and abilities will the student need from each professional with whom he/she has contact? Class/workshop members can sketch these out individually and the instructor can conclude by facilitating discussion and input in recreating such a map on the board.

#### *Readings and Resources*

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- Website describing the role of genetic counselors on an interdisciplinary team.

#### **Module 3: Ethics Essentials**

##### *Learning Objectives*

At the end of this module, students should be able to:

- Describe the unique nature of ethical issues emerging genetic advances
- Describe at least one ethical challenge posed by the genetic revolution for each of the following areas: conflicts of interest, competence, self-determination, informed consent, confidentiality and patient privacy
- Describe the ethical issues raised by the notion of perfectibility
- Articulate a process for exploring and resolving ethical dilemmas
- Illustrate the link between ethical issues and those raised in other modules, such as those on psychosocial implications and traditionally marginalized populations

##### Key Content Areas

###### 1. The unique ethical challenges of genetic advances

- The nature of genetic relationships alters our understanding about patient information and raises a need for "gen-etiquette" when testing results in the indication of others' status
- Pressures for advancement mean that technical expertise may outstrip our appreciation of the implications of such advances.
- The genetic revolution occurs against a backdrop of inadequate basic health care, misuses of certain populations at the hands of researchers and health care professionals, and biases in the conduct of health care research.

###### 2. Conflicts of Interest

For providers and researchers

- Budget and financial pressures lead to excessive claims of success/impact
- Scientific neutrality jeopardized by financial conflict of interest
- Double agenting-dual loyalties of MDs and geneticists between patient and school, employer, insurer, parent, child
- With potential for abortion, MD's moral stance may color advice on genetic tests

- For patients
- Self-interest vs. interest of others
3. Challenges to Informed Consent
- Problems with the accuracy of informed consent for testing and storage of DNA
  - Limits on information provided (especially by for profits) on patient's rights. Direct marketing to consumers compounds the problem
  - Importance of multiple sources of information for adequate patient education
  - Particular implications for testing children
  - Attitude of unquestioned effectiveness may lead to inappropriate recommendations for testing without sufficient concern for voluntariness, informed consent, QA
  - Fetal testing intrusions without consent
  - Weighing risk as moral and social not just physical.
  - Risk is also less immediate, less certain. Can patients and families appreciate multifactorial nature of inheritance and disease risk? How will they use such information?
4. Challenges to Confidentiality and Patient Privacy
- Moral or legal duty to share information with our relatives for purposes of testing or as a result of testing?
  - Is it individual property or family property?
  - Geneticists willingness to breach patient confidentiality
  - Against a backdrop of poor protections for patient privacy
  - Protection/privilege may be limited to MDs but not PhD genetic counselors
  - Screening of egg and sperm donations for certain genetic disorders. Less statutes requiring sperm testing than egg.
  - Insurer or employer discrimination for both parent and fetus
5. Challenges to Competence
- Competence in MDs and others to advise on genetics is questionable and on interpretation of probabilistic data in healthy subjects
  - Disproportionate distribution and limited availability of genetic counselors
  - Competence of labs for complexities of these tests.
- Limits of regulation and licensure of labs.
  - Limited regulation of test quality
  - Complexity of genetic testing and analysis leads to difficulty for patients or other providers in assuring quality
6. Challenges to self-determination
- Coercion, deception and other threats to autonomy in decisions about testing
  - Penalizing patients for not using genetic services
  - Withholding service information based on presumed risk
  - Major source of involuntary genetic testing is secondary testing of tissue sample patient provided for other reasons
7. Reproductive decision-making: Does "knowing" really help?
- The myth of perfectibility - where do we draw the line?
  - Three factors influencing perception of severity:
    - Survival, suffering, and limitations on functions and activities
    - Age of onset
    - Extent to which genes influence the health of the child
  - "Wrongful birth" suits - give birth to a child with serious genetic disorder without doctors informing them of testing options or when results are interpreted incorrectly (These include suits against parents for not aborting)
  - Values about quality of life with or without disease regarding decision to abort or have a second child
  - Genetic testing of children. The purpose is to detect and treat or alter way child is treated and options open to him or her. Yet "planning for the future" may become restructuring the future by self-fulfilling prophecy
  - Embryo selection in IVF changes from random to criteria-based. What are acceptable selection criteria?
8. Ethics in Genomics research
- How to protect research participants from discrimination and stigmatization?
  - How to properly insure informed consent?
  - How to properly secure records?

- IRB preparation for the implications of risk in nontherapeutic research
- 9. Adverse results of genetic knowledge
  - Implications of failure to act on genetic information.
  - Appropriated as a rationale for social policies.
  - Danger of self-fulfilling prophecy or behavior based on fatalism
  - Denial of health coverage, life insurance renewal; Denial of job opportunities; Denial of educational opportunities.
  - Limits as "preexisting condition" leads to potential for deterring testing because some insurers ask if testing has been done, not results
  - Dangers in state mandated genetics testing, given limited number of treatment options even if problems were discovered, may discourage the birth of children with genetic disorders, placing parents rights and state financial interests in conflict
  - Few states have legal protections against employer and insurance discrimination
  - Development of prenatal test to diagnose disability may lead to reductions in funding to research treatment and to provide social services in the notion that such could have been avoided
  - Marketing pressures for tests (even for trivial disorders) may mean that those ordering them have decreased knowledge of what life of a person with that disease might be like.
  - Use of genetic testing in child custody disputes ostensibly to predict who will live longer
- 10. Addressing the ethical challenges
  - 3 steps to address misuse of genetic information
    - Ensure people have control over their genetic information
    - Ensure people have control over who has access to their genetic information
    - Prevent discriminatory practices. See legislative initiatives via ELSI working groups on Employer- and Insurer- discrimination.
  - Genetics Privacy Act
  - Informed consent should include what future decisions patient will face based on results of testing and the impact and range of manifestation of disability for which testing is being done
  - Does probabilistic rather than deterministic influence of genes make a difference in the potential for misuse of genetic information?
  - HIPAA and its limits
  - Records security
  - Need to improve the pre-analytic and post-analytic components of test delivery to ensure the accurate and appropriate communication of test utility to patients and the need for similarly accurate communication of test results and possible interventions.
  - Improve testing through significant provider education to ensure that those requiring services are recognized, that proper tests are ordered, counseling and informed consent are obtained where needed, and results accurately transmitted combined with changes in the presentation of information from laboratories to providers
  - Recommendations for the development of genetics curriculum at four levels
    - A base level for all physicians
    - An intermediate level for physicians in specialties which serve patients with problems with significant genetic components (e.g. cancer and clinical oncology)
    - Enhanced public education
    - Fourth level of the Board certified medical geneticist already has well developed curricula
  - NHGRI commits 5% of its extramural research budget to support research on the ethical, legal, and social implications (ELSI) of advances in genetics. The early goals of the ELSI program focused on four high-priority areas:
    - The use and interpretation of genetic information
    - The clinical integration of genetic technologies
    - Issues surrounding the conduct of genetics research
    - Public and professional education in genetics

*Suggested Activities*

Divide class or group into teams of two. Assign each pair one of the following questions and select one person to argue for the question and one to argue against. Allow adequate time for them to prepare their responses. (In a large group, teams of 4 people may be selected with two members preparing each position but only one serving as the debater). The debate can follow some variation on the following format. The key is to encourage critical thinking about the intended and unintended consequences of these issues.

1. The participants in the debate will decide who goes first by agreement or flip of a coin.
2. The first participant will have 4 minutes to state his/her position and supporting arguments, then the second participant will have 4 minutes to do the same.
3. The first participant, then the second will each have one minute to make follow-up comments, rebut the other's position or provide additional information.
4. Each participant will have two minutes to respond to a question from the audience. The second participant will take the first question.
5. Audience members will privately score each of the presenters using the format below.
6. The class will offer general verbal feedback and debrief about the topic presented.

Presenter \_\_\_\_\_

Topic \_\_\_\_\_

Please rate the presenter on the following:

- |   |  |   |
|---|--|---|
| 1. Demonstrated knowledge of the topic                          | <input type="checkbox"/> Unsatisfactory<br><input type="checkbox"/> Good | <input type="checkbox"/> Satisfactory<br><input type="checkbox"/> Outstanding |
| 2. Ability to support argument (for example, with outside data) | <input type="checkbox"/> Unsatisfactory<br><input type="checkbox"/> Good | <input type="checkbox"/> Satisfactory<br><input type="checkbox"/> Outstanding |
| 3. Ability to address questions or weaknesses in position       | <input type="checkbox"/> Unsatisfactory<br><input type="checkbox"/> Good | <input type="checkbox"/> Satisfactory<br><input type="checkbox"/> Outstanding |
| 4. Clarity in communicating position                            | <input type="checkbox"/> Unsatisfactory<br><input type="checkbox"/> Good | <input type="checkbox"/> Satisfactory<br><input type="checkbox"/> Outstanding |

1. Genetic information should be used in child custody decisions as one method of determining parental fitness by assuring one parent of another has no predisposition for an incapacitating disease.
2. Parents whose first child inherited cystic fibrosis, should not have a second child.
3. Government programs, including special education, should be withheld from families who knew of genetic abnormalities in their unborn children and failed to abort the pregnancy, or, the families should pay for such services out of pocket.
4. Insurance companies should be prohibited from asking about genetic tests and results, even if it means the end up issuing policies to people who know they will be severely disabled or die at an early age.
5. People who know they are susceptible to an illness should be penalized for failing to take whatever steps are necessary to protect themselves from the illness.
6. Parents should ultimately have the power to decide whether a condition revealed by genetic testing is serious enough to warrant ending the pregnancy.
7. If genetic tests evolve so that the propensity for violence or addictions can be predicted with 50% accuracy, society should take steps to keep weapons and substances of abuse away from these persons.
8. Employers have a right to know about an employee's genetic test results if the results provide information on the likelihood of future absenteeism or the excessive use of company health care benefits.
9. A person has the right to sue his or her parents if they knew he or she would be born with dwarfism and failed to abort the pregnancy.
10. Genetic test results should be used in deciding how to allocate scarce resources, moving funds from preventable illnesses that can be avoided by not passing along a defective gene to those that are not preventable.
11. A father has a right to test his young children for Huntington's Disease. There is a family



susceptibility to HD and he wants to decide which of the two of them will benefit most from college, if he can afford to send only one.

*Readings and Resources*

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Zallen, D. T. (1997). Confronting science: The dilemma of genetic testing. *Humanities*, 18(2), 34-39.

<http://genethics.ca>

This website has articles about various topics on ethics and genomics such as genetic testing, counseling, human research, eugenics, gene therapy, stem cell research, etc. The goal of this site (as determined by the site's author) is to serve as a clearinghouse for information on the social, ethical and policy issues associated with genetic and genomic knowledge and technology.

<http://scbe.stanford.edu/pges/>

Webpage for the Stanford University Center for Biomedical Ethics. The center has genomics ethics seminars and a Program for Genetics, Ethics, and Society (PGES), which addresses a range of social, ethical, legal, and political implications of advances in human genetics from multiple perspectives.

<http://www.cdc.gov/genomics/info/books/21stcent5.htm>

This is an article put out by the Centers for Disease (CDC) control about Public Health surveillance of genetic information and the social and ethical ramifications. This article discusses the social implications for the general population and for traditionally marginalized populations.

[http://genomics.duke.edu/home/top\\_flash.cgi](http://genomics.duke.edu/home/top_flash.cgi)

Website for The Institute for Genome Sciences and Policy (Genomics Institute) at Duke University where scholars from many disciplines (economics, engineering, medicine, law, etc) research the ethical, legal, and policy issues surrounding genome science.