Ethics and Research

Ethics Review

- Morals - rules that define what is right and wrong
- Ethics - process of examining moral standards and looking at how we should interpret and apply such standards in real world situations
- Ethical Codes - CRC, APA, AMA, and so on. Know your code!!!

Ethics Review Cont.

- Ethical Principles
  - Autonomy
  - Beneficence
  - Non-maleficence
  - Justice
  - Fidelity

  Think for a moment, how might these principles relate to research?
History of Unethical Research

- Nuremberg Code (Pittenger, page 117)-Created as a result of cruel experiments the Nazis conducted on humans during WWII
- Milgram's Obedience Study-Researchers asked participants to "Pseudo-shocking" confederates in order to examine obedience
- Tuskegee Experiment (1932-1972)-American researchers purposely withheld treatment for 399 African-American people with syphilis for the sole purpose of studying the long term effects of the disease
- Willowbrook Study (1963-1966)-Children with developmental disabilities were deliberately infected with Hepatitis (some were even fed fecal matter). Purpose of the study was to examine the course of the disease and to test a potential immunization.

Institutional Review Board

- To provide standards of conducting ethical research, and to protect human and animal subjects, the National Research Act (law in 1974) established the Institutional Review Board
- Any research project that receives federal money must demonstrate that its methods are ethical
- http://irb.ufl.edu/

Role of the IRB

- The role of the IRB is to protect the rights and welfare of individual research subjects. This is accomplished by having the IRB assure that the following requirements are satisfied:
  1. risk to subjects are minimized
  2. risk to subjects are reasonable in relation to anticipated benefits,
  3. selection of subjects is equitable, i.e. fair
  4. informed consent is sought form each subject or his/her legally authorized representative,
Role of the IRB Cont.

5. informed consent is appropriately documented,
6. when appropriate, the research plan makes provisions for monitoring data collection,
7. privacy and confidentiality of research subjects are appropriately protected, and
8. when some or all of the subjects are likely to be vulnerable to coercion or undue influence, additional safeguards have been included. The IRB has to approve that these requirements are followed before they approve a research study and must review these documents on, at the least, an annual basis.

IRB Levels of Risk

- The IRB categorizes the risk associated with research into Exempt, Minimal, and Greater than Minimal:
  - Exempt
    - Experiment is without risk to the participant, the researcher, and the environment
    - Examples: Anonymous questionnaires, standardized education tests, and anonymous naturalistic observations

IRB Levels of Risk Cont.

- Minimal Risk
  - Although safeguards must be present, usually no more risk than one would face in everyday life
  - Examples: Certain Medical Diagnostic tests, research on individual or group behavior that involves no manipulation of the subjects and is not stressful (i.e., research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, social behavior), and research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies
IRB Levels of Risk Cont.

- Greater than Minimal Risk
  - Can cause stress, pain, injury, or even death. A project that involves greater than minimal risk requires approval by an IRB panel composed of members qualified to review research in that field.
  - Examples: Research with children and other vulnerable populations; research that involves experimental drugs or devices, invasive procedures; and any research involving deception.

HIPAA

- The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a comprehensive Federal protection plan that ensures continuity of healthcare coverage for individuals changing jobs; includes a provision that impacts on the management of health information; seeks to simplify the administration of health insurance; and aims to combat waste, fraud, and abuse in health insurance and health care.

Ethics and Research: Areas of Focus

- Harm
- Informed Consent
- Confidentiality
- Deception
- Reporting Results and Plagiarism
Harm

- As mentioned before, researchers should take every precaution to ensure that participants are not subjected to undue harm or stress
- Please visit IRB website for further information

Informed Consent

- Voluntary Informed Consent is essential for research involving human subjects
- According to the APA, Informed Consent should include:
  - Description of the nature of the research
  - Statement that the research is voluntary and participants can withdraw at any time
  - Identification of Risks and Benefits
  - Description of how confidentiality will be protected
  - Description of compensation
  - Description of what info researchers will share with participants
  - Identification of who is responsible for research with contact information

Confidentiality

- All information collected in a research project should remain confidential
- Participants should be assigned a HIPAA compliant code
- Data should be locked away in a secure setting
- Electronic Databases should also be protected

What do you do if you bump into a research participant in Wal-Mart?
Deception

- At times, researchers may choose to hide from participants the true nature of the study.
- Deception by Omission
  - Withholding important facts from the participants
- Deception by Commission
  - Lie to or purposely mislead research participants

Deception Cont.

- Staged Manipulations
  - Also called Event Manipulations
  - Used for 2 reasons
    - The researcher may need to create some sort of psychological state (anxiety)
    - The researcher may need to stage a manipulation to recreate a real-world scenario
    - Having a participant do one task and then having them do more tasks at the same time
- Staged manipulations usually employ a confederate
  - Also called an accomplice
  - A confederate is someone who appears to be another participant in an experiment but is really a part of the experiment
- Example: Someone who purposely insults a participant in a study in order to provoke anger or frustration

Deception Cont.

- Another example of the use of confederates:
- Asch (1956) study on conformity
  - Which line is bigger?
    1)
    2)
    3)
  - Right before a participant had to choose which line was the longest, a confederate announced an incorrect answer
  - Repeatedly, Asch found that people conformed to the confederate’s incorrect response
Deception Cont.

- According to the APA, researchers can use deception under certain conditions:
  - Participants must be provided with enough information to consent voluntarily
  - Researchers must convince the IRB that deception is necessary to collect data and that it will cause little or no harm
  - Researchers must arrange to fully inform the patients of the true nature of the study in a timely manner

Reporting Research Results

- Results of research studies should be reported in a honest, accurate manner
  - Researchers cannot “massage” data to fit their hypotheses
  - Researchers cannot make up or report false results
  - Researcher must report what they find, even if the data does not support their initial hypotheses
  - Researchers should ensure that data is being collected consistently (do checks of research assistants)
  - Researchers should give the proper credit (authorship) to those who have earned it

Plagiarism

- Comes from the Latin word meaning “to kidnap”
- Examples of plagiarism:
  - Copying someone else’s words without proper citation
  - Stealing someone else’s ideas
  - Stealing someone else’s intellectual property

*Bottom Line: Cite sources properly and minimize quotations in research reports*
The following excerpt is taken from the Code of Professional Ethics for Rehabilitation Counselors:

SECTION F: EVALUATION, ASSESSMENT, AND INTERPRETATION

F.3. RESEARCH AND TRAINING

a. DATA DISGUISE REQUIRED. Use of data derived from counseling relationships for purposes of training, research, or publication will be confined to content that is disguised to ensure the anonymity of the individuals involved.

b. AGREEMENT FOR IDENTIFICATION. Identification of a client in a presentation or publication will be permissible only when the client has agreed in writing to its presentation or publication.

SECTION H: RESEARCH AND PUBLICATION

H.1. RESEARCH RESPONSIBILITIES

a. USE OF HUMAN PARTICIPANTS. Rehabilitation counselors will plan, design, conduct, and report research in a manner that reflects cultural sensitivity, is culturally appropriate, and is consistent with pertinent ethical principles, federal and state/provincial laws, host institutional regulations, and scientific standards governing research with human participants.

b. DEVIATION FROM STANDARD PRACTICES. Rehabilitation counselors will seek consultation and observe stringent safeguards to protect the rights of research participants when a research problem suggests a deviation from standard acceptable practices.

c. PRECAUTIONS TO AVOID INJURY. Rehabilitation counselors who conduct research with human participants will be responsible for the participants’ welfare throughout the research and will take reasonable precautions to avoid causing injurious psychological, physical, or social effects to their participants.

d. PRINCIPAL RESEARCHER RESPONSIBILITY. While ultimate responsibility for ethical research practice lies with the principal researcher, rehabilitation counselors involved in the research activities will share ethical obligations and bear full responsibility for their own actions.
H.2. INFORMED CONSENT

a. TOPICS DISCLOSED. In obtaining informed consent for research, rehabilitation counselors will use language that is understandable to research participants and that (1) accurately explains the purpose and procedures to be followed; (2) identifies any procedures that are experimental or relatively untried; (3) describes the attendant discomforts and risks; (4) describes the benefits or changes in individuals or organizations that might reasonably be expected; (5) discloses appropriate alternative procedures that would be advantageous for participants; (6) offers to answer any inquiries concerning the procedures; (7) describes any limitations of confidentiality; and (8) instructs that participants are free to withdraw their consent and to discontinue participation in the project at any time.

b. DECEPTION. Rehabilitation counselors will not conduct research involving deception unless alternative procedures are not feasible and the prospective value of the research justifies the deception. When the methodological requirements of a study necessitate concealment or deception, the investigator will be required to explain clearly the reasons for this action as soon as possible.

c. VOLUNTARY PARTICIPATION. Participation in research is typically voluntary and without any penalty for refusal to participate. Involuntary participation will be appropriate only when it can be demonstrated that participation will have no harmful effects on participants and is essential to the investigation.
CRC Code of Ethics

- d. CONFIDENTIALITY OF INFORMATION. Information obtained about research participants during the course of an investigation will be confidential. When the possibility exists that others may obtain access to such information, ethical research practice requires that the possibility, together with the plans for protecting confidentiality, will be explained to participants as a part of the procedure for obtaining informed consent.

- e. PERSONS INCAPABLE OF GIVING INFORMED CONSENT. When a person is incapable of giving informed consent, rehabilitation counselors will provide an appropriate explanation, obtain agreement for participation, and obtain appropriate consent from a legally authorized person.

- f. COMMITMENTS TO PARTICIPANTS. Rehabilitation counselors will take reasonable measures to honor all commitments to research participants.

- g. EXPLANATIONS AFTER DATA COLLECTION. After data are collected, rehabilitation counselors will provide participants with full clarification of the nature of the study to remove any misconceptions. Where scientific or human values justify delaying or withholding information, rehabilitation counselors will take reasonable measures to avoid causing harm.

- h. AGREEMENTS TO COOPERATE. Rehabilitation counselors who agree to cooperate with another individual in research or publication will incur an obligation to cooperate as agreed.

- i. INFORMED CONSENT FOR SPONSORS. In the pursuit of research, rehabilitation counselors will give sponsors, institutions, and publication channels the same opportunity for giving informed consent that they accord to individual research participants. Rehabilitation counselors will be aware of their obligation to future researchers and will ensure that host institutions are given feedback information and proper acknowledgment.
H.3. REPORTING RESULTS

a. INFORMATION AFFECTING OUTCOME. When reporting research results, rehabilitation counselors will explicitly mention all variables and conditions known to the investigator that may have affected the outcome of a study or the interpretation of data.

b. ACCURATE RESULTS. Rehabilitation counselors will plan, conduct, and report research accurately and in a manner that minimizes the possibility that results will be misleading. They will provide thorough discussions of the limitations of their data and alternative hypotheses. Rehabilitation counselors will not engage in fraudulent research, distort data, misrepresent data, or deliberately bias their results.

c. OBLIGATION TO REPORT UNFAVORABLE RESULTS. Rehabilitation counselors will make available the results of any research judged to be of professional value even if the results reflect unfavorably on institutions, programs, services, prevailing opinions, or vested interests.

d. IDENTITY OF PARTICIPANTS. Rehabilitation counselors who supply data, aid in the research of another person, report research results, or make original data available will take due care to disguise the identity of respective participants in the absence of specific authorization from the participants to do otherwise.

e. REPLICATION STUDIES. Rehabilitation counselors will be obligated to make sufficient original research data available to qualified professionals who may wish to replicate the study.

H.4. PUBLICATION

a. RECOGNITION OF OTHERS. When conducting and reporting research, rehabilitation counselors will be familiar with and give recognition to previous work on the topic, observe copyright laws, and give full credit to those to whom credit is due.

b. CONTRIBUTORS. Rehabilitation counselors will give credit through joint authorship, acknowledgment, footnote statements, or other appropriate means to those who have contributed significantly to research or concept development in accordance with such contributions. The principal contributor will be listed first and minor technical or professional contributions are acknowledged in notes or introductory statements.
CRC Code of Ethics

- c. STUDENT RESEARCH. For an article that is substantially based on a student’s dissertation or thesis, the student will be listed as the principal author.
- d. DUPLICATE SUBMISSION. Rehabilitation counselors will submit manuscripts for consideration to only one journal at a time. Manuscripts that are published in whole or in substantial part in another journal or published work will not be submitted for publication without acknowledgment and permission from the previous publication.
- e. PROFESSIONAL REVIEW. Rehabilitation counselors who review material submitted for publication, research, or other scholarly purposes will respect the confidentiality and proprietary rights of those who submitted it.