ACOLUG and Research: Some Ethical Issues

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Purpose

• Vulnerable Populations -- convenient research subjects
• Ethical concerns
  – Treatment of vulnerable populations
  – Lack of informed consent
  – Beneficence
• Lessons learned from the past
• New research ethical concerns
• Focus on ACOLUG
Some History Worth Learning

• Human experimentation with vulnerable populations -- ancient history
  – Herophilus - vivisections on prisoners
  – 18th century - Jenner -- Smallpox vaccine
    • James Phillips -- son of gardener
    • 23 other subjects - less privileged
    • Wiped out smallpox, but ethical questions
19th and 20th Centuries

• Darwin’s theory of evolution
  – In US, Social Darwinism lead to sterilization of people with disabilities in US
  – U S Eugenic Sterilization Law of 1922 - 1960
    • sterilization of 64,000 people with mental illness and developmental disabilities
20th Century Germany

- US Eugenics Law
  - Basis for science of racial cleansing
  - Word-for-word Germany’s Eugenics Law of 1933
    - By 1945 - 330,000 Germans with disabilities sterilized
    - German killing centers - Action T4 -> euthanasia of people with disabilities
      - More than 200,000 Germans with disabilities murdered
Nuremberg Trials - 1946 - 1947

Medical Case: USA v. Karl Brandt -- AKA Doctor’s Trials

- 23 doctors
- crimes against humanities - medical experiments and procedures on prisoners & citizens
  - freezing
  - malaria
  - sterilization
  - poison gas
  - bone & nerve regeneration
  - bone transplantation
  - Euthanasia of sick and disabled civilians in Germany

Karl Brandt and 6 others were convicted, sentenced to death; 7 defendants acquitted ("mercy killings")
Nuremberg Code

Outcome of the Doctor’s Trials

Bioethics

10 Principles of Ethical Research

• Voluntary Consent
• Results good for society
• Anticipated results justify experiment
• Experiment avoid physical & mental suffering/injury
• Risk v. Benefit
• Conduct by scientifically qualified persons
• Subject decline participation at any time;
• Scientist to terminate experiment if possible harm

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Radiation experiments on school children with mental retardation.

– No informed consent by the parents
– children were “induced” to participate even if they refused

During the Polio scare in United States, Jonas Salk injected killed Poliovirus vaccine

– 43 children D.T. Watson Home for Crippled Children. Salk also injected children at the
– Polk State School for the “retarded and feeble minded” during the same year

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And More Violations

1946 - 1973  Science Club at Fernald School

- “Mentally retarded” boys - experiments with radioactive isotopes to track absorption of nutrients in cereals.
- Inadequate consent by parents

1963 - 1966  Willowbrook State School

- Studies of hepatitis conducted on children with mental retardation.
- Inadequate consent provided
- Deliberately infected children with hepatitis
Need for ethical guidelines focused specifically on research involving persons with disabilities

7 Ethical Guidelines --> 5 Research Practices

1. Well-being and avoidance of harm
2. Collaboration with people with disabilities in conducting research
3. Consent: Informed and voluntary
4. Respect for participants: Dignity, anonymity & privacy
5. Equality & diversity of people with disability included in research design and planning
Additional Requirements by Farrelly (2004)

Recruitment
- Participation is voluntary
  - “Don’t have to do it”
  - Declining will not effect you
  - Can withdraw at ANY time

(Use Easy English & photos to help ensure full understanding)

Consent
- Voluntary & Informed
  - Describe purpose & procedures
  - Describe benefit to Individual, location & length of procedures & any adverse effects
  - Tell what will happen to results; how and when individual will receive summary of results
  - Tell how information will kept confidential; assure can withdraw any time
  - Sign Consent

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New Challenges

New technologies
- Bio-medical discoveries
- Speech Generating Devices
- Internet
New Technological Advances

Raise significant ethical predicaments:

1. Enrolling research participants,
2. Protecting participants from risk of harm, and
3. Linking public and private data
4. Ensuring centrality of autonomy

*Declaration of Helsinki*
The Internet

Virtual Support Groups

Captured Sample: Recruitment
Public Archives

Ethical Questions

Privacy & anonymity
Consent

*How is informed consent obtained? How are risks and benefits disclosed? How is privacy and confidentiality protected?*
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Augmentative Communication Online Users Group

• **Purpose:** Connect & Support PWUAAC

• More than 20 Years

• **AAC-RERC** - 14 years

• **800 Subscribers:** PWUAAC, Parents, Professionals, Manufacturers, Students

• Archives

• Not Moderated
Research ??

• Enticing, **BUT** Ethical Predicaments

  - Private ---> Public ??
  - Anonymity and Confidentiality ??
  - Informed Consent ??
  - Risks versus Benefits Disclosure (Principle of Beneficence) ?
  - Respecting Autonomy
• Research ??
• No, BUT …. Autonomy of Subjects
• Research Policy for ACOLUG
  – Manager
  – ACOLUG Subscribers -- PWUAAC
Research Policy

“Research not permitted on ACOLUG
– Jeopardize trust & confidentiality
• Violates the purpose of ACOLUG
(Support and information sharing)

“Researchers can post a short description of their research project (information purposes only) with a link to website providing greater detail”

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Augmentative Communication Online Users Group
Researcher’s website include:

1. Research details in Easy English
   Purpose, Funding, Sample, Instruments,
2. IRB/Human protections with IRB approval number,
3. Descriptions of what researcher wants subjects to do,
4. Study protocol
5. Results of study
6. Consent letter in Easy English

No mention of individual’s name nor of ACOLUG in any publication
Summary

• Painful History
• Potential of new technologies
  – Improve lives of PWUAAC
  – New threats to ethical research practices
• Apply principles of Ethical Conduct
• Nothing about us without us!
Thank You

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This presentation was supported, in part, by the AAC-RERC. The Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC) is funded under grant #H133E080011 from the National Institute on Disability and Rehabilitation Research (NIDRR) in the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS).

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