Beyond Confidentiality:

Ethical Considerations in Genetics

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STACEY K. BARTON, MSW, LCSW

Washington University School of Medicine
Department of Neurology
HDSA Center of Excellence

bartons@wustl.edu
314.362.3471

Washington University in St. Louis

Huntington's Disease Society of America Center of Excellence

Objectives

- Define the basic principles of genetics and genomics
- Articulate the ethical issues inherent at the intersection of genetics and mental health
- Expand understanding of the risks, benefits and limitations of genetic testing
- Explain how to use existing Codes of Ethics including NBCC and NASW to inform practice with genetic conditions

Disclosures

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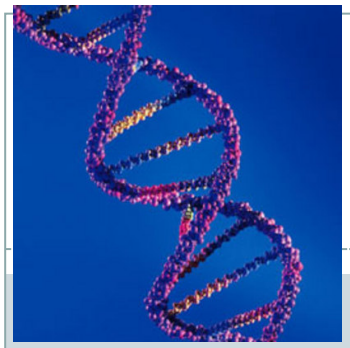
Why Should We Understand Genetics?

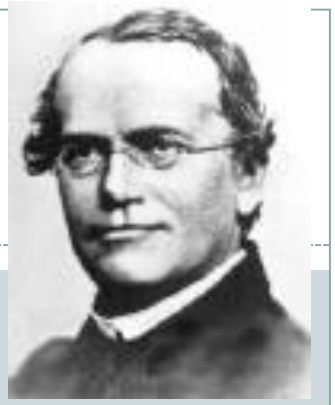
We wear lots of hats!

- Genetic basis for diseases constantly emerging
- Genetic diseases intersect with all the ways we work with individuals and families
  - Education, therapy, medical/mental health, homelessness, adoption…
  - Downstream implications: advocacy, family planning, legal issues, financial impact, education, employment, heath, resources, benefits…
  - Even if genetics is not primary role, it influences the client's world
  - We may take over where genetic counseling ends
- Providing Informed Consent – possible if "informer" doesn't fully understand issues, consequences? (e.g. genetic testing)
- We should incorporate medical Hx in psychosocial assessments [2] including genetics – diseases, alcoholism, dementia, mental illness
- Genetics is a valid field for SW to enter (See NASW Standards for Integrating Genetics into SW Practice)

Basic principles of genetics and genomics



Principles of genetics and genomics



- What is Genetics?
  - The study of single genes and their effects
    - Term often used interchangeably with genomics – the study of all the genes in the genome
- Basic Terminology
  - Genes: Units of inheritance
  - DNA: A molecule comprised of 4 different nucleotides/bases: Adenine, Cytosine, Guanine, and Thymine
  - Chromosomes: Long chains of DNA and protein
    - Humans: 23 pairs, including sex chromosomes

Genetics Terminology

- Mutation
  - Change in DNA which changes the shape, function of a protein
  - Leads to various effects on the organism, such as disease
  - Effect depends on location, type of mutation
- Phenotype is the physical presentation of the genetic trait.
- Penetrance – The proportion of those with the gene who will express the trait (phenotype)
  - Complete penetrance – everyone with gene will develop the disorder
  - E.g. 80% penetrance – 20% will not develop disorder

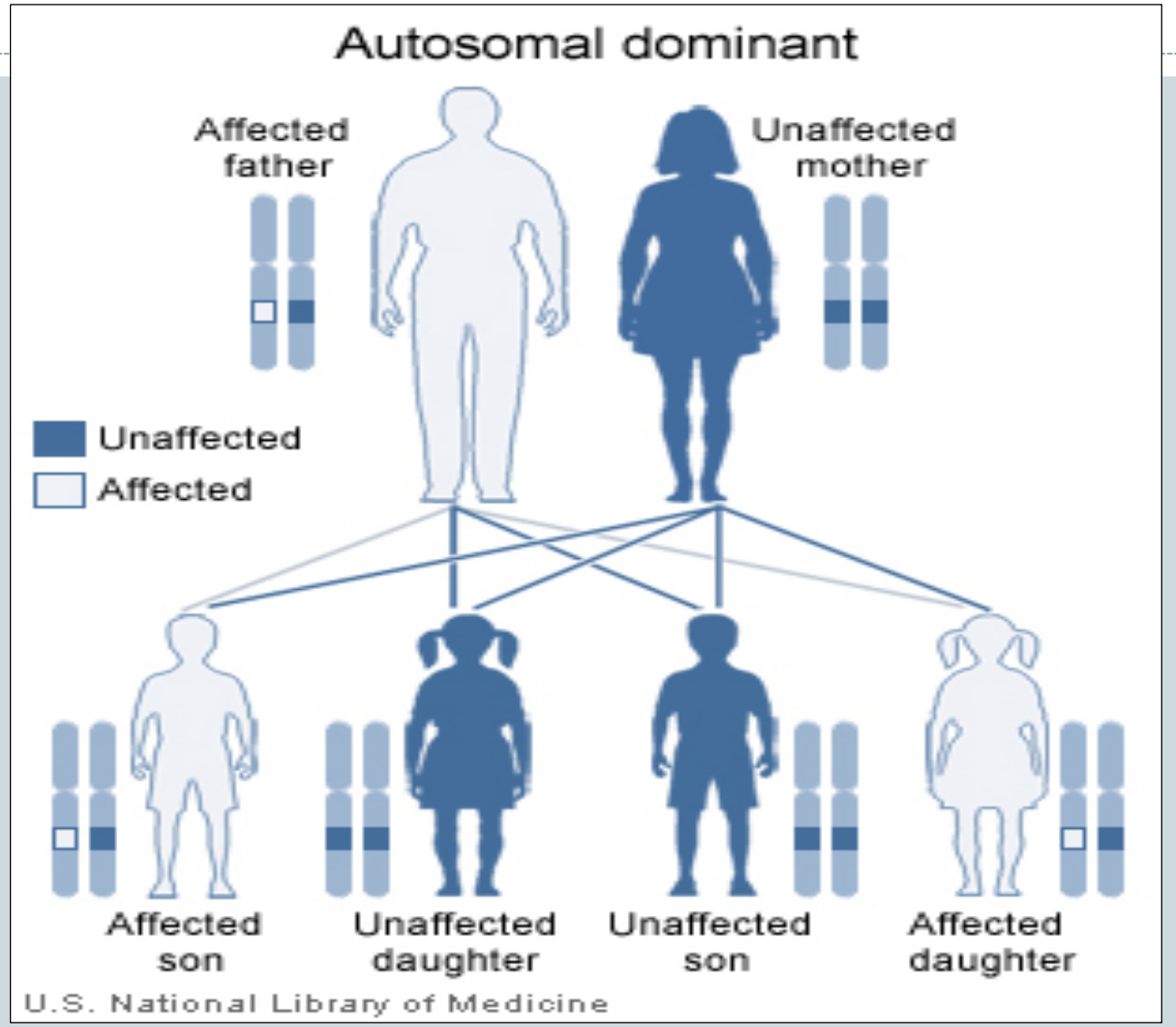
Does gene = disease?

Patterns of Inheritance

- Autosomal
  - Dominant – Gene expresses itself selectively over other gene
  - Recessive – Both parents must be carriers for condition to be expressed
- Sex-Linked
  - Gene is located on X or Y chromosome
  - X-linked disorders – generally, males at risk because they have only 1 copy, women have 50% chance of being a carrier – usually unaffected because normal X covers for mutation
    - Can be recessive (e.g. Duchenne Muscular Dystrophy) or dominant (Fragile X)

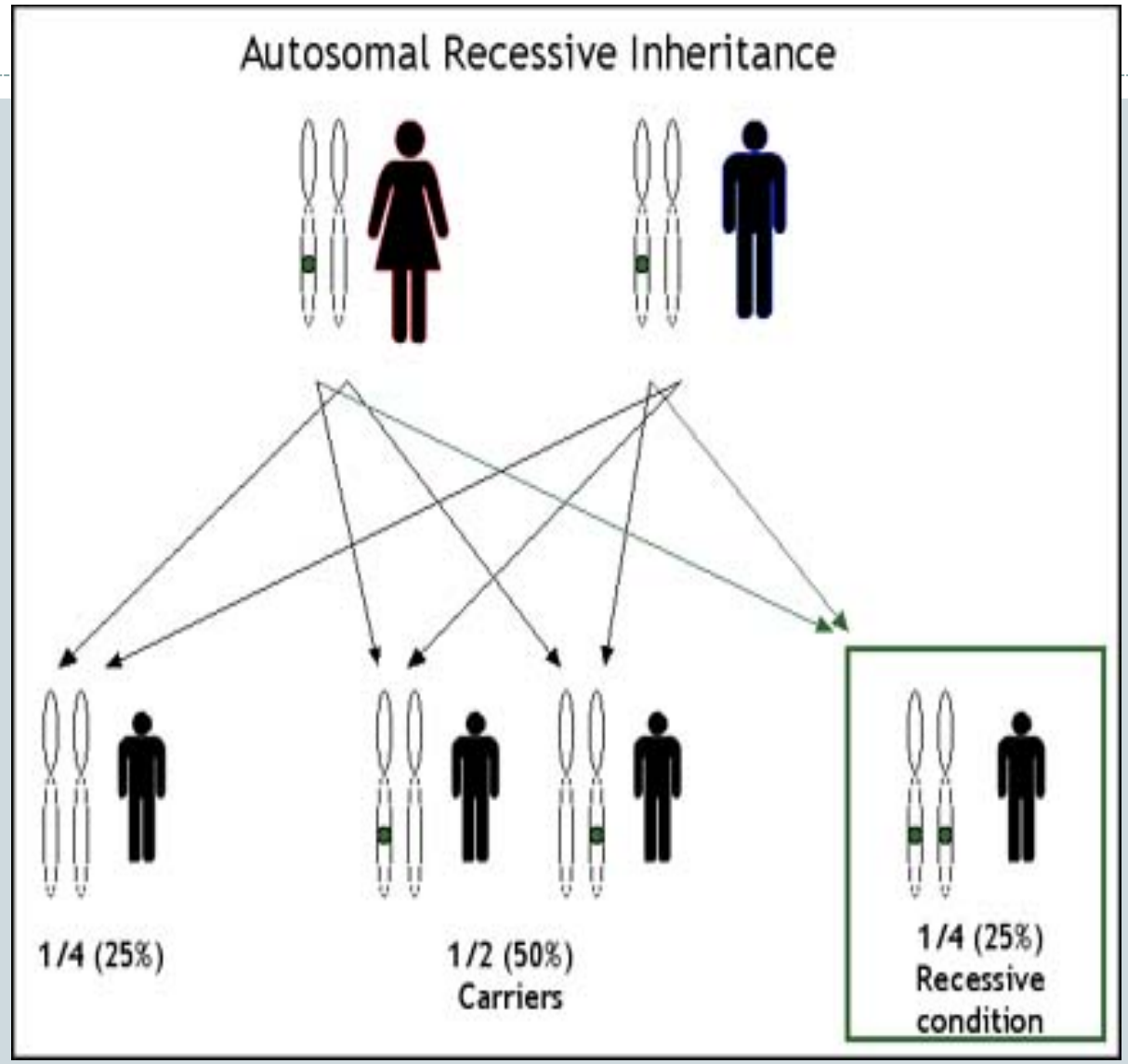
Autosomal Dominant Disorders

- One mutated copy of the gene needed to cause the disorder
- Affected person usually has one affected parent
- Tends to occur in every generation of an affected family



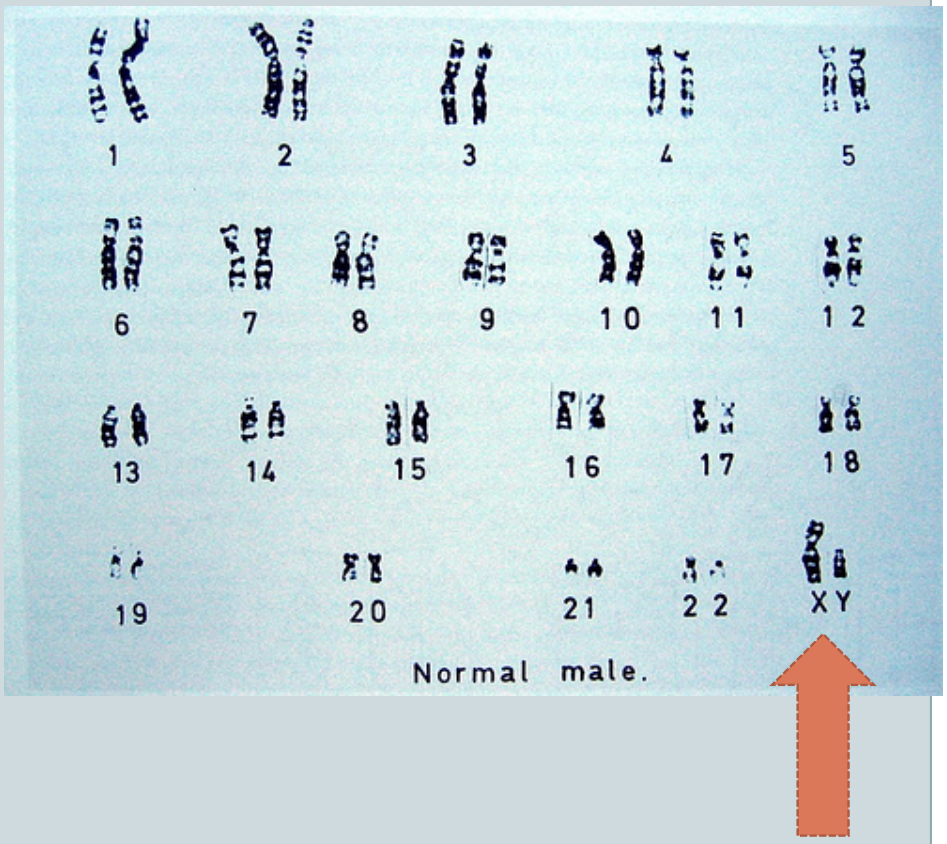
Autosomal Recessive Disorders

- Two mutated copies of the gene must be present to have the disorder (inherited one from each parent)
- Usually parents are unaffected, but each carry a single copy of the gene mutation (carriers)



X-linked

- Gene causing the trait or the disorder is located on the X chromosome
  - Females have two X chromosomes
  - Males have one X and one Y chromosome
- Can be dominant or recessive
- Boys would always inherit their X chromosome from Mom
  - Fathers cannot pass X-linked traits to their sons (no male-to-male transmission)



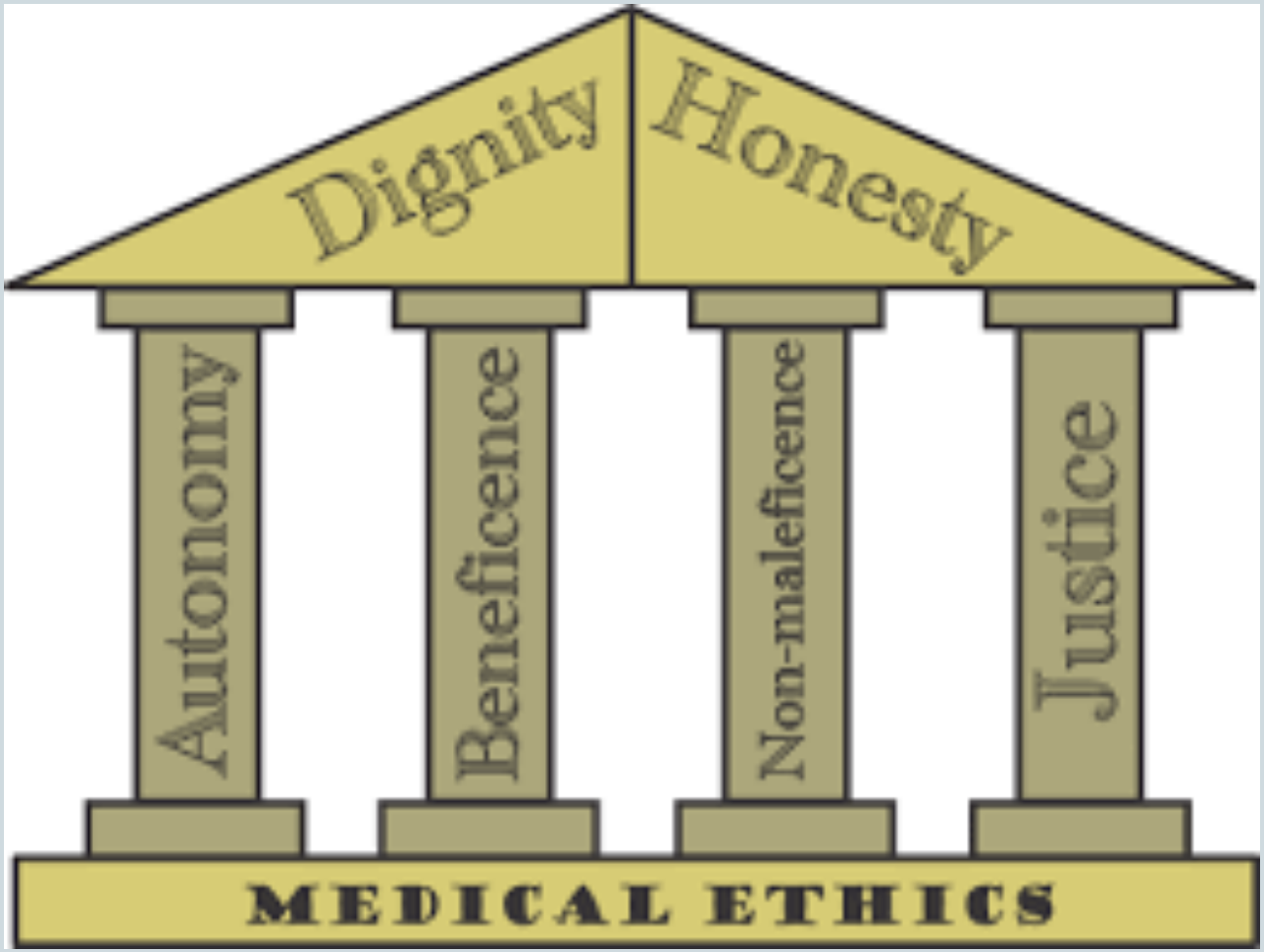
X-linked

- Dominant
  - Rare
  - Affects females > males
  - Pattern of inheritance varies, depending on whether the father or the mother has the gene mutation
  - Families often have both affected males and females in each generation (unlike X-linked recessive)
- Recessive
  - Affects males > females
  - Chance of passing on the disorder differs between men and women
  - Carrier females (one copy of the mutation) do not usually express the phenotype

Other patterns of Inheritance

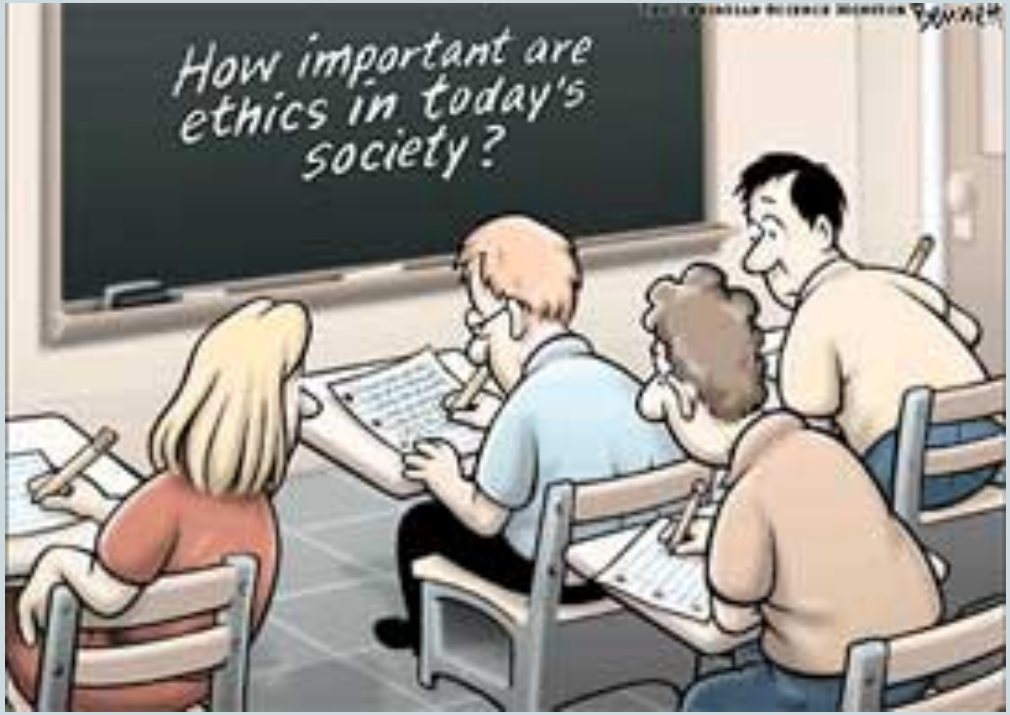
- Y-linked Disorders
  - Few Y-linked disorders: Y chromosome relatively small, contains very few genes
  - Every son of an affected father will be affected
- Codominant
  - Two different alleles are expressed
  - Each version makes a slightly different protein
  - Both alleles influence the genetic trait
- Mitochondrial
  - Maternal inheritance
  - Genes are in mitochondrial DNA (not chromosomes)
  - Can affect both males and females

Principles of Medical Ethics



Ethical Issues in Genetics (Abridged)

- **Eugenics**
- Genetic testing
- Legal issues
- Discrimination – Insurance, employment
- Research



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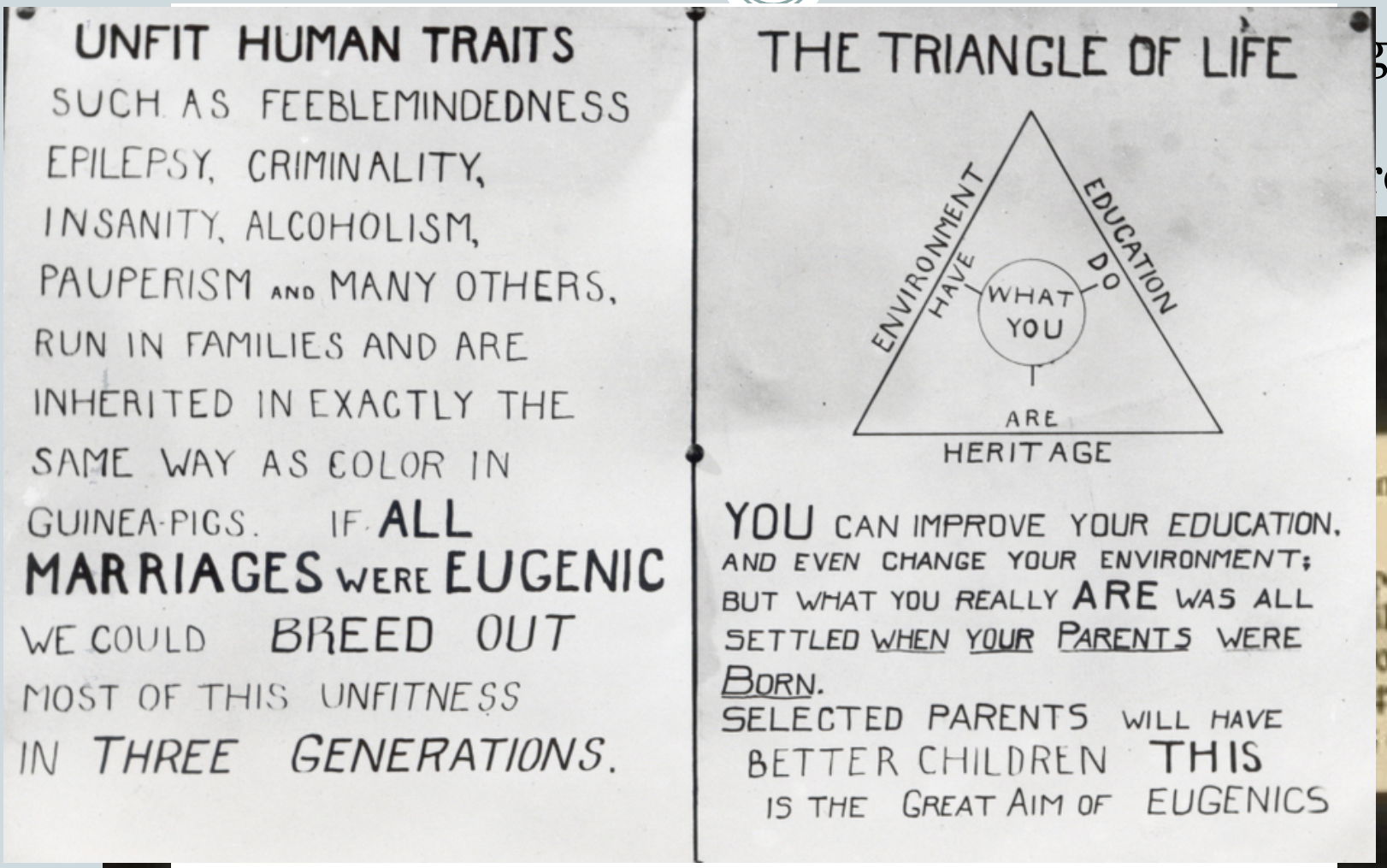
Ethical Issues in Genetics: Eugenics



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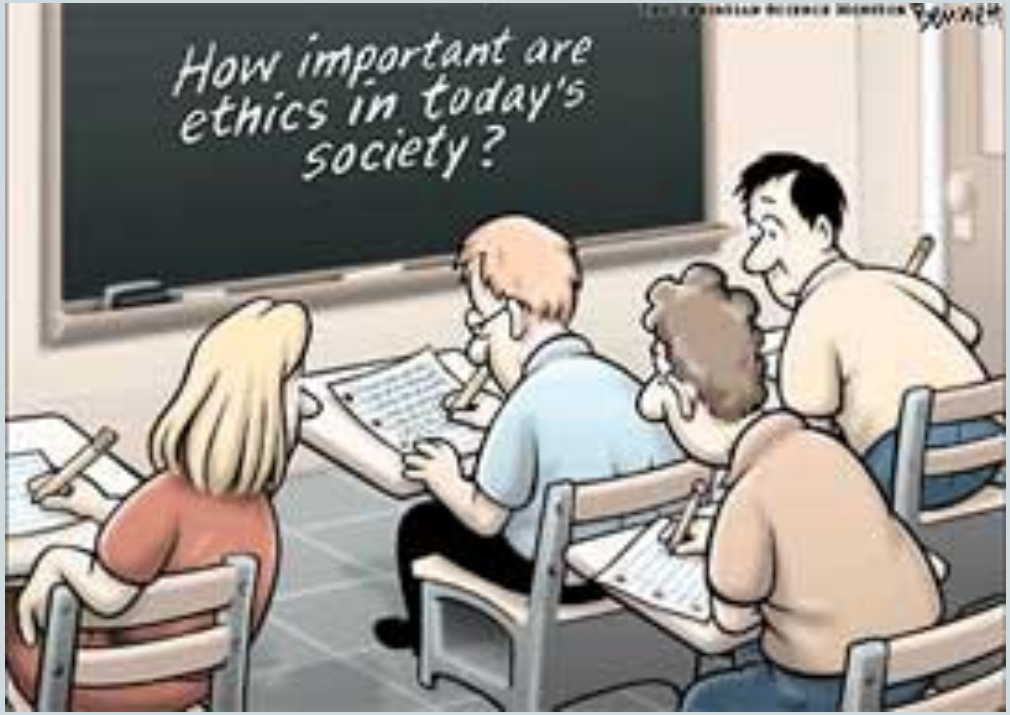

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Ethical Issues in Genetics: Genetic testing

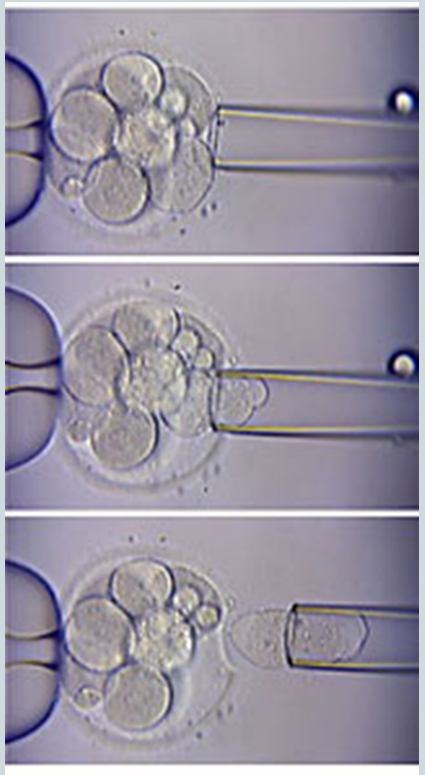
- Currently, ~6000 genetic tests are available [9]
- Would you have a free genetic test for a treatable or risk-modifiable disease?
  - 81% of adults said yes [10]
- What if there was <u>no known Tx nor any other way</u> to reduce the risk of the disease?
  - 49% of adults said yes [10]

(Clinical experience and scholarly research don't support this statistic)

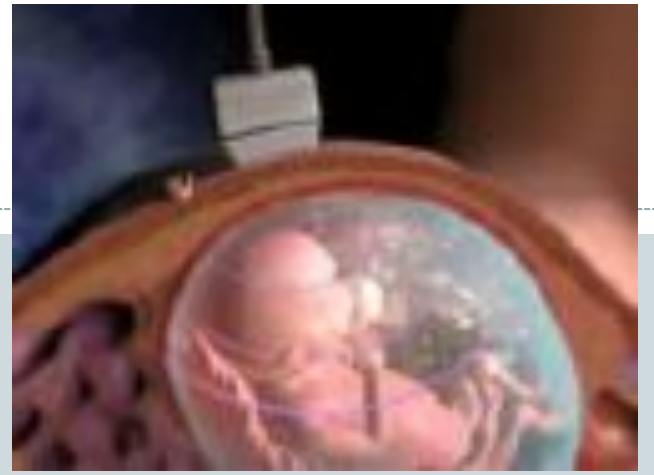
- It is difficult, if not impossible for someone NOT at risk to appreciate the burdens of the choice

Ethical Issues in Genetics: Prenatal Screening

- Pre-implantation genetic diagnosis (PGD)
  - Screens embryos for specific genetic mutation(s) prior to implantation
  - Pros: Ethically better (?)
  - Cons: Cost, success rate
  - Non-disclosing PGD possible
- Prenatal screenings (on babies)
  - Tests for specific gene mutations and also more routinely for
  - Chorionic villus sampling (CVS): 10 - 13 weeks
  - Amniocentesis: 14-20 weeks
  - Pros: Safe, in wide use
  - Cons: What to do with results of tests?
- Prenatal screenings (on potential parents)



Ethical Issues in Genetics: Prenatal Testing



Discussion: Prenatal Testing

Genetic Disease:

A couple has one child with a severe genetic disease. They are thinking of having a second child. The doctor tells them that it has recently become possible to test an unborn child for this disease.

"Designer Children":

There is the promise of manipulating genes to treat or cure genetic diseases. These same tools might also be able to be used to enhance/select for other traits such as height, weight, and intelligence.

Ethical Issues in Genetics: Genetic Testing in Children

- Newborn screening
  - Mandatory; no informed consent
  - ~50 conditions, varies by state
    - http://www.babysfirsttest.org/newborn-screening/states
  - >5,000/yr babies born with a condition included screening panels
  - Issues:
    - Expanded screening for untreatable genetic diseases?
    - What about needless Tx of an otherwise mild phenotype?
    - Diseases "missed" in some states?
- Childhood screenings
  - No routine genetic tests currently done in childhood
  - Confirmatory testing for childhood onset disorders
  - Issue: Ethical to test for adult onset disorders?

Ethical Issues in Genetics:
AMA opinion 2.138 -Genetic Testing of Children, 1996, Abridged

- Benefit of testing must outweigh disadvantages
- Testing decisions depend on condition:
  - Preventable/treatable: testing should be required
  - No prevention/Tx, pediatric onset: parents given choice
  - No prevention/Tx, adult onset: decision deferred until maturity
  - Testing for carrier status: deferred until maturity
  - Testing for benefit of someone else: done only in extraordinary cases
- If determined incidentally, should be entered into medical record
- When a child is being considered for adoption, the guidelines for genetic testing should be the same as for other children

Activity – Role play

- You are a case worker in an adoption agency. Your agency tells you that they are legally responsible for informing potential adoptive families of the risk of genetic diseases in children up for adoption. A potential adoptive family asks that a particular child undergo testing before the adoption is final. What factors, if any, influence whether you comply with this request?

Ethical Issues in Genetic Testing: The Right NOT to Know

Ethically, the principle of respect for autonomy dictates that individuals make these decisions for themselves. Thus, an adult may decide to get tested. But a parent's right to exercise autonomy does not necessarily extend to decisions about his or her children. Arguably, a mutation-positive… test result can harm more than help a young child. Hence, for a parent to test a child may violate principles of beneficence and nonmaleficence – i.e., benefits to an individual should be maximized, and harms minimized.

Klitzman R, Andomo R and Dure L (2009) *Virtual Mentor*. 11(9): 661-672

Ethical Issues in Genetic Testing: Personalized Medicine

- Personalized medicine – Tx based on genetic, genomic, clinical info
- Increasingly a part of routine clinical practice, especially in cancer treatment
- Neuropsychiatric pharmacogenetic testing
  - GeneSight – Analyzes for single gene effects and gene/ drug interactions.
- Advantages: better informed decisions, better outcomes, fewer side effects[37], prevention, early intervention, lower healthcare costs
- Disadvantages: precision of this info, better outcomes?

Genetic testing: Genetics and Mental Health

- "Mental illness and genetics" keyword search in PubMed: >100k results
- Active and complicated area of research
- Emerging clues about genetic basis for depression, depression, autism…
  - E.g.: 22q11.2 Deletion Syndrome (22q11.2DS)
    - 1:5 develop schizophrenia
    - Study [26] of parental/genetic counselor perspectives re: disclosure of 22q11.2DS and risk of psychiatric illness
      - Majority of GCs (N=54) and parents of adults with 22q11.2DS and schizophrenia (N=4) felt increased risk important to disclose
      - However, when Dx made in infancy, GCs significantly less likely to discuss the risk of psych disorders (41%) vs. other later onset features such as hypothyroidism (83 %)
      - Reasons: stigma, GC's limited knowledge about psych illness, Tx
- Predisposition vs. predestination

Ethical Issues in Genetics: Genetic Testing

Discussion

Your family has a history of early onset Alzheimer's Disease. Because a person doesn't develop any symptoms until adulthood, you are uncertain if you have inherited the disease.

A reliable genetic test for autosomal dominant Alzheimer's Disease is available, but there is no effective cure or treatment for the disease.

Ethical Issues in Genetics: Genetic Testing

- Why test?
- Reasons not to test
- "Should I Get Tested?"

"People outside the family think, 'I would have been tested years ago. I don't know how you waited so long.' People just don't understand: it's not easy."

"The test itself has been an unambiguous, positive thing for me. I have not had a single moment, not even in passing, that I wish I hadn't known. I had been aware of HD my whole life…The test result made me feel that the decisions I made in my life were good." [18]

"He does not want me to be tested because he feels: 'We have such a good life right now, why chance that? Why spoil a good thing?' " [18]

Ethical Issues in Genetics: Issues in Genetic Testing

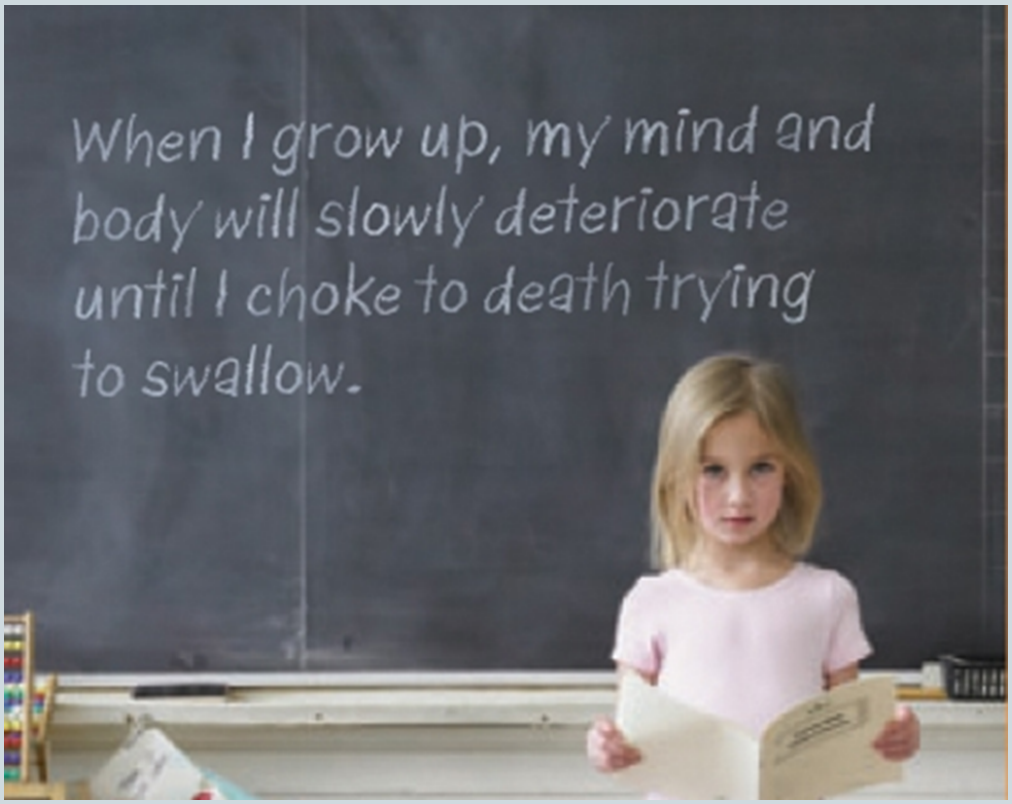
- Informed consent
- Adequate counseling, testing protocols
- Identical twins
- Adult children testing before parents
- Will testing provide the actual answer a person is seeking?
  - Age of onset, severity of disease, change of developing phenotype
  - Can testing help prevent, stall or modify disease?
- Can we communicate all of the possible short and long term ramifications? (Do we even know the ramifications?)
- Testing must be individualized & done by trained professionals
- <u>There must be no coercion</u>
- Anonymous testing?

Genetic Testing Case Study [34]

- 20-year-old female, referred by psychiatrist for genetic testing for Huntington disease (autosomal dominant, fully penetrant)
  - Mother and maternal grandfather both had HD with onset mid-40s
- Patient Sx: Headaches, dizziness, generalized pain and weakness x 2 years. Later developed heart palpitations, SOB, tremor and impaired concentration. Neurological exam mostly normal
- Psychiatric Dx: MDD with SI, GAD, OCD, "possible schizophrenia"

- Pre-test considerations
- Test results
- Implications

Ethical Issues in Genetics: Genetic Testing



Invisible Tiger – On the results of genetic testing for Huntington's Disease

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Genetic Testing: Direct to Consumer Tests

- Benefits: Access, convenience, privacy , hope for better health[24]
- Possible risks: Unable to interpret results, negative mental health impact, financial burden (e.g. follow up testing), genetic discrimination, family dynamics, potential promotion of genetic determinism, potential manipulation of public's fears/lack of knowledge, risk of common illnesses may not be entirely genetically determined, reliability and validity of results.
- What does a negative test result mean? (No disease? No risk? Lab error?)
- What does a positive test result mean? (Will I actually get the disease? When?)
- Is genetic counseling provided? (not always)
- What "conditions" are they testing for? (Varies widely by company)[23]

Genetic Testing: Direct to Consumer Tests

- 23 and Me controversy
  - Founded in 2006, began marketing to consumers in 2007
  - Nov 2013: Told by FDA to discontinue marketing and sale of kit
    - Requires regulatory approval because it offers medical advice
    - "Serious concerns are raised if test results are not adequately understood by pts or if incorrect test results are reported…Could drive consumers to take extreme steps, such as having unnecessary surgery to prevent cancer. Consumers might also abandon or alter prescribed treatments without consulting health professionals." [30]
  - July 2014: 23andMe data used to identify new genetic risks for PD; NIH awards grant to build online "research engine for genetic discovery" database using customer data
  - Jan 2015: 23andMe and Genentech enter into $10-60 m business agreement utilizing customer database. 10+ similar deals made.
  - April 2017: FDA approves 23andMe genetic risk tests

Genetic testing: Client Records

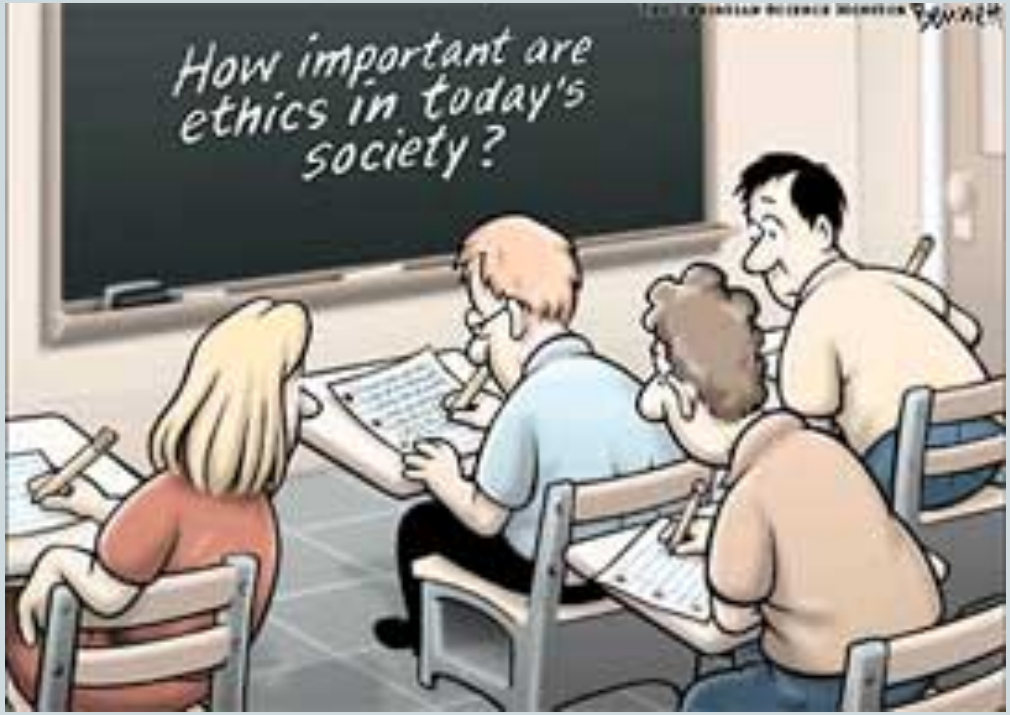
- Who should have access?
- Ever legitimate reason to limit access?
- Post-mortem requests for records
  - Post-mortem requests for testing
    - Paternity, medical and mental health conditions
    - Legal implications?
- Access to records
  - Legal issues with access – e.g. DPOA no longer in force
  - Case study
  - What if the pt never wanted info shared?
- Informing family – duty to warn?

NBCC and NASW Codes of Ethics
Select Topics – Client Records

NBCC	NASW, abridged
Respond to client requests for access to/copies of records. Provide opportunity for client to discuss content of record. If reasonable basis to believe that providing access will cause harm, discuss request and possible effects; however, info ultimately belongs to client, and thus must be released.	1.08 (a) Provide clients with access to records. If concerned that access to records could cause misunderstanding or harm provide assistance and consultation in interpreting records. Limit clients' access to records/ portions of records only in exceptional circumstances with compelling evidence that access would cause serious harm. Document…rationale for withholding some/all of record. 1.08 (b) When providing clients with access to records, take steps to protect confidentiality of others identified / discussed in records.

Ethical Issues in Genetics (Abridged)

- Eugenics
- Genetic testing
- **Legal issues**
- Discrimination – Insurance, employment
- Research



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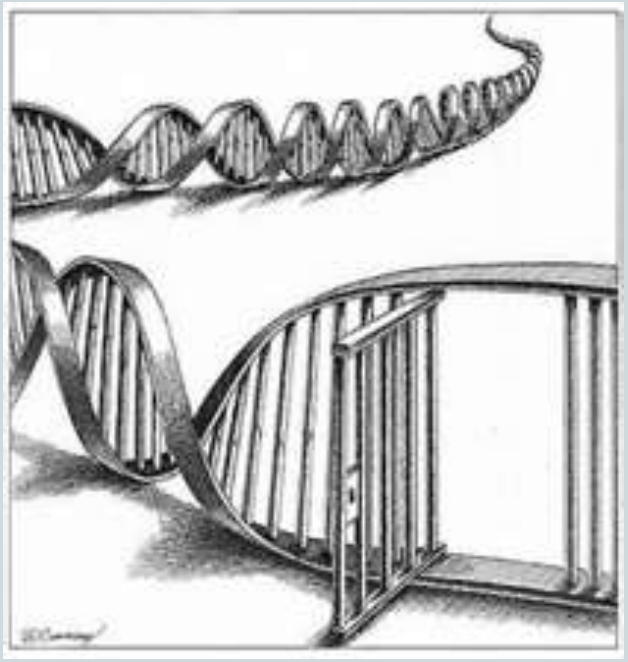
Ethical Issues in Genetics: Legal Issues

Medical ethics

a discipline and/or methodology for considering the implications of medical technology and treatment and what ought to be.[12]

Ethical Issues in Genetics: Legal Issues

- Medical Ethics is derived and expressed through: [12]
  - Law
  - Institutional policies/practices
  - Professional organizations' policies
  - Standards of care
  - Financial obligations
- Law is derived/expressed through:
  - Federal/state constitutions, statutes, regulations
  - Federal/state case law
- We will take a brief look at:
  - Informed consent
  - Competence/decisional capacity
  - Divorce
  - Custody
  - Adoption
  - Criminal system
  - Privacy and Confidentiality
  - Genetic discrimination: HIPAA, PPACA, ADA, Civil Rights Act, GINA



Legal Issues in Genetics: NBCC and NASW Codes of Ethics Select Topics - Informed Consent

NBCC	NASW, paraphrased
Inform clients of purposes, goals, procedures, limitations, potential risks and benefits of services and techniques either prior to or during the initial session. Provide info about client's rights and responsibilities including billing arrangements, collection procedures, confidentiality and its limitations, records and service termination policies.	1.03 (a) Provide services…based on valid informed consent. Use clear, understandable language to inform of purpose, risks, limits…, costs, alternatives, right to refuse/withdraw consent… 1.03 (b) Ensure comprehension such as detailed verbal explanation, interpreter, translator. 1.03 (c) If client lacks capacity to consent, seek permission from appropriate 3rd party. Ensure 3rd party acts in manner consistent with clients' wishes/interests. Try to enhance clients' ability consent.

Legal Issues in Genetics: Informed Consent

- Definition[13]: Individual's autonomous authorization of a medical intervention or research participation
- Informed consent is a *process* not a *document*
- History:
  - 1947 Nuremberg Code: Voluntary consent, no coercion, understanding of risks/benefits, minimize risk, risks not outweigh benefits, ability to withdraw
  - 1964 Declaration of Helsinki: Principles to guide MDs on ethical considerations related in research; emphasized distinction between care that directly benefits pt and research that may or may not
  - 1974 Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research
  - 1979 The Belmont Report: Commission sets forth principles under-lying ethical research: respect for persons, beneficence and justice
  - 1991 — Federal Policy for the Protection of Human Subjects adopted: ensures uniform system of protections, obligation to disclose, quality of understanding and consent

Legal Issues in Genetics: Competence/Decisional Capacity

- Incapacity - Lack of physical/mental ability that results in person's inability to manage own personal care, property, or finances; lack of ability to understand one's actions when making a legal document
- Incompetence - Inability, as determined by a court, to handle one's own personal or financial affairs
- Resources to aid in decision making: Advance directives (Durable Powers of Attorney/DPOA, living will), DNR orders, guardianship
  - Authority ends
    - Document is revoked
    - Document invalidated by court
    - Court revokes the agent's authority
    - Divorce
    - At death

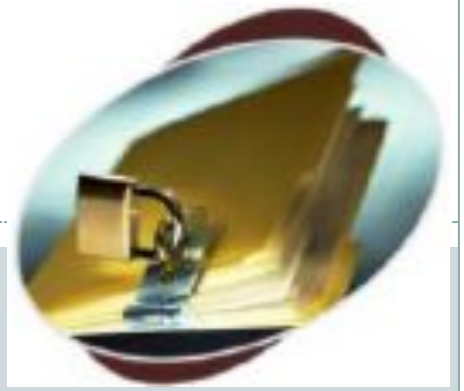
Ethical Issues in Genetics
Legal Issues

- Divorce/custody
  - Forced testing?
- Adoption
  - Disclosure of adoptee's family history?
  - Relevance of adoptive family's medical history?
- Child neglect
- Criminal system
  - Incarceration of someone whose disease may have contributed to the crime?
  - Sex offenders
    - Joseph's story

Legal Issues in Genetics: NBCC and NASW Codes of Ethics Select Topics - Privacy and Confidentiality

NBCC, paraphrased	NASW, paraphrased
Do not share info obtained through counseling or test results w/o written consent except clear, imminent danger to client/ others or when required by a court order. Solicit only info that contributes to counseling goals. If counseling multiple clients together, discuss rights, responsibilities, limitations of confidentiality. Designate in the record the primary client.	1.07 (a) Respect right to privacy. Don't solicit info unless essential to providing services. (b) Disclose confidential info w/valid consent from client/LAR. (c) Protect confidentiality except for compelling reasons except when preventing serious, foreseeable, imminent harm to client /others. Disclose least info necessary to achieve purpose. (e) Discuss limitations of confidentiality, review circumstances where disclosure may be legally required. (f) In group counseling seek agreement re: preservation of confidentiality. (r) Protect confidentiality of deceased clients.

Ethical Issues in Genetics : Privacy Issues



- Duty to warn?
  - Other family members of risk?
  - Family members who choose not to inform relatives of risk
  - Possible consequences of troublesome symptoms (aggressive behavior, suicidal ideation)
  - Legal decisions are often conflicting
- With genetic diseases, often treating multiple family members
  - Imperative be extra vigilant about privacy and who knows what
- Disease-specific clinics – everyone knows what you are there for
- Genetic testing – family members testing on same day
- Research
  - Patients waiving right to feedback, test results
  - Burden of professionals knowing info pt does not

Ethical Issues in Genetics (Abridged)

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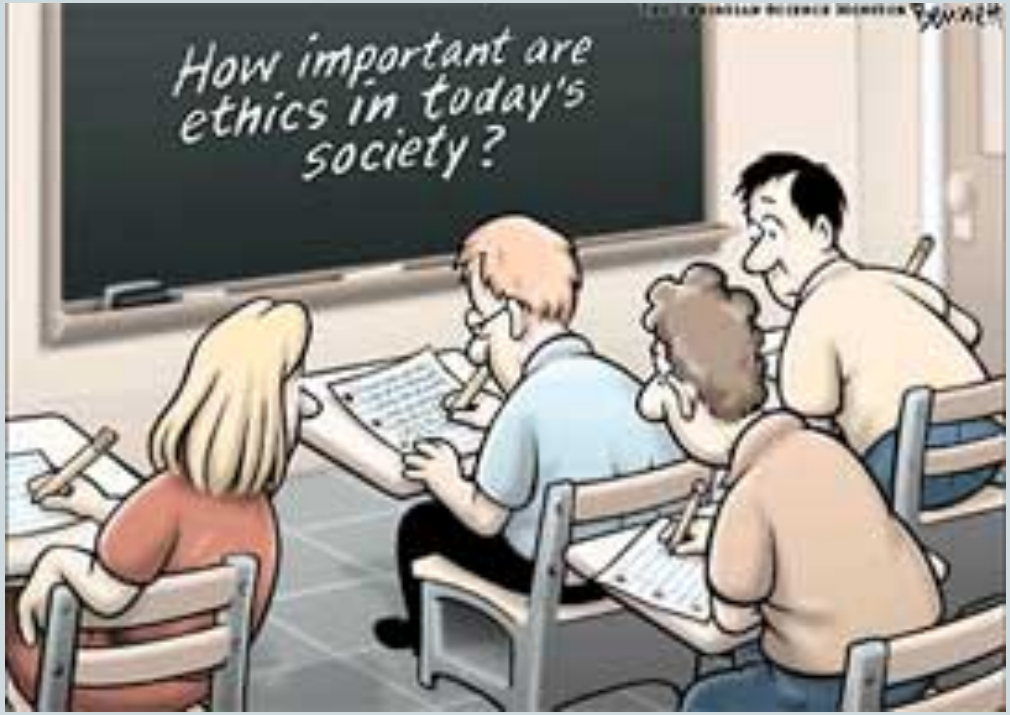
- **Discrimination – Insurance, employment**
- Research



...and more

Ethical Issues in Genetics : Genetic Discrimination

"Genetic discrimination is more than wrong; it's a life-threatening abuse of a potentially life-saving discovery."

- President Bill Clinton, 1997

NBCC and NASW Codes of Ethics
Select Topics - Discrimination

NBCC	NASW, abridged
Not engage in unlawful discrimination.	4.02 Do not practice, condone, facilitate, or collaborate with any form of discrimination on the basis of race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political belief, religion, immigration status, or **mental or physical disability**. 6.04 (d) Act to prevent and eliminate domination of, exploitation of, and discrimination against any person, group, or class on the basis of race, ethnicity, national origin, color, sex, sexual orientation, gender identity or expression, age, marital status, political belief, religion, immigration status, or **mental or physical disability**.

Ethical Issues in Genetics : Genetic Discrimination

- Restrict access – eg – organ transplant if gene risk for something else that will cause death or disability is known. Do you have a different reaction to someone with CF getting a lung transplant vs someone with HD?
- Case: SW advocacy in genetic discrimination[6]: SW advocated for fair treatment, appealed decision by an Australian federal agency to refuse to hire a person at 50% risk unless genetic testing had been undertaken
  - Employer: Those in this career deemed to enter a contract that they would remain in the career until retirement – if full service not medically possible then full retirement benefits not appropriate and applicant is disqualified; substantial public funds would be spent in specialized training; cost and difficulty incurred if/when man became ill; test decision was entirely uncoerced
  - Appeal by social worker

Ethical Issues in Genetics : Genetic Discrimination

- Insurance
  - Health Insurance Portability and Accountability Act (HIPAA)
    - Covers employer-based/commercially issued group health insurance
    - Can't deny/limit coverage, increase premiums due to health info
    - Limits preexisting condition exclusions
    - States explicitly that genetic info w/o Dx is not preexisting condition
  - Patient Protection and Affordable Care Act (ACA)
    - Can't deny ins, impose waiting period due to pre-existing conditions:
    - Cannot cancel policies on the basis of manifesting a condition
  - Future???

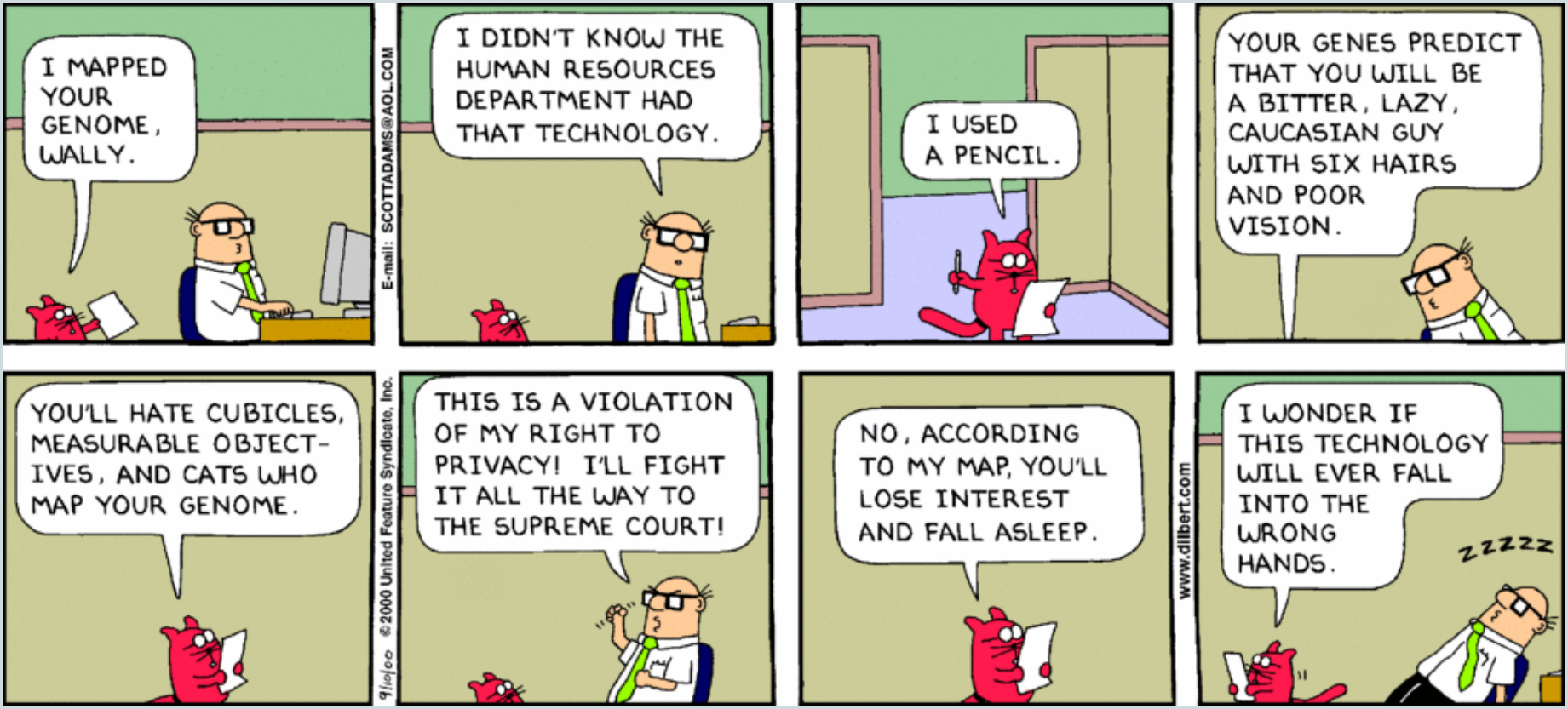
Ethical Issues in Genetics : Genetic Discrimination

Legal Protections minimal, but improving

- Title VII of the Civil Rights Act (1964)
- Genetic Information Nondiscrimination Act (GINA) (2008)
  - Two main provisions: Health Insurance, employment
  - Covers genetic info (tests, counseling, education, family member's disease manifestation, request to participate in research) of an individual and family members, including fetuses and legally held embryos
  - Major gaps
- Future??
  - HR1313: Preserving Employee Wellness Programs Act

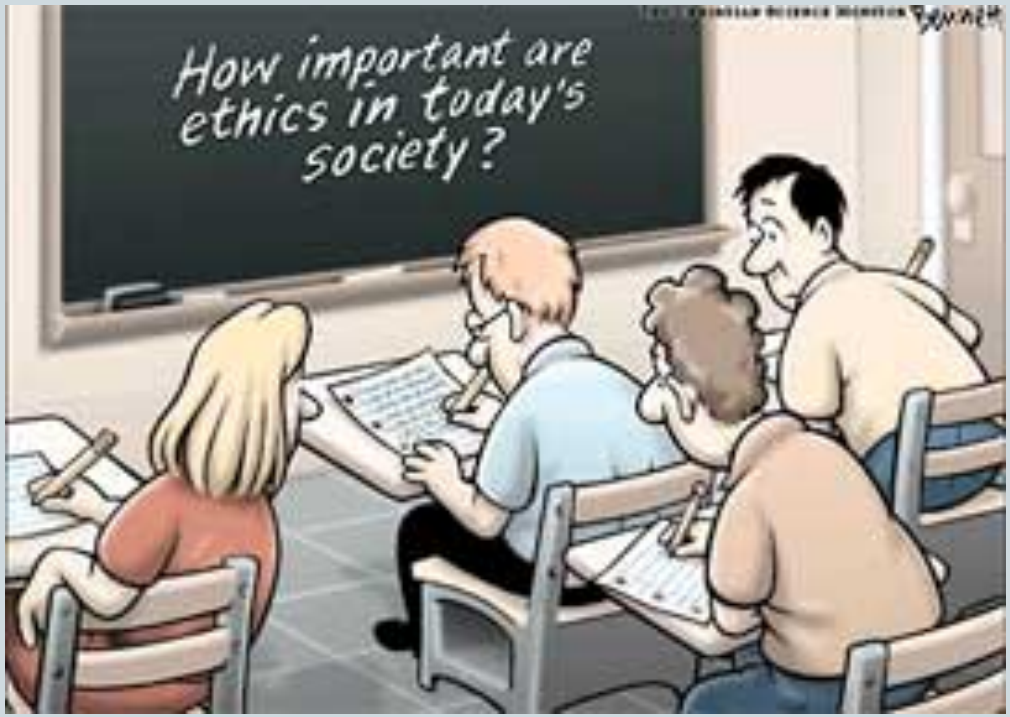
Despite laws, we all know that discrimination still exists in both subtle and overt forms

Ethical Issues in Genetics : Genetic Discrimination at Work



Ethical Issues in Genetics (Abridged)

- Eugenics
- Genetic testing
- Legal issues
- Discrimination – Insurance, employment
- **Research**



...and more

NBCC and NASW Codes of Ethics
Select Topics - Research

NBCC	NASW, abridged
Obtain prior consent from all research participants Protect the welfare of research participants by taking reasonable precautions to prevent negative psychological or physical effects. *Also know your state licensure regulations!!*	5.02 (e) Obtain voluntary, written IC w/ o implied/actual deprivation/penalty for refusal; no inducement; w/regard for well-being, privacy, dignity. Include nature, extent, duration, risks, benefits. (i) Ensure access to supportive services. (j) Protect from physical/ mental distress, harm, danger, deprivation. (l) Ensure anonymity/confidentiality of participants, data. Inform of limits of, measures to ensure confidentiality, and when research records will be destroyed.

Ethical Issues in Genetics: Research

- Are those with genetic diseases, especially w/o Tx or cure, especially vulnerable?
- Placebos: In absence of proven Tx? If Tx available?
- Hope, unproven treatments, stem cells
- Access
  - Compassionate access – pros/cons
  - Socioeconomic and cultural barriers
- Can all of this be addressed in ICF/discussion?
  - Do researchers think everyone would want to know?
  - Do researchers understand the potential stigma, discrimination?
- Discussion:
  - Participate because they can get the test for free?
  - Participate to avoid genetic testing protocols?

Ethical Issues in Genetics: Research

- Revealing "incidental" findings
  - "I mean, what if we found out someone had the gene for something really nasty? You know, something like Huntington's." (Genome researcher)
  - Informed consent: [31]
    - Most researchers, participants support disclosure of incidental findings
      - Concerns: Risks, benefits, impact on family, data security, return of results in the event of death/incapacity, contact after completion
    - Most researchers were willing to devote <30 min to IC
    - Researchers, participants concerned info will overwhelm volunteers
    - Views of researchers and participants do not coincide about amt of info that should be disclosed, time available for consent
- American College of Medical Genetics (2013) recommends return of incidental findings for 24 clusters of conditions

Ethics Issues in Genetics

APPLICATIONS IN DIRECT PRACTICE

Advocacy

- Opportunities to advocate for your clients
  - Health care law
    - Pre-existing conditions exclusions, etc
  - Privacy
  - Social security changes
  - Access to care, services, research
  - Changes in law
  - Testifying
  - Educating clients on rights
  - Advocating with employers, schools, etc

NBCC and NASW Codes of Ethics
Select Topics - Dual Roles

NBCC, abridged	NASW, abridged
Do not engage in harmful multiple relationships with clients. In the event that a harmful multiple relationship develops, discuss the potential effects with the client and take reasonable steps to resolve the situation, including referral. Clearly designate in writing the primary client in the record. Identify in the record individuals who are receiving related professional services in connection with such client relationship.	1.06 (a) Be alert to, avoid CoI that interfere with professional discretion, impartiality. Inform clients when a real/potential CoI arises; take steps to resolve making clients' interests primary. (May require termination with proper referral.) (c) Don't engage in dual/multiple relationships with clients/former clients if risk of exploitation/potential harm. When unavoidable, protect clients, set clear, appropriate, culturally sensitive boundaries. (d) If providing services to 2+ people in a relationship (e.g. couples, families), clarify which are clients. If anticipate CoI among them or anticipate conflicting roles, clarify role, take action to minimize CoI.

NBCC and NASW Codes of Ethics
Select Topics - Dual Roles

NBCC, abridged	NASW, abridged
Carefully consider ethical implications, including confidentiality and multiple relationships, prior to conducting research with clients.	5.02 (o) Avoid conflicts of interest and dual relationships with research participants, inform participants when a real or potential conflict of interest arises, and take steps to resolve the issue in a manner that makes participants' interests primary.

Counseling Families with Genetic Diseases: Social Work's Role in Genetic Services: Practice Skills[3]

- Identify clients with potential genetic disorders
- Identify and develop assistance programs
- Ensure access to counseling: Pre and post-test, family planning
- Be nondirective, explore all options, protect vulnerable members of society
- Determine services needed, availability, payor, nondiscriminatory access
- Develop access to voluntary, confidential genetic screening
- Protect rights of people who participate in genetic screening
- Protect autonomy in choice whether or not to be tested
- Focus on confidentiality, need to protect from misuse of genetic info
- Know and explain limits to confidentiality
- Advocate for insurance coverage of genetic counseling and testing
- Advocate for nondiscrimination in insurance of all types, employment
- Be aware of current, developing standards re: confidentiality of a genetic test as it relates to other family members

Counseling Families with Genetic Diseases

- MUST BE NONDIRECTIVE!
- Competence needed
  - Many issues: Psychiatric, physical, health care decision making, insurability, family support/conflict, family planning, advocacy, legal/financial, LT planning, employment, benefits, family dynamics
- Collaborate and Learn: Reach out to VHO and specialized clinics for info and education, remember that patients and families are the REAL experts, read – using appropriate , current resources – lots of info readily available
- Unique risk for conflicts of interest, multiple roles, possibility of diverging responsibilities to different family members
  - Discussion of examples

NBCC and NASW Codes of Ethics
Select Topics - Professional Competence

NBCC	NASW, paraphrased
Perform only professional services for which they are qualified by education and supervised experience. Use/interpret only tests and assessments for which they have education and supervised experience. Limit tests/assessments to those that specifically necessary for provision of quality services; that have been considered in terms of validity, reliability, limitations, appropriateness for situation/client.	1.04 (a) Provide services, represent as competent w/in education, training, license, certification, consultation, supervision, experience. 4.01 (a) Accept responsibility, employment on basis of existing/intent to acquire competence. 1.04 (b) Provide services or use new techniques, approaches only after appropriate training or competent consultation and supervision. 1.04 (c) When standards don't exist in emerging area of practice, use careful judgment, take responsible steps to ensure competence and protect clients.

NBCC and NASW Codes of Ethics
Select Topics - Professional Competence

NBCC	NASW, paraphrased
Accurately represent current qualifications	4.01 (b) Strive to become, remain proficient in professional practice. Critically examine, keep current with emerging knowledge. Review literature, do CE relevant to practice, ethics. 4.01 (c) Base practice on recognized, empirically based knowledge. 4.06 (c) Ensure that representation to clients, agencies, and public of qualifications, credentials, education, competence, affiliations, services, results to be achieved are accurate. See NASW Standards for Integrating Genetics into Social Work Practice, 2003 (handout)

NBCC and NASW Codes of Ethics
Select Topics - Consultation and Supervision

NBCC, abridged	NASW, abridged
Seek supervision/ consultation w/qualified professionals when unsure about client treatment, professional practice responsibilities. Protect confidentiality, unnecessary invasion of privacy by providing only info relevant to the consultation and in manner that protects the client's identity. Limit opinions to areas within expertise.	2.05 (a) Seek the advice/counsel of colleagues when it in client's best interests. (b) Keep self informed about colleagues' areas of expertise, competencies. Seek consultation only from colleagues who have demonstrated knowledge, expertise, and competence related to the subject of the consultation. (c) When consulting with colleagues, disclose the least amount of info necessary to achieve purposes of consultation. 3.01 (a) Supervise or consult only within areas of knowledge and competence.

NBCC and NASW Codes of Ethics
Select Topics - Referral

NBCC	NASW
Shall not provide references if they have reasonable belief that the individual counselor is not qualified, is not able to provide competent professional services or presents a risk of harm	2.06 (a) Refer clients to others when the other professionals' specialized knowledge or expertise is needed to serve clients fully or when social workers believe that they are not being effective or making reasonable progress with clients and that additional service is required.

Case Study: Ms. X

Eugenics
Genetic testing
Competence/ Decisional Capacity
Life planning
Research
End-of –Life Care
Health Care System responsibility
Legal issues
Discrimination
Privacy issues

Questions?

Resources

- NASW Standards for Integrating Genetics into Social Work Practice

  http://www.socialworkers.org/practice/standards/GeneticsStdFinal4112003.pdf
- Understanding Genetics: A New England Guide for Patients and Health Professionals

  http://www.geneticalliance.org/sites/default/files/publicationsarchive/UnderstandingGeneticsNewEngland.pdf
- National Human Genome Research Institute
  http://www.genome.gov/
- National Information Resource on Ethics and Human Genetics
  http://bioethics.georgetown.edu/nirehg/
- Making Sense of Your Genes
  http://www.geneticalliance.org/sites/default/files/ksc_assets/publications/guidetogcfinal.pdf
- Gene Tests http://www.ncbi.nlm.nih.gov/sites/GeneTests/

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